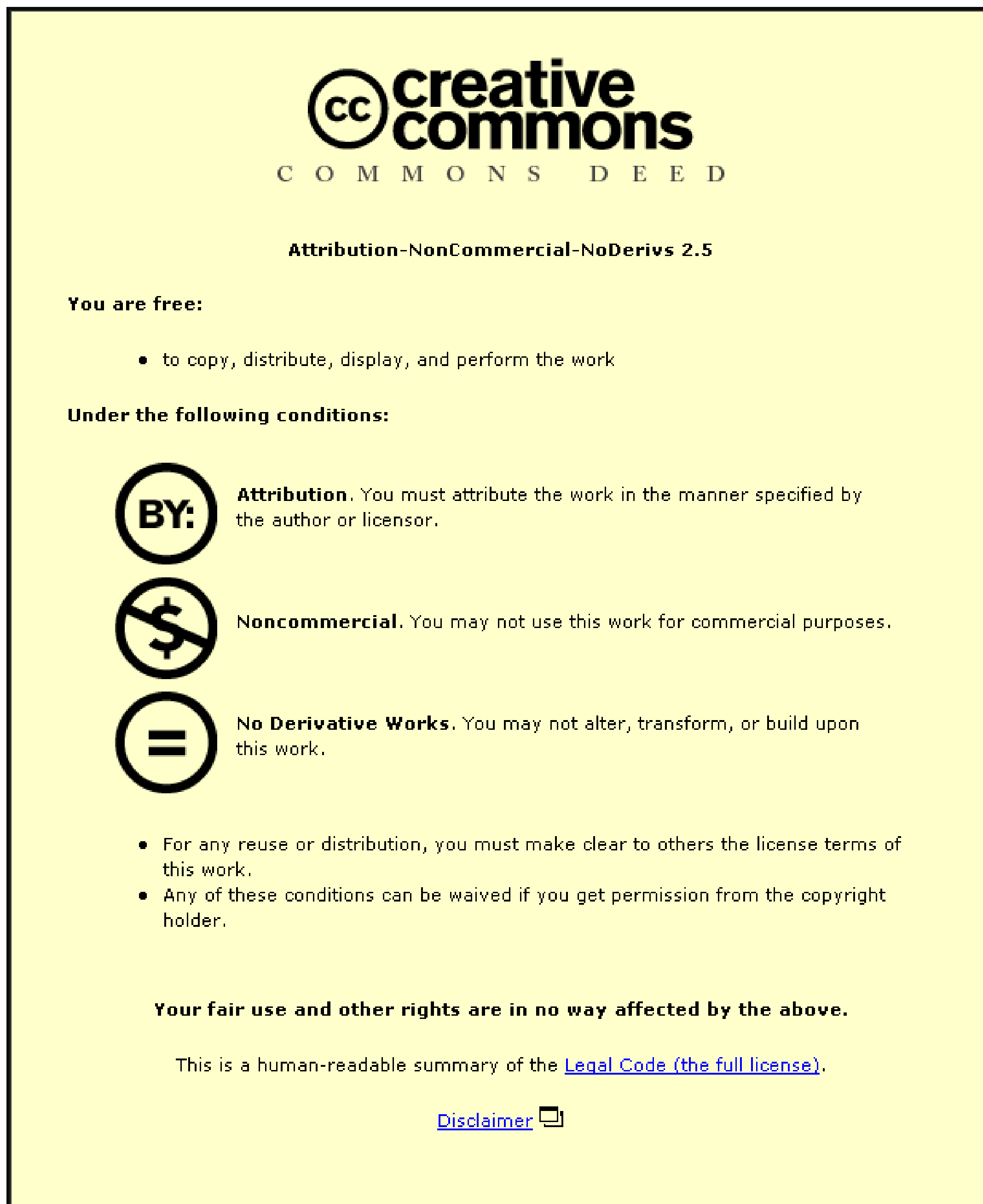


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MIND AND BODY
IN THE DISCURSIVE CONSTRUCTION OF M.E.
A Struggle for Authorship of an Illness

by

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ABSTRACT

This thesis is an analysis of the discursive construction of a controversial medical condition (Myalgic Encephalomyelitis) and how it has been made sense of, in and through the discourse of medical scientists, general practitioners, and M E sufferers.

Various kinds of text and talk are analysed from the perspective of discursive psychology, arguing that versions of reality are a product of participants' constructive and dialogical practices. (I include my own text as an example of this.) The analysis of scientific texts, illness narratives, diagnostic narratives, and M E self-help group discussions, show how explanations about the status of M E and its causes are embedded in accounts of the identity of sufferers, the nature and status of medical explanation, and the competencies of medical practitioners.

There is a sense in which the controversial topic of this thesis provides an ideal forum for examining both lay and professional reasoning practices about illness, in a context where the 'objective' world of 'medical facts' threatens to disintegrate into merely subjective points of view. One of my concerns has been to show how the participants themselves orient to, and manage this 'reality disjuncture' by means of a variety of discursive devices.

The main body of the thesis addresses this problem through issues such as: the significance of diagnostic labels, different models of medicine, and the relevance of mind and body in explanations for illness. Finally, there is an analysis of the narrative constructions of M E sufferers and GPs, to show how psychosocial 'evidence' is used to warrant the speaker's interpretation of illness as either a mental or physical phenomenon.

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CHAPTER ONE : An Introduction

This thesis is about a ‘mystery illness’, and how it is constituted in and through the discourse of participants in my study, *and* in the field of ‘M E’ research. For the time being, I will introduce the term ‘M E’ as an abbreviation of the term myalgic encephalomyelitis, and indicate that this is a controversial medical category. As with all controversies, there is, by (participants’) definition, more than one version of reality. Any attempt to define M E would therefore implicate me in producing a version of my own, and thereby entering the debate as a participant. My purpose in this thesis is not to produce yet another contribution to the question, ‘What is M E?’ The point of the project is rather to leave the privilege of definition and sense-making to the participants themselves, who manage this as a practical activity.¹

Taking M E as a participants’ topic allows me to contribute something to the understanding of how different versions of reality are constructed in talk about illness, and what kinds of concerns are made relevant by both lay and professional people in and through their discourse. My analysis of text and talk in later chapters addresses itself to exactly these issues.

The first task of this introductory chapter is to set my topic in the more general context of a social constructionist approach to the study of health and illness, and medical discourse. Second, I shall outline the background and theoretical approach of discursive psychology that I intend to apply in the construction of this thesis and the analysis of data. Third, I shall outline the project itself, and the kinds of discourse that have been treated as data for analysis. Finally, I shall provide a synopsis of the thesis, in which I provide an analyst’s gloss on the version of reality that this thesis has constituted. In certain parts of the text of the thesis I have appropriated and anticipated the voices and commentary of others to accomplish some analytic and rhetorical

¹ Starting with chapter two, in which I construct a “plausible history of M E”, where my aim is to show how the participants in the field of medicine and social science have constructed M E as a mystery illness and a medical controversy.

business relevant to both the content and the form of the text as a constructed version. My use of such 'alternative literary forms' in parts of the thesis, is indicated in the synopsis at the end of this chapter, where I call attention to their (de)constructive, reflexive, and dialogical properties.²

Health and Illness as a General Context

Although I shall focus on the specific topic of M E, my intention is to make a much more *general* contribution to the understanding of the discourse of health and illness, and medicine. Therefore, the analysis of talk about M E is used as a forum for the discussion of more general issues that are likely to be made relevant in *any* kind of discourse about health and illness, and medicine. Before I go on to discuss the theoretical and analytical approach taken in this thesis, I shall first outline the general distinction between traditional realist, social constructionist, and discursive approaches in terms of the concepts of 'disease', 'illness' and 'sickness' and the relationship between them.

It is usual for social scientists to distinguish between the terms 'disease', 'illness', and 'sickness', where

Disease is something that physicians diagnose and treat [...] it can be said that disease refers to pathological changes in the body [...] *Illness* can be taken to mean the experience of disease [...] a way of being for the individual concerned [...] *Sickness* can be defined as a social condition that applies to people who are deemed by others to be ill or diseased. It refers to a particular status or role *in society* and is justified by reference to either the presence of disease or to the presence of illness (Eisenberg, 1977). (Radley, 1994: 3)

Alan Radley points out how the different terms are each related to a different 'conceptual focus', respectively; the physical body, individual experience, and society, which are the business of biomedicine, psychology, and sociology. Thus, 'disease' is something physical, 'illness' is experiential and thus the subject matter of psychology, and 'sickness' makes sense as a category where people have 'diseases' and experience

² "Alternative literary forms, used in SSK* analysis (e.g., Ashmore, 1989; Ashmore et al, 1989; Ashmore et al 1991; Latour, 1980; MacMillan, 1995, 1996; Mulkay, 1984, 1985; Pinch and Pinch, 1988; Stringer, 1985; Woolgar and Ashmore, 1988), reflexively display SSK's concern with the construction of knowledge, and exemplify the way that the analyst's/author's claims are inextricably embedded in the textual forms she uses to present such knowledge." (MacMillan, 1966: 6) (* footnote to footnote 2: SSK stands for Sociology of Scientific Knowledge).

‘illness’ in the context of cultural meanings and in relationship to other people, social duties and obligations.

From a traditional realist perspective, the phenomenon of ‘disease’ is potentially discoverable by the scientific techniques of biomedicine. There are observable ‘signs’ and symptoms that can be described and interpreted within the framework of medical knowledge about disease and its categories. The experience of ‘illness’ is also treated as a discoverable phenomenon, albeit with a lesser ontological status,³ which is available to the social science researcher through the reports of its sufferers. However, the social status of ‘sickness’ is negotiated in terms of the cultural meanings of bodily signs and symptoms, and the extent to which such phenomena are deemed to be a sufficient and legitimate justification for opting out of social duties and obligations.⁴ In other words, “we need to look beyond the experience of the individual patient to understand how the term ‘sickness’ relates to the public awareness and designation of disease.” (Radley, 1994: 4).

Alan Radley claims that as soon as we start to *consider* the separation of the physical body, from individual experience, and society in terms of a conceptual distinction between the categories of ‘disease’, ‘illness’, and ‘sickness’, it becomes clear that the separateness is merely an *artefact* of different theoretical perspectives. The distinction between the three has been constructed and is used “to justify the different interests of social science as compared with medicine” (*ibid*: 5). What this accomplishes is to assert that “the concepts of biomedicine cannot define the field of interest for a social science approach to the topic”(*ibid*: 5).

³ Phenomenological enquiry in the social sciences has often been regarded as having a lesser scientific status than its positivistic counterparts, since its findings are based on the interpretative work of analysing participants’ subjective reports. Nonetheless, from the realist point of view, the findings of phenomenological enquiry refer to an objective reality that exists beyond a participant’s subjective and distorted interpretation.

⁴ Parsons (1951a; 1951b) has referred to this withdrawal from the normal demands of everyday life as the adoption of the ‘sick-role’. From a functionalist perspective in sociology, Parsons defined sickness as a form of deviance from the social norm of health. Sickness is seen as a threat to the social order, and the work of medical practice is to act as an agent of social control by policing access to the sick role and helping people to get well as soon as possible.

From the social constructionist perspective, therefore, the distinction that is traditionally made between the social and the biological appears much less clear cut. Social constructionism derives from the approach of Berger and Luckmann (1966) who contested the idea that social reality exists independently of our constructive practices. The theoretical stance of social constructionism therefore challenges the notion that there is any such thing as the *prior* reality of disease. Alan Radley illustrates this latter point with the following example of the menopause as a socially constructed disease.

This 'deficiency disease' can be seen to be the product of medical definitions, and of certain social assumptions. These suggest that women's biological condition associated with ovulation is linked to their youthfulness, attractiveness and hence their social worth.[...] the initial case for oestrogen therapy was based on its known effects on bone condition and the possibilities of it preventing atherosclerosis ('furring' of the arteries). Kaufert and McKinlay (1985) point to this as implying that once women had passed through the menopause, and produced less oestrogen, they were then considered to be in a state of oestrogen deficiency. This effectively turned the menopause into (i.e. constructed it as) a 'deficiency disease', and hence into something that physicians are obliged to treat. The development of replacement therapy was the necessary condition for this to occur, tying it into a conception of the menopause as a reduction in women's psychological and social worth. This was required to justify its use, in spite of several contrary indications about the treatment's long-term effects. That is to say, the isolation of a reduction in oestrogen among women after the menopause is not enough to make this variation into a disease. (Radley, 1994: 29)

Another example that Radley cites to illustrate the social constructionist approach is coronary heart disease which started to appear in the official statistics as a cause of death only in the 1920's (Bartley, 1985). This is interpreted as partly due to changes in the way that doctors attributed the causes of death specifically to degeneration of the coronary arteries, rather than to general arteriosclerosis as they had previously done (Radley, 1994). This linking of the mortality figures to a specific pathology of the coronary arteries provided the ground for theories about risk factors in heart disease, such as diet, physical activity, and lifestyle, and therefore, it follows, a justification for medical intervention in the way people live their lives.

One further example can help us to understand how medical knowledge can be understood as a socially constructed phenomenon. In his study of haematologists in hospital settings in Britain and the U.S.A., Paul Atkinson (1995) analysed the everyday talk of practitioners, and how they produce and represent medical

knowledge. Atkinson's discussion of the 'clinical gaze' (Foucault, 1973) points out how "the body of the patient is rendered legible via a detailed scrutiny of its constituent parts" (Atkinson, 1995: 61). The 'clinical gaze' is a way to read the body and its signs and symptoms as a kind of text, where the clinician's reading is based on medical techniques and anatomical knowledge, and is privileged over other kinds of accounts, such as the patient's own interpretation of bodily feelings. Atkinson (*ibid*: 70) demonstrates, however, that this medical 'reading' of the body is by no means clear cut or straightforward:

the expert (primary physician, specialist, laboratory scientist) acts as a practical phenomenologist. He or she is concerned, as a matter of everyday work, with the nature of *appearances* and the production of *descriptions*.[...] Observations are not self-evident to the 'uninitiated'. In the absence of a conceptual framework and a descriptive vocabulary there is no socially shared 'observation': there is no agreement as to a stable world of phenomena.

Atkinson goes on to analyse the discursive processes by which medical trainees are taught by experienced practitioners, to 'see' and interpret 'blood pictures' under the microscope, in a context where shared knowledge and the visual recognition of objects is a practical, collaborative, and interpretative accomplishment. The argument that Radley and Atkinson develop is that medical knowledge is not neutral, but has always been, and is ongoingly constructed within the framework of the social, cultural and discursive context. On the other hand, the social constructionist position does not necessarily imply a disagreement with medicine's categories and practices, only that there is no bottom line non-constructed criterion against which to measure them (Edwards, Ashmore, and Potter, 1995).

The upshot of the social constructionist position as this relates to the concepts of 'disease', 'illness', and 'sickness', is that definitions of disease have to be seen as a product of cultural contexts and the social processes of constructing knowledge. Since that is the case, the *experience* of 'illness' is to some extent dependent on such cultural and social definitions. For example, as implied above (Radley, 1994), the *experience* of the menopause as a 'deficiency disease' for which women should be given medical 'treatment', only makes sense in the context of certain cultural and social definitions. Furthermore, the social sanctioning of 'sickness' is dependent upon what is treated as

a warrantable claim to have a disease or an illness experience. So what is treated as a legitimate 'sickness' is likely to vary historically, and between different cultures according to prevailing notions of what counts as *bona fide* medical knowledge.

It was pointed out earlier, that the distinction that is commonly made between the categories 'disease', 'illness', and 'sickness', can be seen as a product of the theoretical divisions that have been constructed between the biological, the psychological and the social. In other words, these have been constituted as the focal *analytic* concerns of academic disciplines. However, I shall demonstrate, in this thesis, that they are also concerns that people orient to in their commonsense talk about health issues. In other words, the *biological* definitions of disease, the *personal* experience of illness, and the *social* and *moral* context of sickness, are *precisely* the topics that participants in discourse about health and illness are concerned to *manage* in and through their accounting practices.⁵

The nature of this position, and its analytical application can be elaborated by outlining the general approaches of discourse analysis (Gilbert & Mulkay, 1984; Potter & Wetherell, 1987) and more specifically, discursive psychology (Edwards & Potter, 1992; Potter, 1996; Edwards, 1997).

Discursive Psychology

The main theoretical areas that have influenced the development of a discursive psychology approach have been summarised by Edwards and Potter (1992: 27) as follows: The relationship between knowledge and language use in linguistic philosophy (Austin, 1962; Wittgenstein, 1953); a functional approach to language in speech act theories (Grice, 1975; Searle, 1969); the study of members' everyday sense-making practices in ethnomethodology (Garfinkel, 1967; Heritage, 1984); the application of ethnomethodological principles to the analysis of mundane conversations in conversation analysis (Atkinson and Heritage, 1984; Button and Lee,

⁵ For example, in chapter two, the question of whether M E is a disease entity is precisely what is at issue for the participants in the controversy. Also, in chapter six, the question of defining a disease entity is the very issue that is at stake in a narrative of personal illness experience.

1987; Levinson, 1983; Sacks *et al*, 1974); the study of scientists' discursive practices in the sociology of scientific knowledge (Ashmore, 1989; Gilbert and Mulkay, 1984; Potter and Mulkay, 1985); the application of this kind of discourse analysis⁶ to the social psychology concept of attitude (Potter and Wetherell, 1987), to the analysis of memory accounts (Edwards and Potter, 1992), to the analysis of racist discourses (Wetherell and Potter, 1992), and to the analysis of topics such as categorisation, emotions, narrative, and shared knowledge (Edwards, 1997). Another area of influence has been the post-structuralist focus on the reality constructing nature of text in cultural and literary theory (Barthes, 1974; Derrida, 1977b; Shapiro, 1988).

In order to explain how discursive psychology is applied in this thesis, I shall elaborate *three* of the main influences that are referred to above. These are, the study of scientists' discursive practices in the sociology of scientific knowledge (SSK); a functional approach to language, and ethnomethodology.

Scientists' Discourse, and a functional approach to language.

Gilbert and Mulkay's (1984) study of scientists' discursive practices focused on the discourse of bioenergeticists whose specialty was an interest in oxidative phosphorylation. This refers to "the formulation of a complex molecule called ATP (adenosine triphosphate), which plants, animals, and bacteria use as a means of moving and temporarily storing energy within the cell." (*ibid*: 18) Gilbert and Mulkay's analysis departs from previous sociological work on science, which had sought to demonstrate a discrepancy between the orthodox view of scientists as neutral and disinterested, and the social realities 'revealed' by sociological research (*ibid*: 1). They cite, as an example of this, Blissett's (1972) study of the role of politics in science, where the point was to show how political manoeuvring is a routine aspect of

⁶ The kind of discourse analysis applied by Potter & Wetherell (1987) can be distinguished from another form of discourse analysis that treats discourses as historically evolved constructions that exist in some kind of abstract but structural form (e.g. Foucault, 1980; Parker, 1992). Wetherell & Potter (1992: 90) point out that "One of the dangers of this view is that the social practices of discourse often disappear from sight altogether...Discourses become seen as potent causal agents in their own right, with the processes of interest being the work of one (abstract) discourse on another (abstract) discourse...In contrast to this, we wish to place much more emphasis on discourse as social practice, on the context of use and on the act of instantiation."

the process of scientific enquiry that directs scientific perception and helps to determine whether or not a scientific theory will be accepted. Blisset's justification for making this claim was drawn from scientists' interview talk and written accounts, in which the scientists gave descriptions of such political activity. These statements were counted, by Blisset, as consistent evidence that accurately *describes* the social reality of science as a political activity.

This kind of analysis is typical of a more general kind of qualitative research, where participants' discourse is treated as a *descriptive* resource to illustrate the version of social reality that the analyst has chosen to endorse. Any variability in the participants' discourse is either ignored, explained away as the product of inaccuracy or bias, or managed by claiming privileged insight into what was really meant. As Gilbert and Mulkay (1984: 10) put it, "It is proposed in this line of argument that sociologists can tell good from bad accounts of action and belief; and that they do so by acquiring tacit craft skills which enable them to assess the veracity of different kinds of account."⁷

Gilbert and Mulkay's approach is distinct from this in the sense that it treats participants' discourse as topic, not resource, and language as *functional* rather than merely descriptive. From this view, there is taken to be "a strong connection between the form and substance of discourse, on the one hand, and the social situation in which discourse is produced, on the other hand" (*ibid*: 7). It is therefore argued that the similarity between different statements that participants make is likely to bear some relationship to a similarity in their social contexts of production. For example, Gilbert and Mulkay showed how scientists use two functionally distinctive interpretative repertoires to give an account of their actions and beliefs in different social situations; the formal, and the informal. The empiricist repertoire and the contingent repertoire (as Gilbert and Mulkay termed them) were found to be used by scientists to construct asymmetrical accounts of truth and error.

⁷ The original endnote in Gilbert & Mulkay (1984) reads: "Collins is the most enthusiastic advocate of this kind of approach in the sociology of science. See his 'Respondents' talk and participatory research', a paper given at the University of Surrey Accounts of Action Conference, December 1981. For a general discussion of the craft element in social research, see C. Wright Mills, *The Sociological Imagination*, Oxford: Oxford University Press, 1959."

Empiricist and Contingent Repertoires

The empiricist repertoire employs a way of speaking that *obviates* agency and promotes the notion of objectivity. It is the kind of formal writing that appears in experimental reports.⁸ Gilbert and Mulkay showed how an ‘empiricist repertoire’ was commonly used by scientists in making factual claims and in support of favoured theories. First, it is full of impersonal grammatical constructions such as, ‘it was found that’, ‘evidence has emerged from’, or ‘results suggest that’, which minimises subjectivity. Second, as a rule, theory develops *from* empirical data, rather than preceding it (e.g. ‘facts show that’). Third, laboratory work is described according to recognisably standard scientific methods and procedures (e.g. “mitochondria were prepared by the method of Wong”, *ibid*: 44).

On the other hand, error accounts must be managed by scientists as a matter of routine, even though, within the canons of scientific method, errors should not occur in the first place. In practice, Gilbert and Mulkay found that a ‘contingent repertoire’ was typically used by scientists in more informal settings, and interview talk, where appeals to the *personal* context- motive, bias, speculation and intuition, and also the *social* context of research (that are normally excluded from scientific reports), functioned to account for error, discredited findings, and particularly in making reference to the work of rival laboratories.

The two repertoires constitute competing accounts of scientific practice and discovery, such that if they appear together, a contingent repertoire is likely to threaten the legitimacy of an empiricist repertoire, and the truth of scientific findings. But error and truth, disagreement and consensus must also co-exist in the processes of scientific practice, and scientists made use of a ‘Truth Will Out’ device (TWOD), which functioned to manage these competing concerns and reinforce the idea that

⁸ And also in much of this thesis. For example, in the preceding paragraph where I have written the sentence “The empiricist repertoire and contingent repertoire *were found* to be used by scientists to construct asymmetrical accounts of truth and error.” The use of this kind of grammatical form deletes the authors, Gilbert and Mulkay, as *agents* of the discovery of the two repertoires making it sound as though the repertoires were just *there* waiting to be discovered.

despite temporary setbacks, disagreements, and glitches, that are attributable to *human* error, scientific empiricism will itself eventually prevail.

Jonathan Potter (1996: 155-158) has given some examples of the use of an empiricist repertoire *outside* the realms of the scientific community, where the factual grounds of reports and the objectivity of claims are important participants' concerns. For example, in news reports, constructions of impersonality (e.g. 'it is believed that'), and fact agency (e.g. 'facts show that'), are in common use. Latour (1987), and Pomerantz (1984) have also shown how in the context of controversy, people are concerned to provide a technical basis to support their truth claims. Clearly then, an empiricist repertoire, as a collection of fact constructing devices, has a wider application than to strictly scientific settings, and it certainly warrants more than a passing mention here, in this thesis. First, because such devices can be deployed by both lay and professional people to construct 'out-there-ness'⁹, secondly because the topic of my research relates to medical talk, where traditional empiricism is the canonical discourse of medical science, and thirdly because my topic is an *unresolved* medical controversy, where the very issue at stake is the ontological status of 'the mystery illness'. Of course, the implication of this claim is that a contingent repertoire is the other side of the coin in both lay and professional reasoning practices, where it can be drawn on to make relevant the subjective and constructed nature of people's claims and accounts in a way that undermines their factual basis.

Discourse as Social Action

It is useful next to explicate some of the features of discursive psychology, in which a central claim is that discourse is analysable as social action, rather than as a way to find out about internal (cognitive) or external reality. The 'discursive action model' has been suggested as a "conceptual scheme that captures some of the features of participants' discursive practices" (Edwards & Potter, 1992: 154) and therefore focuses on action rather than cognition. Memories are treated as accounts, or *versions*

⁹ This term is used to refer to the discursive construction of an external objective reality that exists 'out-there' independently of people's constructive activities.

of what happened, that are produced “on and for occasions of talk” and “may perform social actions-in-the-telling” (Edwards, 1997:266). This is a functional approach to language, where accounts and descriptions are *not* seen as merely representative of an external social reality that exists prior to people’s descriptions. Causal attributions and descriptions or reports are taken to be linked together in people’s accounts as a discursive activity, where speakers attend to issues of blame and accountability, rather than accounts being interpreted as evidence of people’s internal cognitions, or being evaluated for their truthfulness or accuracy.

From this view therefore, factuality is *itself* a participants’ concern. It is constructed in people’s accounts by means of a variety of discursive techniques, one of which is an empiricist repertoire. The possibility of denial is itself oriented to in the way that reports are rhetorically organised to undermine possible alternative versions (Billig, 1987). This is *not* necessarily to imply that an objective and recoverable social reality lies beyond the rhetorical organisation of people’s versions, but rather to claim that such versions are all we have. In other words, they are constitutive of social reality, and they work to dismiss other versions of social reality in the context of everyday talk.

One of the points made earlier was that in traditional qualitative research, variability in participants’ accounts is typically accounted for by the analyst by means of appeals to inaccuracy, or bias. In other words, the participant may not be giving a truthful, accurate, disinterested account. One of the conclusions of Gilbert and Mulkay’s study (and those which look at non-scientific settings) was that the empiricist repertoire functions as a set of fact-constructing devices, whereas a contingent repertoire can be drawn on to construct accounts as inaccurate, or in some way subjective and motivated. It can therefore be argued that the traditional qualitative analyst is doing the same thing as Gilbert and Mulkay’s scientists; bolstering their own version of a ‘reality beyond the talk’ in terms of an empiricist repertoire, and using a contingent repertoire to challenge the validity of anything that confuses or contradicts their own selected and formulated version of social reality.

Accuracy and Bias, as Participants' Concerns

On the other hand, a discursive psychology approach treats factuality, accuracy, and stake and interest, as *participants'* concerns, rather than as a methodological problem for the analyst to solve. For psychology in general and for the qualitative approach specifically, the accuracy of people's accounts is an important analyst's concern. This threatens to undermine the validity of any kind of research that treats language as a representation of a reality that exists beyond the account. From a realist point of view, the problem would be to establish how far people's memories of events are accurate representations of that reality. Robinson (1990: 1173) attends to this almost as an apologia¹⁰ in the introduction to his paper on illness narratives:

Personal accounts of illness are often viewed with considerable ambivalence as a research resource. On the one hand they provide a density of texture, a depth of personal meaning, and an insight into the experience of illness not readily available through other means. On the other hand these very qualities seem to make any systematic, valid and reliable attempts to create generalisable propositions difficult, if not impossible.

Robinson's comments here orient to the difficulty of finding a systematic way to get from people's accounts to events and experiences. However, from the perspective of discursive psychology, the accuracy or truthfulness of an account is not something that the analyst needs to be concerned to establish.¹¹ From a relativist view, constructed versions are all we have to work with. So from the viewpoint of discursive psychology, factuality and authenticity are relevant only as a discursive *accomplishment* in the construction of an account, or as participants' *concerns* that are sometimes the topic of their talk.

However, that is *not* to agree with Robinson's concern that systematic analysis is impossible. There are many discursive devices, which have been identified by different authors in discourse and conversation analysis, that are commonly used by participants in mundane everyday talk to accomplish factuality. Jonathan Potter (1996) has written a comprehensive review of fact-constructing devices, some of which will

¹⁰ Of course this apologia works discursively to disarm *precisely* such a critique of qualitative research.

¹¹ Unless of course the account is their own! Discursive psychologists obviously employ exactly the same fact-constructing devices as everyone else in writing their texts and constructing arguments. What I mean to emphasise is that discursive psychology does not seek to discover a reality beyond the talk.

be explicated in the later chapters of this thesis as an ongoing activity in the process of analysing participants' discourse. However, for the purposes of this introduction, I will provide a couple of examples that might help to clarify the rationale of discursive psychology.

Memory as a Social Practice

Remembering (and not remembering) can be seen as a social practice (Middleton & Edwards, 1990), rather than more or less accurate accounts of mental representations. Any account of past events is an *occasioned* discursive activity, that accomplishes rhetorical work. However, in the following example of John Dean's testimony to the Watergate committee, (taken from Edwards & Potter, 1992: 45-46), the accuracy of recall is analysable as a *participant's* concern.

Dean: . . . I've told you I'm trying to recall. My mind is not a tape recorder. It does recall (0.3) impressions of conversations very well, and the impression I had was that he told - the - he told me that Bob had reported to him what I had been doing. That was th- the impression that very // clearly came out.

Gurney: In other words, your - your whole thesis on saying that the President of the United States knew about Watergate on September 15 is purely an impression, there isn't a single shred of evidence that came out of this meeting.

(Slightly simplified from Molotch and Bogen, 1985: 281)

One of the analytic points made by Edwards and Potter (1992) about this extract is that it appeared in the context of "a series of turns where he [Dean] had found difficulty in answering questions" (*ibid*: 46), where Dean was working to emphasise both the accuracy of his memory, and also its limitations. He was thereby able to disclaim accountability for the apparent inadequacy of some of his previous answers, whilst at the same time warranting the *essential* accuracy of his testimony. Thus he claimed it was the "impressions of conversations" that he remembered very well, even though his "mind is not a tape recorder". This combination constructs "a cooperative concern for truth and accuracy" whilst leaving "some scope for 'plausible deniability' (Bogen and Lynch, 1989: 203).

A display of cooperative concern with the accuracy of memory, and ‘plausible deniability’ is also a feature of interview talk, as the following two extracts illustrate.

Extract 1 (MHS/ Dr Evans)

- 22.MHS have you seen any patients in your practice with M E ?
23.Dr Evans = mm
24.MHS = yeah? (.) can you describe a particular case that you had ?
25. ...
26.Dr Evans ri:ght er (.) that’s why I was going to get these notes out

Extract 2 (MHS/Dr Evans)

- 260.Dr Evans you do find people, who really, you think (.) probably haven’t
261. got M E at all (.) they’ve got something else (.) [er]
262.MHS [mm] have you
263. got any patients like that?
264. ...
265.Dr Evans I can’t think of any off the top of my head (.) but yes there certainly
266. have been

In extract 1, Dr Evans’ response at line 26 displays his cooperative concern to describe the case as accurately as possible by using the case notes to enhance his memory. Later in the interview (extract 2, line 260) he makes a general claim, which could be heard as a perjorative comment about some of his patients, who (immediately before this extract) he has described as people who “simply fall out with their previous doctor and join a new practice which may be us”. These are patients whom he argues “probably haven’t got M E at all”, but they claim that they *have*. When pressed for more specific detail, Dr Evans responds at lines 265-266 with ; “I can’t think of any off the top of my head (.) but yes there certainly have been”.

Here, the device of not being able to remember any specific details without some kind of memory aid, displays a concern to be co-operative, accurate and truthful, but also, in the context of having made a potentially contentious claim, allows him a rhetorical space for ‘plausible deniability’. If he has given no detailed description of cases that he knows well, his claim cannot be easily contested, and if he cannot remember “off the top of my head” (line 265), nor can his comments be easily followed up by the interviewer.

Stake Management

One of the concerns that participants attend to in telling their version of events, is that their description might be contested. For example, someone may construe them as 'having an axe to grind', or having something to gain by constructing one version of events (rather than another) as factual.¹² In the giving of an account, particularly a controversial one, there is always the possibility of having one's version denied or queried on the grounds of stake and interest.¹³ This is very evident in the context of the courtroom, where the famous line attributed to Mandy Rice-Davies¹⁴, 'he would [say that] wouldn't he?' was used to discredit as motivated, a testimony that had challenged her own.

The dilemma of stake and interest is not, however, restricted to the context of the courtroom. In ordinary conversation also, participants attend to the possibility that their version of events may be dismissed as motivated. They attend to this possibility in their talk by means of either a device that Jonathan Potter (1996: 125) has termed 'stake inoculation', or alternatively by 'stake confession'. Both are constructed to manage the imputation of stake or prior motive. The following example from an interview with a general practitioner on the topic of M E illustrates how 'stake inoculation' works.

Extract 3 (MHS/Dr Turner/ 69-81)

¹² Certain approaches to narrative psychology that give a 'nod in the direction of rhetoric', construe people in this way themselves. For example, Reissman's (1990) analysis of an illness narrative, "Strategic uses of narrative in the presentation of self and illness: A research note," which points out the rhetorical context of the discourse, but rather than looking in detail at the actions that discourse performs in the illness narrative, she interprets the data in Goffman's terms of 'self presentation' and the strategic choice of genre and forms of narrative that enable the participant to accomplish 'impression management'.

¹³ Social scientists do this when they examine the replies of participants for bias and distortion. For example, Reissman's (1990) analysis of an illness narrative uses the notion of rhetorical structure to attribute a 'motive' to the participant: that of presenting a particular view of himself to the interviewer. The difference between this and a discursive psychology approach is that the latter looks at the *actions* that discourse performs, rather than construing those actions as in some way motivated. A discursive analysis has no need to make inferences about the internal psychology of the individual, since these are the very topics that are attended to by participants in their talk. In other words, stake and interest is a concern that participants *manage* in their discourse rather than bias being a problem for analysts to solve.

¹⁴ Mandy Rice-Davies was a witness for the prosecution in the notorious court case of 1963, where John Profumo and other leading public figures had become implicated in a scandal involving prostitution and espionage. The remark was made in response to having her own version of events denied by a defence witness (in Edwards and Potter, 1992).

69.MHS I mean what do you make of the whole M E thi:ng?
 70. ...
 71.Dr Turner I was very sceptical initially, I have to say, for a while it seemed to
 72. be y'know this decade's thing, and went along the same sort of lines as
 73. Total Allergy Syndrome and things like that, which ultimately became
 74. pretty well discredited (.) er as diagnoses and so I think initially, I think
 75. it was seen as this year's trendy illness to have (.) er and people that
 76. read about it, knew about it, developed it, sort of thing, that was my
 77. original scepticism (.) about ten years ago it received that sort of
 78. treatment, however I think it probably is an entity, a diagnostic
 79. entity, a disease entity (.) whether or not it's post viral (.) whether it's a
 80. slow virus or whatever (.) er (.) er (.) is still under debate, but as I say I
 81. tend to think of it now as a disease entity

The interesting thing to notice about this extract is Dr Turner's response to the interviewer at line 71, "I was very sceptical initially". This signals to the listener that Dr Turner might at one time have had a prior motivation to categorise M E as a dubious kind of condition. At lines 72-76, he lists some grounds for his "original scepticism"(line 77). But later, at lines 78-81, he makes a statement about his *current* approach that contrasts with his former position (and that of other doctors); "however I think it probably is an entity, a diagnostic entity, a disease entity..."(lines 78-79). This makes available the implication that Dr Turner's *current* position on M E is based on rational grounds, that were previously unavailable, rather than being based on some kind of prior *prejudice* that he has. On the contrary, his "original scepticism" has somehow been overcome. In this case, the 'stake inoculation' works to foreclose the possible suggestion that Dr Turner is someone who had an prior interest in recognising M E as a disease entity, even whilst others in the medical profession were sceptical, or that he was in the first place easily duped by "this year's trendy illness"(line 75).

'Stake confession' is another way to manage the dilemma of stake and interest in the giving of a version of social reality. An example of this appears in footnote 18 (this chapter), where I call attention to my own interest as a member of the self-help group, and I refer to my personal involvement with two close family members who have suffered from M E. As Jonathan Potter points out, "confessing stake shows that the writer is live to its relevance and is not trying to dupe the readership. It may also work

as a display of honesty and objectivity; the author is someone who can stand outside his [her] interests and is well aware of their distorting potential. In this sense it is disarming.” (Potter, 1996: 130).¹⁵

Ethnomethodology

Ethnomethodology, the study of mundane practices for producing and making sense of everyday social life, was founded by Harold Garfinkel (1967), and is one of the main roots of both SSK and discursive psychology. What distinguishes ethnomethodology is that it does not adopt a position on the accuracy of those sense-making practices, but rather analyses them as they are used *in situ* as a practical activity, or as Heritage puts it, “some of the ways in which the world is rendered objectively available and is maintained as such” (Heritage, 1984: 220). The approach of ‘ethnomethodological indifference’, parallels SSK’s emphasis on ‘methodological relativism’, where the point is to avoid buying into a particular version of scientific truth or social reality.

The question of how “actors come to know, and know in common, what they are doing” (Heritage, 1984a: 76), in other words, how they construct and maintain a sense of orderly reality, is central to the ethnomethodological approach. Garfinkel (1967) reformulated Mannheim’s terminology¹⁶ to refer to this process as the ‘documentary method’ in which

Not only is the underlying pattern derived from its individual documentary evidences, but the individual documentary evidences, in their turn, are interpreted on the basis of ‘what is known’ about the underlying pattern. Each is used to elaborate the other. (Garfinkel, 1967: 78)

In other words, the underlying pattern is constituted in and through the accumulation of instances that are worked up as such by the actors themselves.

¹⁵ Of course by making this remark I am *not* claiming to ‘stand outside my own interests’ in writing this thesis. Indeed, the point is that my text (like any other account) is analysable as a *version*. And, of course, the more we are conscious of the functions of stake management, the less effectively disarming it is likely to become!

¹⁶ Mannheim proposed that the ‘documentary method’ involves the search for “an identical homologous pattern underlying a vast variety of totally different realisations of meaning” (Mannheim cited in Garfinkel, 1967c: 78).

There are, however, occasions when that sense of a definitive orderly reality threatens to disintegrate into different versions of the world, or points of view. Melvin Pollner (1987) referred to these as 'reality disjunctures'. In his study of mundane reasoning in traffic courts, he analysed the discursive methods by which people managed to resolve such disjunctures, and reinstate the existence of an objective reality beyond people's competing versions. The procedures that he identified function in the same way as Gilbert and Mulkay's 'contingent repertoire', such that disjunctures are explained away as being a product of differences in individual perception and interpretation, or discrepant, incomplete or distorted reporting. In this way, members are able to sustain a recognisably factual and objectively real world.

There is a sense in which the controversial topic of this thesis provides an ideal forum for examining precisely those kinds of mundane reasoning practices, in a context where the objective world of medical scientific facts threatens to disintegrate into merely subjective points of view. In other words, the controversy surrounding M E constitutes just such a 'reality disjuncture', and how that is constituted and managed as a practical activity by both lay and professional participants, is the project of this thesis.

The Project

In later chapters I shall treat all kinds of discourse on the topic of M E as analysable data. I have included in this; a selection of academic literature on M E, naturalistic data from M E self-help group discussions¹⁷, 'official' reports on M E, and interview data with ten M E sufferers and ten general practitioners, which was collected specifically for the purposes of this study. I initially approached the M E sufferers through a support group, where I became both a member and a researcher.¹⁸ My access to general practitioners was negotiated in different ways; some were referrals by

¹⁷ By 'naturalistic data' I mean that this is discourse that was not 'set up' for the purposes of research. I was able to gain access to the data since the M E group tape record (and sometimes video-record) their sessions with visiting speakers as a matter of routine. The purpose of this is to make a 'library' available to housebound members of the support group.

¹⁸ My status as a *member* of the group relates to my own experiences as a caregiver with two close family members who have suffered from this debilitating condition. (See page 16 of this chapter for a discussion of the rhetorical work of 'stake confession'.)

patients, others were referrals through personal contacts, and the rest were negotiated by sending letters (followed up by telephone calls) to doctors' surgeries in two different counties.

My purpose here was to treat interview data as a dialogue about M E between two interlocutors (both researcher, and participant), rather than to use the participants' talk as a way to discover a reality beyond their accounts, such as the events of an illness, patient's beliefs, doctor's attitudes, or the relationship between doctors and their patients. Although the interviews were collected for the purposes of research, they are treated as 'naturalised' data, in the sense that the interaction between researcher and participant is treated as integral to the object of analysis, and the researcher's questions and comments are also treated as data to be analysed. (For a further discussion of the 'naturalisation' of data, see Potter and Wetherell, 1995; Edwards, 1997). The analysis of such data will therefore use the analytical techniques and rationale of discursive psychology, to examine the kinds of actions that discourse *performs* in the contexts of interviews, academic literature, and official reports.

As I pointed out in the introduction to this chapter, taking M E as a participants' topic allows me to contribute something to the understanding of how different versions of reality are constructed in talk about a 'mystery illness', and what kinds of concerns are made relevant by both lay and professional people in and through their discourse. My analysis of talk and text, in later chapters, addresses itself to exactly these issues: for example, the biological or medical definitions of disease, the experiential dimension of illness, and the question of what counts as disease or illness in the first place.

A (foot)note on reflexivity

In case it was overlooked the first time, perhaps I should introduce footnote 2 (this chapter) into the main text:

Alternative literary forms, used in SSK* analysis (e.g., Ashmore, 1989; Ashmore et al, 1989; Ashmore et al 1991; Latour, 1980; MacMillan, 1995, 1996; Mulkay, 1984, 1985; Pinch and Pinch, 1988;

Stringer, 1985; Woolgar and Ashmore, 1988), reflexively display SSK's concern with the construction of knowledge, and exemplify the way that the analyst's/author's claims are inextricably embedded in the textual forms she uses to present such knowledge." (MacMillan, 1966: 6) (* footnote to footnote 2: SSK stands for Sociology of Scientific Knowledge).

MacMillan coins the phrase "alternative literary forms" (ALFs) to re-work the notion of 'new literary forms', initially used by Ashmore, 1989; Mulkay, 1984, 1985; Stringer, 1985; and Woolgar, 1983. These refer to "reflexive textual forms which are used to highlight the *construction of knowledge*." (MacMillan, 1996:15).

At the beginning of this chapter I have indicated my own use of ALFs in certain parts of the text, where they work to (de)construct my own version as reflexive, highlight its intertextual properties, or display the 'rhetorico-responsive' nature of discourse (Shotter, 1993b). The latter refers to a feature of talk or text that has been discussed by theorists such as Mikhail Bakhtin (see for example, Morson and Emerson, 1990: 131), who has argued that a single utterance is dialogical in the sense that it embodies 'addressivity' to an actual or imagined Other. This feature of text and talk has also been discussed by Michael Billig (1987), who has pointed out how accounts are organised so as to dismiss alternative or contrastive rhetorical positions. I have indicated my use of alternative literary forms in the chapter outline below. They constitute a form of analysis which can not only highlight the textual and dialogical construction of reality, but can also make explicit the alternative 'voices' that are implicit in a single utterance, account or argument.

A Synopsis of Chapters

The main body of the thesis has been organised in three parts that are glossed here as follows:

Part One: The Construction of M E

CHAPTER TWO: The Construction of a Medical Controversy is designed to serve several purposes. It provides an introduction to the topic of M E and gives a

background history to the controversy that surrounds it. Rather than writing a straightforward historical review of the literature, I have drawn attention to the reflexive implications of doing this at the beginning of a thesis that purports to analyse how M E is discursively constructed as a controversial category by the participants themselves. As pointed out earlier in this chapter, the social constructionist approach challenges the assumption that either 'natural' or social phenomena have an existence prior to our own constructive practices. A review of literature can be argued to perform exactly such a construction of reality, both in its choice of content, the form of text, use of the empiricist repertoire, and the way that it obscures some of its intertextual features.

The advantages of piecing together a 'dialogue' in the way that I have in chapter two, is that it calls attention to the constructive processes that are normally obscured in the craft of writing such a review. The extracts included in the chapter are quotations (albeit selective) from articles and letters that have appeared in medical journals, rather than being my own gloss on what the authors have to say. This allows me to treat the literature in the medical journals (and the correspondence that addresses it) as empirical data to be analysed, just as the interview data that is analysed later in the thesis using the approach of discourse analysis. Of course, this does not mean to say that by doing this I have managed to produce a 'versionless version' of events - on the contrary, I have obviously selected what to include. The point is to call attention to my version *as* a version that is constructed using the same kinds of discursive techniques as the participants use. One way that I celebrate this symmetry of versions in chapter two, is to draw on Rachael Jenkins' (1991) historical literature review of "The recorded history of M E" as a reflexive commentary device, in parts of the text, in the chapter heading, and in the footnotes.

One of the analytic and rhetorical advantages in appropriating the 'voices' of participants to piece together my chapter is that an analysis of their discourse allows me to identify *their* concerns and use them, as an analyst's narrative 'scene-setting' device, to justify the subsequent chapters of my thesis. The literature is analysed as

data in an ongoing dialogue between participants, where the nature of the ‘mystery illness’ is itself a topic. As pointed out earlier, the construction of the dialogue is itself part of my analysis. Otherwise, my purpose is neither to enter the debate as a participant, nor to privilege one version over another, but to analyse the discursive techniques of constructing M E.

In other words, I can claim that what the controversy amounts to has been constructed by the participants as the juxtapositioning of alternative versions of reality, such that the nature of the ‘mystery illness’ can be formulated in terms of either the mind, or the body, or possibly a more integrated combination of the two. The later chapters address this concern with mind and body, and also some of the other participants’ concerns that are at stake in the ‘dialogue’; for example, the labelling process, the management of ‘reality disjunctures’ in accounting for illness, the use of different models of medicine, and the categories of mind and body, and the relationship between them.

Part Two: Discursive Resources in a ‘struggle for authorship’

CHAPTER THREE: Labels and Things takes the participants’ concern with diagnostic labels as its topic. Issues of definition and nomenclature have been problematised in recent ‘official’ reports, and in the past medical literature, and review articles, where authors have attempted to define their terms of reference. The chapter looks at the way that labels and their meanings are the *topic* of discourse as well as being deployed as part of that discourse.

CHAPTER FOUR: Repertoires of Mind and Body takes up the relationship between mind and body, as a participants’ concern in the ‘M E controversy’, and also as a more general concern in medical discourse. The chapter aims to examine the rhetoric of mind and body by looking at the different ‘models of medicine’ that have been written about by practitioners and researchers in the fields of medicine, social science, and psychiatry. Rather than being conceptualised here as explanatory models

that have provided a framework to guide doctor's diagnostic thinking and practice, these are reformulated as explanatory repertoires that can be deployed variably by both lay and professional participants in the rhetorical context of their accounting practices, to accomplish particular kinds of discursive business. In this chapter I have used an 'alternative literary form' to *perform* the construction of my text as a dialogical practice, rather than merely presenting the *product* of construction. This mirrors the dialogical practices involved in the construction of chapter two, and also serves to explicate some of the central theoretical concerns of chapter four.

CHAPTER FIVE: The Authorship of Meaning in 'Mind and Body Talk'

analyses how the categories of mind and body, and the relationship between them is *ongoingly* constituted in and through the activity of talking about CFS and M E. In this chapter, I argue that the very separateness of the categories of mind and body, in talk about illness, *itself* signifies their indexical usefulness as discursive resources. The accusation that there has been a 'failure to challenge dualism' (which is a metaposition taken by some writers in both the literature on M E *and* in the discourse of 'official' reports) is re-considered in the context of the discursive *utility* of the separate categories of mind and body as resources to manage sickness as a practical realm of accountability.

In chapter five I point out that personal accountability is built into the assumptions of psychosocial explanations for illness, and also the medical interventions deemed appropriate for its successful management. The norms of the 'sick-role' are re-worked here from the perspective of ethnomethodology, as a resource to make patients' actions accountable in relation to health and illness issues. The categories of mind and body are conceptualised as being *primarily* constituted and deployed in and through the activity of such everyday accounting practices, and in the second place as an analyst's *distillation* of these commonsense categories, re-formulated as philosophical dualisms and psychosocial theories of health.

The analysis of data in this chapter focuses on how the categories of mind and body are constituted *variably* in talk, how these constructions work *in situ* to construct or delete agency, and thereby avoid or implicate personal accountability. The variability of mind/body constructions is seen here as constituting a rich resource for the management of accountability as a practical activity in talk about illness. The authorship of meaning is taken up as both an analyst's concern, and a participants' concern in this chapter. In one section of the chapter I use the reflexive device of a 'fictional' dialogue to explore the implications of the ethnomethodological insistence on the indexicality of meaning. In the latter part of the chapter I analyse a piece of dialogue recorded at an M E self-help group meeting, to show how participants orient to the meaning of terms such as mind and depression in their 'struggle for authorship of the illness'.

Part Three: The Narrative Construction of Illness

CHAPTER SIX: The Narrative Construction of 'Self' and M E examines the relationship between attributional discourse and moral accountability in the context of an M E illness narrative. First I provide some background on the different forms of narrative analysis that have been applied to psychology and social science. My purpose here is to show how the approach of discursive psychology, differs from these other approaches and can make a contribution to our understanding of medical talk, and the analysis of illness narratives. I have used the device of a courtroom metaphor in this chapter, to organise my analysis of an illness narrative in a way that shows how Angela and Joe construct 'a case for the defence' of Angela's illness as physical and real. Psychosocial information and a biomedical 'theory of M E' have been woven together in a co-implicative way in their account, to produce a particular version of the illness and the identity of the sufferer.

CHAPTER SEVEN: Doctors' Cases, Patients' Stories: The psychosocial repertoire as a flexible resource goes on to analyse doctors' case narratives about their patients, and compares these with patient's stories about their illnesses. In

chapter four, I described two different models of medicine, the biomedical, and the biopsychosocial, which I reformulated as interpretative repertoires that can be deployed as a discursive resource, rather than being cognitive models that guide the doctors reasoning and diagnostic practices. I argued that these repertoires are deployed by both professional and lay people alike in constructing claims about the nature of illness, the identity of its sufferers, and the skills of medical practitioners to diagnose, treat, heal, and advise.

In chapter seven I argue that doctors' case narratives can be analysed in the same way as patient's stories about their illness. More specifically I work to show how 'documentary evidence' of a psychosocial nature, and the underlying pattern that it points to, are aligned in a co-implicative way that functions to make a particular interpretation of the patient's illness available, whilst dismissing other possible kinds of explanation. My analysis in this chapter focuses on three kinds of participants' concerns that are common in the case narratives of doctors, and in the illness narratives of patients. These are; 'before and after' stories, a concern with 'where the story starts', and the process of categorising people as mentally or physically ill.

CHAPTER EIGHT: **An Analyst's Gloss** provides an outline summary of the main analytic conclusions of the thesis, explores how these can challenge and extend existing approaches to the study of health and illness, and suggests some directions for further research and also some implications for medical practice.

The thesis concludes with a dialogical postscript, in which the participants (nearly) have the last word.

CHAPTER TWO

The Construction of a Medical Controversy.

“This chapter aims to introduce the reader to the recorded history of ME, including the early epidemics, the development of the concept, and the realisation that endemic cases also existed; to the debate about whether it is an ‘organic’ or ‘hysterical’ illness and to the importance of placing all diseases within a multiaxial framework of aetiology and host response; and to the development of present day nomenclature and diagnostic criteria. It is not exhaustive, which would have taken a whole book in itself, but I have tried to bring to the interested reader’s attention some of the key literature on ME [...] and to set the scene for the other contributions in this book...”

Rachael Jenkins (1991: 3).

The demands of this chapter are to provide an introduction to my topic that displays my knowledge of the field, to raise some problems, and to give a background context for the later analysis of data. I could approach this by writing a review that traces the “recorded history of M E” (Jenkins, 1991: cited above). But the problem with writing such a recorded history is how to manage the reflexive dilemma of authorship that is inherent in the social constructionist approach to analysis taken in this thesis. The social constructionist approach has its roots in the work of Berger and Luckmann (1966), who argued that reality is constructed by a range of social processes and therefore that knowledge cannot be seen as the product of discovering objective, natural phenomena that exist independently of our constructive practices. One of the consequences of taking this approach is that authors become implicated in a ‘*tu quoque*’,¹ which means that in the process of analysing the constructive practices of others, they are *themselves* engaging in the business of constructing their own version of reality.² A second (and related) implication is the necessity of adopting a position of methodological relativism with respect to the status of scientists’ claims about the nature of reality. In other words, rather than adopting any particular version of what is

¹ This translates as ‘you also’ (Ashmore, 1989), and can be used to criticise an argument that might appear to be self-refuting. Also, according to Ashmore, “countercritical *tu quoque* arguments attack the negative or critical arguments of the opponent by claiming that these criticisms also, or perhaps only apply, reflexively, to the opponent’s own claims and positive arguments.” (*ibid*: 172).

² See Katie MacMillan’s footnote (MacMillan, 1996: 25); “As Woolgar himself suggests (1988: 23), the social scientist ‘produces knowledge claims about the production of knowledge claims’, and in doing so ‘aims to explain how explanation is done, to understand how understanding is produced.’ See also Pollner (1991).”

true and what is false, the social analyst should rather take a symmetrical approach to analysing what is constructed as truth, and what is constructed as error.

The advantage in taking this approach to the social study of science can be highlighted with reference to the comments of Harry Collins in the field of the Sociology of Scientific Knowledge (hereafter, SSK). Collins (1985) has pointed out how established scientific knowledge appears like a 'ship in a bottle', such that it is difficult to see how it came to be constructed in the first place. In contrast, the study of an ongoing controversy such as M E, has the advantage that the nature of scientific knowledge itself is precisely what is at stake in participant's accounts, and therefore the constructive practices are likely to be more evident.

My aim in this chapter is to show how M E has been constructed as a medical controversy by the participants who have written about it. In theory, the controversial nature of M E should make it easier to adopt a relativist stance. However, I have already become implicated in a reflexive dilemma,³ since I (and not the participants) have chosen a name for my topic, and I have already defined 'it' as 'a medical controversy' and then accused the participants of constructing 'it' as such. In my own defence I quote from the introduction to the CIBA Foundation's symposium on chronic fatigue syndrome, in which Kleinman and Straus (1993: 1) give their account of the aims of the conference:

The aims were to provide a forum for debate among different and even contending perspectives on CFS and to grapple with the many different challenges that make this condition ambiguous and controversial. Undertaking this symposium was an uncertain venture. The Foundation is accustomed to reasoned dialogue along lines of established findings. CFS research, however, is beset with uncertainty and riddled with inconsistency.

Nevertheless, in order to call attention to my own constructive practices (and thereby at least acknowledge the *tu quoque* in advance of my critics⁴), I have chosen to

³ "And you have already defined it as a 'reflexive dilemma' and not as a 'reflexive pleasure' ..." Mushakoji (1997: Personal comment). Evidently I had approached reflexivity as if it were a 'problem to solve', or possibly the 'the monster of reflexivity' that Woolgar (1982; 1988b;) refers to as a 'methodological horror'. On the other hand perhaps I could 'celebrate' reflexivity (Ashmore, 1989), or construct it as an opportunity to 'have my cake and eat it', which according to MacMillan (1996: 42) is "as good a definition of reflexivity as you can get".

⁴ Which of course works to disarm just such criticism.

formulate this chapter as a kind of textual ‘dialogue’⁵ in which I appropriate the voices of the participants to piece together a “plausible history of scientific developments”. The notion of a “plausible history” is taken from the writing of Gilbert & Mulkay, (1984: 18-19) who presented an outline of the history of bioenergetics, compiled from interview data with several leading bioenergeticists. They acknowledged that this historical account was but a possible *version* of the field, but point out that “this ‘weakness’ cannot be remedied by relying instead on other kinds of data. Other versions of the history will remain both possible and plausible.”(*ibid*: 33-34).

Similarly, in the introduction to the CIBA Foundation symposium on Chronic Fatigue Syndrome, Kleinman and Straus point out that: “This was not a consensus conference, but rather an occasion to press distinctive approaches, and to explore the implications of present knowledge for future directions. *There was no single version of the history of the syndrome.*” (Kleinman and Straus, 1993: 2, *my emphasis*).

My version will therefore necessarily be a selective textual construction, using extracts from contributions to the literature and correspondence in some of the main medical journals⁶, which will allow me (as analyst) to make the claim that I have identified what participants treat as concerns from the discourse itself.⁷

In the narrative of my thesis, this chapter also does the work of a ‘scene setting device’, which reflexively attends to its own constructive work in doing that business. ‘Scene-setting’ is here conceptualised as being a narrative device that works rhetorically to construct an author’s adequate grounds for giving a particular version of events.⁸ (See Edwards, 1997: 264). In constructing the following “plausible history”, I will necessarily have to begin my story somewhere, at a particular place and point in

⁵ My use of the term ‘dialogue’ refers here to the *intertextuality* inherent in the development of a field of literature and knowledge, and also to the notion of *addressivity* (Bakhtin, [in Morson & Emerson, 1990: 131]), and the “*rhetorico-responsive*” nature of discourse (Billig, 1987; Shotter, 1993b). The notion of a dialogue also refers to the relationship between the main text, the reader and the footnotes, which intervene as the “reflexive next turn” (MacMillan, 1996), variously offering bits of ‘neutral’ information, analytic comment, or (like a Greek Chorus) a nod in the direction of irony.

⁶ The two main ones used here, *The British Medical Journal*, and *The Lancet*, were chosen because they are the ones to which most general practitioners are likely to have access.

⁷ There is an important distinction here between participant and analyst concerns, that is central to the approach of ethnomethodology, and also discursive psychology. (See Schegloff, 1997, for a discussion of this.)

⁸ See also this chapter, page 26, where I appropriate Jenkins’ introduction to her “recorded history of ME” in order to “set the scene for the other contributions in this book...”. See also chapter 7, this thesis, where I analyse doctors’ scene-setting practices in the narrative reconstruction of a diagnosis.

time (say for example, in summer 1955, at the Royal Free Hospital in London). This of course means that the parameters will already be more or less set to exclude the telling of a different kind of narrative.⁹ For example, I might have appropriated Rachael Jenkins' version of 'where the story starts', (cited at the beginning of my story of this chapter). In her article, she goes on to claim:

The first recorded epidemic occurred among the doctors and nurses of several hospitals in Los Angeles, USA in 1934. (Jenkins, 1991: 4).

A "Plausible History" of M E (in multiple 'voices' ¹⁰).

A new virus?

This narrative begins in the summer of 1955 when the following announcement appeared in *The Lancet* under 'Public Health'.

Extract 1: *Outbreak at the Royal Free.*

"At the Royal Free Hospital in London during the past four weeks 83 of the nursing staff, 5 of the medical staff, 11 of the ancillary medical staff, 8 of the students, and 22 of the domestic staff at Gray's Inn Road and Liverpool Road have had what was initially referred to as "glandular fever". But as the outbreak has progressed, so many unusual features have been observed that it is now difficult to sustain that, or any other diagnosis. A preliminary statement has been issued for the guidance of practitioners who may encounter similar cases. In this outbreak there is an involvement of lymph-nodes liver and spleen with in most cases, signs and symptoms of encephalomyelitis or polyneuritis [...] On clinical grounds it seems doubtful whether this is an outbreak of infectious mononucleosis [...] laboratory tests have failed to support a diagnosis of infectious mononucleosis [...] The studies that are in progress may establish that the infection is due to a known virus or its variants, but it is possible that a new virus is involved."

The Lancet. August 13. 1955, p.351

This initial announcement introduced the outbreak as one of an "unusual infection" that was first mistaken for glandular fever (infectious mononucleosis) and later, on the grounds that clinical testing proved negative, was attributed to "a known virus or its

⁹ This activity mirrors a rhetorical move that is explicated elsewhere in this thesis as a discursive device used by participants in the construction of an illness narrative. See for example, 'Angela and Joe's narrative' in chapter 6; also chapter 7, "Where the story starts" in doctor's case re-constructions.

¹⁰ In the following textual construction (and these footnotes), the analyst celebrates her attempt to 'have her cake and eat it'; (or should I rather say) she presents her *version* of 'how ME has been constructed, by participants, as a medical controversy', and reflexively, how her version attends to its own constructive work in doing that business. The author builds up the factuality of her narrative by 'allowing' the participants to speak for themselves (MacMillan, 1995). This is a rhetorical move to take the empirical 'high ground' with respect to the analysis of how the participants *themselves* construct 'the controversy' as being exactly that.

variants” or “a new virus”. The following year, nine months later on May 26, 1956, four articles appeared in *The Lancet*. The first was written by a Physician and a Senior Registrar at the Infectious Diseases Department, Royal Free Hospital, London.

Extract 2: *Encephalomyelitis resembling Poliomyelitis.*

“In the summer of 1955 cases of encephalomyelitis simulating poliomyelitis appeared in North-West London. The general picture and the results of investigation, however, have shown that a diagnosis of poliomyelitis is untenable; pareses unaccompanied by wasting, tendon-reflexes generally unaffected or exaggerated, sensory disturbances, normal cerebrospinal fluid, and electro-myographic studies which fail to reveal any evidence of neuronal degeneration indicate a different aetiology and pathology. Similar outbreaks have been reported from Adelaide (Pellow 1951), Coventry (MacCrae and Galpine 1954) and Durban (Cheetham, personal communication). The obscure infection responsible for an epidemic among the nurses of the Royal Free Hospital, Gray’s Inn Road (see Lancet 1955) was probably of a similar nature. It is probable that the outbreak in Iceland in 1948 (Sigurdsson et al 1950) was an aberrant form of poliomyelitis, as the spinal fluid proved abnormal in every instance in which it was examined.

We describe here 8 cases, variously notified as meningitis, poliomyelitis and pyrexia of unknown origin, which occurred between April 1 and October 31, 1955.”

Ramsay, A.M. & O’Sullivan, E. *The Lancet*. May 26 1956, p.761-4.

Ramsay and O’Sullivan refer here to the outbreak of 1955 as an “obscure infection” which is now being likened to, and also distinguished from, poliomyelitis. The construction of an infectious disease phenomenon is grounded in references to the initial diagnoses of meningitis, poliomyelitis, and pyrexia, which are here being re-defined *in situ*. Comparative links, made between this “obscure infection” and earlier outbreaks¹¹ in Britain and around the globe, serve to construct the existence of a discrete identifiable disease phenomenon, and these reported cases as examples of it.

The next contribution was written by the resident Medical Officer of Health at the Manchester Royal Infirmary:

Extract 3: *Further Outbreak of a Disease Resembling Poliomyelitis.*

“From time to time since 1948, outbreaks have been reported of an illness which in many respects resembles poliomyelitis, but which differs from poliomyelitis in its epidemiology, in the mildness of the illness itself, in the high proportion of normal cerebrospinal fluids (c.s.f.) found, in the absence of any detectable virus, and in the frequent psychological changes (Sigurdsson et al, 1950, Pellow, 1951, Acheson 1954, MacCrae and Alpine 1954, White and Burtch 1954). I report here another such outbreak - a very small one - because it may help to

¹¹ These authors trace the origin of *their* story to 1948.

establish the existence of a disease which has been graphically, if somewhat negatively named “not poliomyelitis” (Lancet 1954).

The patients in the present series were previously fit young soldiers, of whom all but 1 lived in the same barrack block in Berlin. The 1 exception was an orderly, who, having nursed the other patients, was himself a close contact. Although the numbers involved were small - 7 cases only - the disease was clear-cut and the outbreak explosive, the last case being taken ill only eight days after the first. [...] When the first case was seen, with headache, limb pains, photophobia, neck stiffness, and an abnormal c.s.f., non-paralytic poliomyelitis was diagnosed with a fair degree of confidence, and the illness was notified as such; and the 2nd case a day later, with normal c.s.f., was again regarded as poliomyelitis. When, however, all the cases appeared, none with persistent paralysis and only 1 with abnormal c.s.f., it was clear that this diagnosis could no longer be entertained.”

Sumner, D.W. *The Lancet*, May 26 1956. pp. 764-766.

In this report Sumner works up his grounds for claiming the existence of a separate disease by emphasising its similarity to and difference from poliomyelitis. It was *so* similar to poliomyelitis that this was initially “diagnosed with a fair degree of confidence”. But pathological differences later made it clear that “this diagnosis could no longer be entertained”. In other words, the disease exists as such by virtue of *not* being something else; it had been “graphically, if somewhat negatively named ‘not poliomyelitis’ (*The Lancet* 1954).”

In order to make a claim about the *factual* existence of a new disease entity, the authors of extracts 1, 2, and 3, need to show that they are knowledgeable scientists whose claim is based on sound empirical evidence, rather than personal interest, or speculation. They all make use of a discursive pattern commonly used by people who are reporting unusual or paranormal experiences. This has been glossed in Sacks (1984; 1992) and Wooffitt (1992) by the clause ‘at first I thought, but then I realised’. In extracts 1-3, the authors formulate the first assumption (at first I thought, X) as a fairly ordinary one; the disease was sufficiently like polio, or glandular fever to be initially “diagnosed with a fair degree of confidence”. This presents the authors of the papers as ordinary and rational medical practitioners, who were initially looking for a known medical explanation for illness, rather than perhaps as scientists who might have been interested in contributing to the field of virus research. These initial mundane accounts work to construct the later ‘realisation’ that there might be a *new* and strange disease phenomenon, as something that just happened as a result of empirical facts contradicting the initial diagnosis.

These accounts were followed by an article in *The Lancet* by the Director of the Institute for Experimental Pathology, and a Clinical Neurologist in Reykjavik, Iceland.

Extract 4: *Clinical findings six years after outbreak of Akureyri Disease.*

“ In 1948-9 there was an extensive epidemic of 465 cases simulating poliomyelitis in the town of Akureyri in northern Iceland (Sigurdsson et al 1950) [...] Faeces were treated for poliomyelitis virus and for Coxsackie virus, but no virus was found. Since 1950 several outbreaks have been described which very much resemble Akureyri disease (Pellow 1951, Acheson 1954, MacCrae and Galpine 1954, White and Burtch 1954, Gear 1955). The symptoms and epidemiological behaviour of these infections are hardly sufficiently characteristic to enable all these various outbreaks to be classified together before information on their specific cause is obtained. However, it seems very likely that these epidemics constitute a nosological entity, but the relationship, if any, to poliomyelitis remains obscure. Several workers besides ourselves have attempted to isolate an infective agent from this type of case, but nobody seems to have succeeded so far. [...] There is increasing evidence that a previously unrecognised infection has presented in various parts of the world during the past seven years [...] we suggest that this condition be called (as in Iceland) Akureyri disease rather than (as some call it) Iceland disease until a more appropriate name can be suggested when we know more about its cause and the anatomical basis for the signs and symptoms which characterise it”.

Sigurdsson, B. and Gudmundsson, K.R. *The Lancet* May 26 1956, pp.766-767.

A caveat is offered here by Sigurdsson and Gudmundsson by which the similarity of the outbreaks to each other is queried at the same time as it is reinforced. The criteria for categorising illness phenomena as similar to one another is here predicated on “isolating an infective agent” and explaining how it works. On the other hand, these outbreaks *look* like a “nosological entity” which is a “previously unrecognised infection” that has “presented in different parts of the world during the last seven years”. Note also how the proposal that “this condition be called (as in Iceland) Akureyri Disease”, not only *constitutes* “this condition” as an actual object of reference, but also *reinforces* the notion of ‘its’ similarity to an outbreak in Iceland which had earlier been categorised as an “aberrant form of poliomyelitis” (extract 2).

The following editorial appeared in the same edition:

Extract 5: *A New Clinical Entity?*

“ A study of the available material in group 2 shows sufficient common ground to suggest that this is a new clinical entity which may be expected to appear again here or elsewhere in the late summer and autumn. From the purely practical standpoint it would be useful to have a name for this syndrome.[...] The objection to any but a purely descriptive name for a disorder without a known cause or established pathology are obvious. For this reason, the term “benign myalgic encephalomyelitis” may be acceptable.[...] It remains to identify this

syndrome more precisely; but we believe that its characteristics are now sufficiently clear to differentiate it from poliomyelitis, epidemic myalgia, glandular fever, the forms of epidemic encephalitis already described, and, need it be said, hysteria.”
The Lancet May 26 1956. p.790.

The possibility of heterogeneity is raised here by a sub-categorisation of outbreaks, where the common ground between only *certain* outbreaks (those in “group 2”) is emphasised. The “new clinical entity” is also ambiguously referred to as a “syndrome”, and a “disorder without a known cause or established pathology”, as if to open up a ‘rhetorical space’ for differential outcomes. Even so, an entity, syndrome or disorder implies a discretely separate phenomenon. Again the issue of an appropriate name is raised; and the term “benign myalgic encephalomyelitis” is suggested as being a “purely descriptive name”, rather than one that might implicate a specific cause. This could be heard as a distancing move from Sigurdsson’s suggestion of “Akureyri Disease”, which has associations with some form of poliomyelitis virus. *The Lancet* stresses that although the “syndrome” has yet to be identified, it can already be differentiated from “poliomyelitis, epidemic myalgia, glandular fever, the forms of epidemic encephalitis already described, and, need it be said, hysteria.”¹²

In September of the same year a Medical Registrar of the Royal Victoria Hospital, Boscombe in Hants, wrote the following:

Extract 6: *Benign Encephalomyelitis*

“Several cases have been described of an apparently new disease affecting the central nervous system. The two cases reported resemble in many respects this type of encephalomyelitis. [...] These two cases not only resemble one another closely but also in many respects those described by Ramsay and O’Sullivan (1956).[...] It is suggested that the disease was closely allied to recent outbreaks at the Royal Free Hospital and elsewhere. “Benign subacute encephalomyelitis” is suggested as a generic term for this group of diseases.”
Jelinek, J.E. *The Lancet* September 1956. p.494-5.

Here, an “apparently new disease” which is a “type of encephalomyelitis” that resembles the Royal Free outbreak and others like it, becomes reformulated as a heterogeneous “group of diseases” and named “benign subacute encephalomyelitis”.

¹² Evidently it *did* need to be said (as a rhetorical device to define the claim that it *didn’t* as unassailable and obvious)!

After this there were several more references to outbreaks of “encephalomyelitis” in *The Lancet* and the *British Medical Journal* in 1957.

Extract 7: Benign Myalgic Encephalomyelitis

“ Reports have lately appeared of several outbreaks of acute paretic illness of which four occurred in Britain and the term “benign myalgic encephalomyelitis” has been suggested for this condition (Lancet 1956). [...] We report here 7 further cases which arose sporadically in the Coventry area in 1956.[...] These 7 cases, though resembling those seen in the outbreak of “poliomyelitis-like illness” in Coventry in 1953, were less severe than some in that year. The kaleidoscopic clinical picture did not hide their similarity to each other. [...] The anomolous clinical picture and negative or minimal laboratory findings in some instances aroused suspicions of hysteria. Against this is the cumulative weight of such considerations as the underlying consistencies in the clinical picture, the local prevalences, the lack of general correlation with the hysterical temperament, the pyrexia of some patients and the abnormal electromyographic findings. The latter are of particular value in confirming the presence of an organic lesion (Lancet 1956).”

Galpine, J.F. & Brady, C. *The Lancet*. 13 April 1957, p757-8.

Again, this account from Galpine and Brady emphasises the similarity of the 7 cases that they report here, with other “outbreaks of acute paretic illness”¹³, and an outbreak of “poliomyelitis-like illness” in Coventry in 1953 (see Galpine & Brady, 1954, extract 2). The authors use of the name suggested by *The Lancet* in 1956 (extract 5), further specifies these 7 cases as examples of the same recognisable phenomenon. The author of extract 7 (and the previous author’s) grounds for grouping these cases together as examples of the same disease are warranted here by formulating that the resemblance between the cases is *so* strong as to offset the “kaleidoscopic clinical picture”, which might ordinarily be taken as *prima facie* evidence for making distinctions between them.

The question of hysteria is addressed again by the authors of this report who describe the clinical picture as both “kaleidoscopic” and also “anomolous”. The use of these terms works to construct the collection of clinical signs and symptoms as incongruous, or inconsistent with any known medical condition. Combined with the lack of positive scientific evidence for the existence of a pathogen, this “in some instances aroused suspicions of hysteria”. The authors dismiss this interpretation by pointing out an underlying pattern that linked cases to one another; that it usually occurred in people

¹³ Paresis is defined as “partial paralysis, affecting muscular motion but not sensation” (Concise Oxford Dictionary, Seventh Edition: 744)

who had no history of psychological illness; and that the cases were associated with fever and “abnormal electromyographic findings”, which are cited as clinical evidence for an “organic lesion”.

The following three accounts appeared in the October edition of the British Medical Journal in the same year. The first report (extract 8) is authored by the Medical Staff of the Royal Free Hospital, and refers to the events of August 1955 documented earlier by the Lancet (extract 1); the second report (extract 9) refers to a later outbreak in 1956; and the third account (extract 10) is an editorial article that appeared in the same issue of the British Medical Journal.

Extract 8: *An outbreak of Encephalomyelitis in the Royal Free Hospital Group, London, in 1955.*

“On July 13, 1955, a resident doctor and a ward sister on the staff of the Royal Free Hospital were admitted to the wards with an obscure illness. By July 25 more than 70 members of the staff were similarly affected, and it was plain that there was in the hospital an epidemic of a highly infectious character, producing amongst other things manifestations in the central nervous system [...] Between July 13 and November 24 292 members of the medical, nursing, auxiliary medical, ancillary, and administrative staff were affected by the illness, and of these 255 were admitted to hospital [...] The clinical picture has been drawn on 200 of the cases admitted to hospital, in which the diagnosis seemed certain and the records complete [...] laboratory investigations gave no aid to diagnosis [...] extensive investigations with the help of outside laboratories have failed, so far, to reveal either an infective agent or a causative factor. The relationship of the outbreak in the Royal Free Hospital Group to similar epidemics reported in recent years from almost every quarter of the globe is discussed.”

The Medical Staff of the Royal Free Hospital. *British Medical Journal*. October 19, 1957: 895-904.

Extract 9: *An Outbreak of Acute Infective Encephalomyelitis in a Residential Home for Nurses in 1956.*

“A small outbreak of acute infective encephalomyelitis is described in a residential training school for nurses. Of 38 individuals resident and at risk 7 developed the disease.”

Geffen, D. & Tracy, S.M. (Medical Officer of Health and Deputy Medical Officer of Health to the Metropolitan Borough of St. Pancras) *British Medical Journal*, 19 October, 1957, pp. 904-6.

Extract 10:

“A number of outbreaks of an illness in which encephalomyelitis is a prominent feature and which, in the early stages, could be confused with poliomyelitis have recently been observed in different parts of the world. From published reports it is clear that no clue to the cause has yet been obtained, so that any assumption that such outbreaks are of the same aetiology is purely hypothetical. Nevertheless, in many of the outbreaks the clinical and epidemiological pattern is so similar that it seems justifiable at the present to consider them as a clinical entity.”

British Medical Journal. October 19, 1957. p.927-8.

This next article, by a Physician at the Infectious Diseases Department at the Royal Free Hospital, London, was published on December 14, 1957.

Extract 11: *Encephalomyelitis in North West London. An endemic infection simulating poliomyelitis and hysteria.*

“Sporadic cases of encephalomyelitis simulating poliomyelitis in North West London in 1955 (Ramsay & O’Sullivan 1956) formed the background to the sudden explosive outbreak of an unknown infection of the central nervous system among the staff of the Royal Free Hospital Group (Compston 1956, Richardson 1956, Dimsdale 1957, Crowley et al. 1957, British Medical Journal 1957).[...] All the patients, whether with or without neurological involvement, have shown two characteristics and very insistent sequelae: (i) Proneness to fatigue [...] (ii) Emotional lability [...] it is quite understandable that a neurologist seeing these patients with their bizarre jumble of neurological signs and emotional disturbance is likely to diagnose hysteria [...] Nevertheless it constitutes a grave injustice to diagnose hysteria in these cases without recognising that the condition is organically determined.”
Ramsay, A.M. *The Lancet*. December 14, 1957. pp. 1196-1200.

And later, in 1957, the Journal of Hygiene published an article by members of the Bacteriology Department of the Royal Free Hospital School of Medicine.

Extract 12: *Epidemiological Aspects of an Outbreak of Encephalomyelitis at the Royal Free Hospital, London, in the Summer of 1955.*

“In the latter half of 1955, The Royal Free Hospital Teaching Group, with a total of about 3500, experienced an epidemic of an obscure illness which affected more than 300 people. More than half the cases occurred in July and August. Between 13 July and 24 November, 255 people were admitted to the Royal Free Hospital, while the remainder were either nursed at home or admitted elsewhere.[...] The epidemic invited comparison with those simulating poliomyelitis which have occurred during the last decade in Iceland (Sigurdsson, Sigurjonssen, Thorkelsson & Gudmundsson, 1950), New York (White & Burtch, 1954), Adelaide (Pellow, 1951), Middlesex Hospital, London (Acheson, 1954), Coventry (Macrae & Galpine, 1954) and Durban (Hill, 1955).
Crowley et al. (1957). *Journal of Hygiene*. vol. 55, pp. 102-122.

In April, 1959 the following articles in *The Lancet* further documented outbreaks of a mysterious/obscure illness simulating poliomyelitis.

Extract 13: *Epidemic Myalgic Encephalomyelopathy. The Durban Outbreak.*

“In February, 1955, towards the end of a Durban summer, a disease, superficially resembling poliomyelitis, occurred amongst the nursing staff of Addington Hospital (Hill 1955).[...] The Addington Hospital outbreak resembled epidemics in other parts of the world. The significant characteristics were the closed nature of the epidemic; its onset, the acute infection occurring concurrently with poliomyelitis; the disseminated lesions; the tendency to relapse; the permanent sequelae; and the psychiatric concomitants.[...] It was also significant that the outbreak, as in the case of the Royal Free Hospital (Medical Staff of the Royal Free Group of Hospitals 1957) followed a hot dry summer, and was associated with a poliomyelitis epidemic. The above facts would lend support to the theory that the condition is infective,

closely related to poliomyelitis, and of virus origin. [...] A disturbing feature in our cases has been the psychiatric changes. These have been fully described by Pellow (1951) in Adelaide, and White and Burtch (1954) in New York. They have occurred both in patients with a psychoneurotic diathesis and in stable, emotionally mature individuals. Some of these have displayed features remarkably akin to hysteria. Despite various hypotheses, this disease remains a mystery."

Hill et al (1959) *The Lancet*, pp 690-693.

Extract 14: *Benign Myalgic Encephalomyelitis. An outbreak in a Nurses' School in Athens.*

"In June, 1958, an obscure neurological illness, involving 27 cases, spread epidemically in the Queen Frederica School for Midwives, which is attached to the Alexandra Maternity Hospital.[...] The disease had many features in common with those in several other outbreaks recorded in the past decade (Sigurdsson et al. 1950, Acheson 1954, Macrae and Galpine 1954, White and Burtch 1954, Alexander 1956, Medical Staff of the Royal Free Hospital 1957, Shelokov et al 1957). These outbreaks have been regarded as representing a new entity-benign myalgic encephalomyelitis (Lancet 1956) or epidemic neuromyasthenia (Shelokov et al. 1957). On the Continent such an epidemic was described in Denmark by Fog (1953). Three outbreaks in Switzerland between 1937 and 1939, then thought to be of atypical poliomyelitis, were probably, according to Gsell (1958), of a similar nature.[...] Although hitherto no viral or bacterial agent has been isolated, the contagiousness of the syndrome strongly suggests an infectious (probably viral) aetiology."

Daikos et al. (1959) *The Lancet* pp. 693-696.

Extracts 8-14 variously raise the issues that participants in the earlier accounts have constructed as being the centrally important concerns. These can be identified as:

- the infectious nature of the illness
- its similarity to poliomyelitis
- the similarity of various outbreaks to one another
- the lack of laboratory evidence to support the claim for a specific organic aetiology
- the incidence of psychological sequelae and the question of hysteria

In April 1959, the first review article since the Royal Free outbreak, appeared in the *American Journal of Medicine*.

Extract 15: *The Clinical Syndrome Variously Called Benign Myalgic Encephalomyelitis, Iceland Disease and Epidemic Neuromyasthenia.*

"The purpose of this article is to review a number of obscure outbreaks of paralytic illness, the majority of which were at first confused with poliomyelitis but which were later differentiated on clinical and epidemiological grounds.[...] The outbreaks will be compared, and the basis for the view that they constitute a clinical entity will be discussed. [...] It is significant that the first review of the syndrome under discussion was entitled, "Not poliomyelitis" (Lancet, 1954, 2:1060); the second, "A New Clinical Entity?" (Lancet, 1956, 1: 789.). in later articles entitled, "Epidemic myalgic encephalomyelitis" (British Medical

Journal, 2: 927, 1957.), “Benign myalgic encephalomyelitis” (Galpine, J.F. 1958), and “Epidemic neuromyasthenia” (Shelokov et al, 1957; Poskanzer et al, 1957), the authors considered themselves on sufficiently strong ground to describe and name the syndrome. This sequence indicates that the first and minimum requirement in the definition of an entity is the essentially negative one of showing that the syndrome is not an unusual manifestation of a disease already recognized. Later, as evidence accumulates, it may be possible to define the disorder in positive terms.[...] The question of hysteria has been raised in five outbreaks (Gilliam, 1938; Sigurdsson et al, 1950; Fog, 1953; The Medical Staff of the Royal Free Hospital, 1957; Clinical Meeting of the Natal Coastal Branch, 1955) and by Galpine and Brady (1957) and Ramsay (1957) in the discussion of their endemic cases. Most authors agree that hysterical manifestations have occurred in a few patients (Gilliam, 1938; Fog, 1953; Ramsay, 1957), particularly in the later stages (The Medical Staff of the Royal Free Hospital, 1957), but none has ever felt that it has contributed significantly to the pattern of the disease.[...] The mental symptoms which are a constant feature of all the outbreaks are not typical of hysteria.[...] symptoms are more consistent with cerebral damage than with hysteria. Many years ago Von Economou (1931) stressed the ease with which the mental symptoms of encephalitis may be confused with those of psychoneurosis. [...] In its epidemic form the illness is distinctive and therefore has a rightful place in medical literature as a clinical entity. Its epidemiological features suggest that it may be an infection. However, in the absence of any pathological evidence it remains uncertain whether it is due to a single agent or to a group of related agents.[...] The wisdom of naming a disorder, the nature of which cannot at present be proved, and which may be due to more than one agent, is debatable.[...] It is unlikely that an adequate term will be found until fresh evidence is available. In the meantime “benign myalgic encephalomyelitis” may act provisionally as a rallying point in the current list of medical literature for patients with the clinical features already described.”

Acheson, E.D. (1959). *American Journal of Medicine*, pp. 569-595.

Acheson’s review summarises the findings of other authors and formulates the concerns of participants in the field as the question of definition and naming of a new disease entity, and the question of what part (if any) is played by hysteria in the cause or perpetuation of the illness. His review points up the close relationship between medical entities and the social processes by which they are defined and agreed. This is formulated as being a problem of demonstrating sufficient grounds for the categorisation of a new disease, such that:

- “the first and minimum requirement in the definition of an entity is the essentially negative one of showing that the syndrome is not an unusual manifestation of a disease already recognised.”
- even though “Later, as evidence accumulates, it may be possible to define the disorder in positive terms.”

Acheson also makes certain equivocal claims with respect to the issues raised by other authors, for example:

- that the illness (“in its epidemic form”) is distinctive as a clinical entity (even though it is not possible to define it as such in positive terms)
- that it may be due to an infective agent or a group of agents
- that the mental symptoms that were common to all of the outbreaks are not typical of hysteria, even though they are easily confusable with psychoneurosis
- and therefore, even though he questions the “wisdom of naming a disorder, the nature of which cannot at present be proved”, he suggests that the currently used name (benign myalgic encephalomyelitis) should “act provisionally as a rallying point in the current list of medical literature”

The “uneasy spectre of hysteria”

In her more recent historical review article, Rachael Jenkins (1991: 13) glosses the research conclusions on the question of hysteria as follows:

The question of hysteria had been raised in several epidemics, including the Los Angeles outbreak, and most authors agreed that hysterical manifestations occurred in a few patients, particularly in the later stages, but none felt that it contributed significantly to the pattern of the disease. However, illness with a selectivity for young women and few positive laboratory findings often raises the uneasy spectre of hysteria. Epidemic hysteria has been recognised for many centuries as a particular hazard in institutions containing women or female adolescents.

So an alternative version of this history would actually begin many centuries ago, rather than at the Royal Free (1955), where *my* narrative begins, or else in Los Angeles (1934), where Jenkins claimed “the first recorded epidemic occurred”. Apparently, however, Jenkins did not (at any point in her review) see fit to make any evaluative comment on the historical construction of a normative relationship between young females and epidemic hysteria. She *could* have mentioned that the very origin of the term ‘hysteria’ inherently implicates women in a specific tendency to psychiatric illness.

Hysteria and the feminine are closely related in Western thought. There is a tradition of women as dominated by passion, ruled by their bodies, and essentially irrational (Fortenbaugh, 1975; Phillips, 1984; Spelman, 1983).[...] Hysteria owes its name to the causal theory of antiquity which implicated the womb (Gr. *hysteria*, cf. Veith 1965). The uterus was a sort of “wild animal” that moved within the body in response to sexual frustration or other

privations. Floating or pressing upward against the stomach, liver or diaphragm, the uterus gave rise to the myriad symptoms of hysteria.(Kirmayer, 1988: 70)¹⁴

The suggestion of hysteria is picked up again in the following two extracts. In 1961 a small epidemic (extract 16) and two isolated cases at the Infectious diseases Unit, St. George's Hospital,(extract 17), were reported in the same edition of *The Lancet*.

Extract 16: Benign Myalgic Encephalomyelitis in Newcastle upon Tyne.

"In 1955 an obscure illness appeared among members of the medical, nursing, auxiliary medical, ancillary, and administrative staff of the Royal Free Hospital, London [...] The present report describes a small epidemic in late 1959 in St. Mary's Training College for teachers in Newcastle upon Tyne.[...] 46 out of about 200 students in the college were affected and 2 of the resident staff. [...] The signs and symptoms were those observed in other outbreaks- initial headache, fever, myalgia, muscular weakness and emotional lability. In the severe cases the course of the disease was lengthy with repeated remissions and relapses. [...] Emotional upset was sometimes so great as to suggest hysteria. [...] The cases occurred in a completely random fashion. No males were affected. All the available evidence suggests that benign myalgic encephalomyelitis is an infection but this cannot be confirmed at present."

Hope Pool et al. (1961) *The Lancet* pp.733-737.

Extract 17: Myalgic Encephalomyelitis

"So-called "benign encephalomyelitis" generally arises in well-defined epidemics. Isolated cases are sometimes suspected, but are usually mild and in the absence of pathognomic signs defy definite diagnosis. [...] These two patients had illnesses, which, in pattern and natural history, resembled those in the Royal Free Hospital group outbreak of encephalomyelitis (Medical Staff of the Royal Free Hospital 1957) and the Durban epidemic of myalgic encephalomyelopathy (Hill et al. 1959). [...] This illness is probably commoner than is usually realised and mild sporadic cases may easily be labelled as hysteria, glandular fever, or myalgia."

J. Lewis Price (1961) *The Lancet* pp.737-738.

Extract 16 draws attention to the suggestion of hysteria, the randomness of the cases, and also points out that "no males were affected". In extract 17, it is suggested that since "so called benign myalgic encephalomyelitis" arises in isolated cases as well as epidemics, and that it might often be difficult for doctors to identify and therefore might easily be misdiagnosed as hysteria, glandular fever, or myalgia. This provides an account for *why* the illness is said to more commonly arise in well-defined epidemics rather than sporadic cases. *And* (in a circular way) sporadic cases, by definition, do not conform to the *pattern* of how M E arises, and can therefore be misdiagnosed.

¹⁴ See also Richmond (1989) for a further discussion of these issues.

The Question of Hysteria - revisited

“In 1970, two young psychiatrists, McEvedy and Beard, re-examined the case notes of patients from the Royal Free epidemic of 1955...” (Jenkins, 1991: 20).

Extract 18: *Royal Free Epidemic of 1955: A Reconsideration*

“Summary: From a re-analysis of the case notes of patients with Royal Free disease it is concluded that there is little evidence of an organic disease affecting the central nervous system and that epidemic hysteria is a much more likely explanation. The data which support this hypothesis are the high attack rate in females compared with males; the intensity of the malaise compared with the slight pyrexia; the presence of subjective features similar to those seen in a previous epidemic of hysterical overbreathing; the glove-and-stocking distribution of the anaesthesia; and the normal findings in special investigations. Finally, a deliberate attempt by one of the authors to produce an electromyographic record similar to that reported in Royal Free disease was successful [...]

The year after the epidemic, a leading article appeared in the *Lancet* entitled “A New Clinical Entity?”. In this article the name “benign myalgic encephalomyelitis” was proposed for Royal Free disease and certain similar illnesses (*Lancet*, 1956). When the medical staff at the Royal Free Hospital wrote their account of the outbreak (Medical Staff, 1957)- referred to hereafter as the Medical Staff report- they also described the illness as an encephalomyelitis. The nature of the infective agent was admitted by all concerned to be obscure, but considerable definition was claimed for the clinical syndrome. To quote the end of the *Lancet* article, “we believe that its characteristics are now sufficiently clear to differentiate it from poliomyelitis, epidemic myalgia, glandular fever, and the forms of encephalitis already described, and, need it be said, hysteria.”

The concluding words seem to us non sequiturs. The case for hysteria was not examined in the article; indeed it received no consideration apart from this summary dismissal. In our opinion the case is a good one, and the purpose of this paper is to obtain a fair hearing for it. Firstly we present the findings reported from the epidemic and then our interpretation of them.” McEvedy, C.P. & Beard, A.W. *British Medical Journal*. January 3, 1970. pp.7-11

This piece by McEvedy and Beard constitutes a response to *The Lancet* editorial that appeared in 1956 proclaiming a “new clinical entity”(extract 5). The authors of extract 18 object to the cursory dismissal of an explanation of hysteria which was specifically manifest in the rhetoric of “need it be said” (in extract 5). They continue here, in an attempt to counter that dismissal, to provide epidemiological evidence for the high attack rate in females (10.4%) compared with males (2.8%); they also gave a list of subjective symptoms (headache, weakness, dizziness, nausea, pain in back or abdomen, pain in chest or neck, feeling of panic, vomiting) that they claimed were common features of both the Royal Free disease and also of what they described as a ‘schoolgirl epidemic of hysterical overbreathing’ (Moss and McEvedy, 1966). Finally, some of the most empirically convincing pieces of clinical evidence (electromyograph

records) reported by earlier authors (e.g. Galpine & Brady, 1957) to support their claims for an organic lesion, were called into question by a successful, deliberate attempt to reproduce a similar result. McEvedy and Beard claim that “In practice it is quite easy to obtain this type of trace by encouraging one’s rigid outstretched arm to tremble.”(1970: 10).

The following review article by the same authors appeared in the same issue of the *British Medical Journal*. It addresses the same outbreaks as Acheson’s review (extract 15) and again reaches a different set of conclusions about the causes of the illness.

Extract 19: *Concept of Benign Myalgic Encephalomyelitis.*

“Summary: The reports of the 15 recorded outbreaks of benign myalgic encephalomyelitis have been reviewed and in one instance the original data studied. We believe that a lot of these epidemics were psychosocial phenomena caused by one of two mechanisms, either mass hysteria on the part of patients or altered medical perception of the community. We suggest that the name “myalgia nervosa” should be used for any future cases of functional disorder which present the same clinical picture.

Acheson (1959), in a review article on benign myalgic encephalomyelitis, enumerated 14 epidemics that he considered belonged in this category. A fifteenth has been reported since (Daikos *et al*, 1959). The term “benign myalgic encephalomyelitis” was proposed in 1956 (*Lancet*, 1956), so the dozen outbreaks before this date have received the label retrospectively. The outbreaks, however, have so many features in common that the case for regarding at least the epidemic form of the illness as a unitary phenomenon is a very fair one. In the preceding paper (McEvedy and Beard, 1970) we have presented the evidence for regarding one of the most striking epidemics in the series-the Royal Free Hospital outbreak of 1955- as an hysterical phenomenon. Can this formulation be applied to any or all of the other 14? After looking at the published reports on these epidemics (which we review below with our comments), and in one instance studying the original clinical data, our conclusion is that two mechanisms are at work, both psychosocial. We believe that between them they account for the phenomenon of benign myalgic encephalomyelitis.”

[...]

As there seems to be a total lack of objective evidence in support of the view that in cases of benign myalgic encephalomyelitis the brain and spinal cord are the site of an infective, inflammatory disease process, we would suggest that the name be discarded. Even if the view that the symptoms are hysterical is not accepted, it would seem prudent to shorten it to “benign myalgia”. Our own inclination is for “myalgia nervosa” on the analogy of “anorexia nervosa.” This could serve both for the epidemic illness and for any isolated cases of functional disorder which conform to the same clinical picture.”

McEvedy, C.P. & Beard, A.W. January 1970, *British Medical Journal*. pp.11-15

This re-interpretation of the Royal Free (and the other 14 outbreaks) in terms of “mass hysteria on the part of patients”, and “altered medical perception of the community” was offered in the absence of “objective evidence” for “an inflammatory disease process”(extract 19). The authors argue that although there was not a strong case to

defend claims for the existence of a new disease entity, the alternative explanation of hysteria, had not been given serious consideration (extract 18). They present their first article (extract 18) as a 'case for the defence' of a diagnosis of hysteria, with the aim of obtaining "a fair hearing for it".

"However they [McEvedy and Beard] unfortunately did not go on to examine the reasons which had led earlier observers ultimately to reject the hysteria hypothesis, and which have been discussed earlier in this chapter." (Jenkins, 1991: 20)

The potential for their contribution to be taken as controversial and perjorative is constituted by McEvedy and Beard in the discussion section of the first paper as follows:

Extract 19a.

"Many people will feel that the diagnosis of hysteria is distasteful. This ought not to prevent its discussion, but makes it worthwhile to point out that the diagnosis of hysteria in its epidemic form is not a slur on either the individual or the institution involved. Whereas it is true that sporadic cases of hysterical disability often have disordered personalities, hysterical reaction is part of everyone's potential and could be elicited in any individual by the right set of circumstances. The occurrence of a mass hysterical reaction shows not that the population is psychologically abnormal but merely that it is socially segregated and consists predominantly of young females."

(*ibid*: 10-11)

The authors manage the potential for a hostile response in two ways. First, by normalising the category of "hysterical reaction" as something that is "part of everyone's potential" given the right circumstances; and second, by attributing the cause of a hysterical reaction in this case (and epidemics in general) to situational rather than individual (or institutional) ones; that is, "the right set of circumstances". These circumstances were constructed in the first article as gendered:

Extract 19b.

"Characteristically epidemic hysteria occurs in populations of segregated females- in girl's schools, convents, and among female factory hands.¹⁵ At the Royal Free, as at any other hospital, the female population is segregated to a very considerable degree." (*ibid*: 9)

¹⁵ This footnote appeared in the original article. "The literature is surprisingly thin. Specific instances are (for girl's schools) Schuler and Parenton (1943), Tan (1963), Moss and McEvedy (1966), McEvedy et al. (1966); for convents Huxley (1952); for factory hands Kerckhoff and Back (1968)." (So the claim that "Characteristically epidemic hysteria occurs in populations of segregated females", is actually based on one-off case studies, whereas the use of the terms "characteristically" and "occurs" work discursively to script up the phenomenon as being a more general or typical pattern, of which the Royal Free [or any other predominantly female institution] may be an example.)

...and in the second article as being linked to a more general *medical* concern with the threat of paralytic poliomyelitis.

Extract 19c.

“...all illnesses not immediately diagnosable as something else were regarded as “query polio”. In our view the “epidemic” was an artefact due to an altered medical perception of the community. The corollary to this view is that the syndrome which characterised the patients after admission was due to: (1) a rising anxiety level on the part of the patients who were under threat of paralysis, and (2) a concentration of medical examination on the central nervous system.” [...] We think that the 14 patients [in the Middlesex hospital outbreak of 1952 (Acheson, 1954)] became a homogeneous clinical group only after admission, and that the symptoms then produced were due to a preoccupation with poliomyelitis on the part of both doctors and patients. (*ibid*: 13)

What is interesting in McEvedy and Beard’s account is how the nature of an epidemic is being defined as a social construction. They view the “epidemic” as “an artefact due to an altered medical perception of the community”. In other words they are claiming that the categorisation of the cases as similar was constructed by doctors having prior expectations which guided their diagnostic practices.

The Eye of the Storm

On the topic of hysteria, despite their (paradoxically rather provocative) attempts to anticipate and counter such a response¹⁶, McEvedy and Beard's articles "elicited a storm of protest" (Jenkins, 1991: 20) in the *Correspondence* section of the next issue of the *British Medical Journal* (January 17, 1970), under the heading; *Epidemic Malaise*. This took the form of several 'eye-witnessed' reports.¹⁷

Extract 20.

"Sir,- I have read with interest but incredulity the papers by Drs. C.P. McEvedy and A.W. Beard (3 January, p.7).

I am a general practitioner in North London, and the epidemic of benign myalgic encephalomyelitis which occurred there between the autumn of 1964 and the summer of 1966 was mainly in my practice. I saw about 370 patients of whom at least 20 were seriously ill and a high proportion of whom have not been restored to their previous good health.[...] Psychiatric disturbance was not observed if an early diagnosis was combined with bed rest.[...] It is my hope that the views expressed by Drs. McEvedy and Beard will not be taken seriously, especially as the implied diagnosis of "hysteria" to a seriously ill patient can cause acute distress and prolong the illness indefinitely [...] if a diagnosis of "hysteria" is even hinted, the patient experiences a profound loss of confidence in his medical advisers. Restoration of confidence may take months. It is essential to treat this disease seriously, and to give strong reassurance and encouragement in the difficult period when the patient is learning to "come to terms" with his disability.-I am, etc.,

Betty D. Scott.

Extract 21.

"Sir,- I regard the conclusions of the Royal Free epidemic (3 January, p.7) as nonsense. Many of these girls were known to me. Illness was alien to their nature. [...] Take another look at the Royal Free. I'm sure the adage "what we know we recognise" applies here. In the meantime I advise those of us who have to deal with epidemics in institutions: don't be hasty in calling in the psychiatrist, but first read the small print in your chapter on the central nervous system.-I am, etc.,

B. Judge.

"One writer with postgraduate experience in psychiatry and infectious diseases had been a clinical student at the time of the Royal Free epidemic (Gosling, 1970). She made a number of telling points."(Jenkins, 1991: 20).

¹⁶ See extract 19a. where the category of gender is drawn on to define the social circumstances surrounding the epidemic.

¹⁷ See Geertz (1988) on "I-witnessing" and the textual construction of eye-witnessed reports in ethnography. (Which I insert here to show how the participants *themselves* use the device of eye-witnessed reports to challenge the footing of other people's accounts.)

Extract 22.

Sir,- I am glad that Drs. C.P. McEvedy and A.W. Beard have had the grace to say that their opinions (3 January, p.7), on the Royal Free Hospital epidemic of 1955 are their own, as their paper is an example of the errors that one is apt to make in retrospective assessments of case notes made by people one doesn't know well. It also betrays considerable lack of historical awareness of the situation obtaining at the Royal Free Hospital at that time and of the full history of the epidemic.[...] Anybody who believes that the female population of the Royal Free Hospital was segregated just doesn't know the Free. I can only think that Drs. McEvedy and Beard must have led a very sheltered student life.[...] Nobody who really knew the physicians who looked after most of the cases would ever suggest that they would overlook hysteria in the differential diagnosis of an obscure and bizzare illness, and indeed the tendency would have been to put this higher on the list for students and nurses than for the general population.[...] As psychiatrists, Drs. McEvedy and Beard should be aware that a diagnosis of hysterical illness should be made on positive grounds of finding evidence of both primary and secondary gain, and not just on negative grounds of not being able to explain the symptoms in another way...

Paula H. Gosling.

In the last three extracts, McEvedy and Beard's reinterpretation of the Royal Free Disease as 'mass hysteria' is challenged by three contributors who ground their entitlement to speak with authority, on their own direct experience.¹⁸ Betty Scott (extract 20) bases her entitlement to speak on her personal experience with an epidemic of about 370 patients in her medical practice; B.Judge cites an acquaintance with some of the victims of the Royal Free epidemic, and Paula Gosling claims that McEvedy and Beard's claims about hysteria make no sense if taken in the context of a detailed knowledge of the circumstances surrounding the Royal Free epidemic (which of course she herself goes on to display in making the following claims:

- first, they betray a "considerable lack of historical awareness of the situation at the Royal free Hospital at that time"
- second, "anybody who believes that the female population of the Royal Free Hospital was segregated just doesn't know the Royal Free"

¹⁸ The entitlement to epistemological warrant is discussed in Potter (1996) with reference to the work of Harvey Sacks (1992), Whalen & Zimmerman (1990), and Widdicombe & Wooffitt (1995). Category entitlement provides a speaker with a warrant to knowledge about a particular domain. For example, being a doctor provides a warrant for being able to speak with authority on medical matters, and being a patient provides a warrant to speak about personal experience of illness. The writers of extracts 20, 21 and 22, are all medical practitioners who can claim to have been personally involved with victims of the Royal Free epidemic, and to have personal knowledge of the hospital, the doctors, and the circumstances surrounding the outbreak. Their accounts might therefore be taken to carry more epistemological authority than the account of researchers who had only re-interpreted the documents nearly twenty years after the event, as in the case of McEvedy & Beard.

- and third, “Nobody who really knew the physicians who looked after most of the cases would ever suggest that they would overlook hysteria”, particularly given the tendency to “put this higher on the list for students and nurses than for the general population”. On the contrary, it is argued that the physicians of the Royal Free would have had a prior inclination to look for *precisely* such an explanation.

On the other hand, McEvedy and Beard are accused of making errors and omissions, such as:

- not carrying out good science
- specifically “making retrospective assessments of case notes made by people one doesn’t know well”
- and not finding evidence of the “primary and secondary gain” that is considered necessary for a diagnosis of hysteria.

Gosling’s comments thus work to undermine McEvedy and Beard’s contribution as being contingent on ‘their own opinions’, since it was a re-analysis of the data, undertaken twenty years after the event, rather than being based on personal involvement with empirical investigation at the time of the epidemic. Their claims are construed as based on little or flimsy evidence, and therefore not to be taken seriously.

In the same issue of the *British Medical Journal*, a general practitioner wrote in to point out that:

Extract 23.

Most astute practitioners have observed diseases which were not described in the textbooks. However, the clinical features of some of these, such as ‘drop attacks’, epidemic myalgia, and hand, foot and mouth disease have now become clear and well-known, and I would agree that one should hesitate before attributing any unaccountable bizarre syndrome to hysteria because the entity does not fit any disease mentioned in present medical books.(Hopkins, 1970)

“This advice is as important today as it was then.” (Jenkins, 1991: 21)

The last two contributors to the correspondence page (B.Judge, extract 21; and P.Gosling, extract 22), also cautioned against the folly of making the category of

hysteria a 'diagnosis of exclusion'; that is, "not being able to explain the symptoms any other way". In her (1991) review article, Rachael Jenkins later goes on to make the observation that:

Sex ratios in illness are a fascinating study, and can provide important epidemiological clues to the origin of disease. But it is nonsensical to suggest that any disease which is more common in women is therefore likely to be hysteria on those grounds alone. Many physical diseases are more common in one sex than another, and sex ratios often change, reflecting changes in the frequency of important aetiological factors.[...] MS is more common in women and its cause is unknown, although the organic pathology is well documented.

A "fruitless dichotomy"?

In the same issue of the *British Medical Journal*, Gill (1970) made an appeal for a less dualistic framework to understand the illness.

Extract 24.

Can we not acknowledge that there is never one cause for a patient getting ill? Virus and hysteria are with us always, and the wise doctor never thinks in terms of 'either or'.
(Gill, C.H. 1970: 299)

Twenty one years later, Jenkins (1991: 30-31) made a similar observation:

Many doctors tend to oscillate uneasily in the 'either or' framework, i.e. either there is an organic disease present, or the patient is psychologically ill. McEvedy and Beard (1973) regrettably only proposed the two alternatives of definite physical illness or definite psychiatric illness, without taking a more coherent multi-axial approach to the Royal Free patients, and this fruitless dichotomy of organic versus functional has greatly hampered research on ME (David *et al.*, 1988). Abnormality may of course be present on any of the physical, psychological, social, personality and illness behaviour axes, and the presence or absence of abnormality in one axis does not preclude its presence or absence on another axis (Balla, 1985). Thus there is a major logical fallacy in the diagnostic approach, unfortunately all too common, that takes the view that a constellation of symptoms, where no physical abnormality has been demonstrated, must be psychological in origin. It may or may not be so. Physical abnormalities may be present but undetected. For example, several conditions previously regarded as hysteria are now thought to have an organic basis, including spasmodic torticollis, blepharospasm and writers' cramp (Lloyd, 1986). Therefore it is vital to diagnose psychological abnormality, not on the negative grounds of absent physical abnormality, but on the positive grounds of the presence of psychological phenomena, and to place the psychological phenomena in their multi-axial framework (Jenkins *et al.*, 1988a). Such a scheme has been proposed for use in general practice (Jenkins *et al.*, 1988b).

Yet another letter, in the May 16, 1970 issue of the *British Medical Journal* suggested that a *reversal* of the reasoning, that had previously described the mystery illness as being caused by hysteria, might be more appropriate.

Extract 25

The articles of Dr. C.P. McEvedy and A.W. Beard (3 January, pp.7 and 11) are of considerable concern because of the author's contention that benign myalgic encephalomyelitis (epidemic neuromyasthenia) is a phenomenon related to mass hysteria or to altered medical perception in the community. Their erroneous conclusions about this illness may impair future investigations of similar outbreaks.

It is apparent that the authors failed to do their homework, and demonstrated a surprising lack of information about the principles of epidemiology and of psychiatry. [...] The question of mass hysteria has been considered by the authors of most papers relating to this disease and in each instance has been discarded for a number of reasons- namely, (1) cases occurring within the same household are varied in their features and course; (2) separate illnesses appear at random intervals instead of simultaneously; (3) epidemiologically, the consistency of course and similarity of symptoms despite the variety of people and communities that were affected make hysteria unlikely. The disease is consistent from outbreak to outbreak in different countries, different years and different peoples. (4) The mental symptoms of depression, emotional lability, impaired memory and difficulty concentrating are consistent with organic disease as compared with the shallowness and indifference of hysteria. (5) Muscle pain is a striking feature of most outbreaks. It is clear that sporadic cases of this disease cannot be readily identified. It is only in the epidemic form that the distinctive epidemiological features allow characterisation.

Instead of ascribing benign myalgic encephalomyelitis to mass hysteria or psychoneurosis, may I suggest that the authors consider the possibility that all psychoneurosis is residual deficit from epidemic or sporadic cases of benign myalgic encephalomyelitis?

D.C. Poskanzer, M.D.

Department of Neurology

Harvard Medical School

Poskanzer's contention that McEvedy and Beard's conclusions about M E are "erroneous" is constructed here by accusing them of not doing rigorous, competent research, claiming that they "failed to do their homework, and demonstrated a surprising lack of information about the principles of epidemiology and psychiatry". This is contrasted with the "authors of most papers" who have already discarded the diagnosis of hysteria "for a number of reasons" which he then goes on to list as a set of general research conclusions. Rhetorically this display of information-giving serves as a sharp contrast to the 'ignorance' imputed to Evedy and Beard, whose views are formulated here as marginal to the agreed consensus, and based on incompetent research.

Reinstating myalgic encephalomyelitis

In 1978 a Leading article in the *British Medical Journal* gave a summary update that re-constituted current perspectives and problems relating to M E as follows.

Extract 26: Epidemic myalgic encephalomyelitis

“Outbreaks of the paralytic disease known as epidemic myalgic encephalomyelitis have puzzled doctors all over the world in the past 30 years. One of the best known of these epidemics was that at the Royal Free Hospital in London in 1955, which affected more than 300 people. Most outbreaks tend to occur in the summer, young adults are predominantly affected, and the incidence is higher in women. The evidence suggests that infection is spread by personal contact, and young hospital personnel seem particularly at risk.[...] The clinical outcome may take any of three courses: some patients recover completely, some follow a relapsing course, and some are permanently incapacitated.

At a symposium held recently at the Royal Society of Medicine¹⁹ to discuss the disease and plan research there was clear agreement that myalgic encephalomyelitis is a distinct nosological entity. Other terms that have been used to describe the disease were rejected as unsatisfactory for various reasons: the cardinal features show that the disorder is an encephalomyelitis [...] The adjective epidemic is correct, since most cases occur in an epidemic, but the disease may be endemic, and sporadic cases may occur.

Some authors have attempted to dismiss this disease as hysterical, but the evidence now makes such a tenet unacceptable. Some purely psychiatric symptoms may well occur, particularly in patients entering the chronic phase. No doubt, too, in an epidemic some hysterical persons will simulate the symptoms of the disease. Nevertheless, the organic basis is clear [...] At this symposium more evidence was produced to support the organic nature of the disease. [...] A perplexing finding, suggesting the possibility of a persistent virus infection, was the ability of lymphocytes from patients to proliferate and survive in vitro for up to 19 weeks.

We still know nothing about the nature and cause of epidemic myalgic encephalomyelitis, but outbreaks are still occurring.”

Leading Article, *British Medical Journal*, 3 June, 1978, 1436-7.

In this update we see the original claims for an organic explanation of the illness, myalgic encephalomyelitis, being reinstated as authoritative and legitimated by reference to a consensus of findings at a symposium of the Royal Society of Medicine. There was “clear agreement that myalgic encephalomyelitis is a distinct nosological entity”, furthermore M E is cited here as the preferred term, and is referred to as “a paralytic disease”, “an infection”, “an encephalomyelitis”, and “possibly a persistent virus infection”. However, some of the central claims in this article were subsequently contested in the following issue of the *British Medical Journal* (June 24, 1978: 1696).

Extract 27: Epidemic myalgic encephalomyelitis.

Sir,- I disagree with the view you express in your leading article (3 June, p 1436) that the many epidemics you cite compose a single nosological entity. Outbreaks in hospital staff apart, these miscellaneous episodes and others described at the Royal Society of Medicine may well have been as diverse aetiologically as they were geographically. Nor do I agree that

¹⁹ The proceedings of the symposium on “Epidemic neuromyasthenia. 1934-1977” at the Royal Society of Medicine were reported later in the November 1978 issue of the *Postgraduate Medical Journal*.

the Royal Free Hospital outbreak has now been proved to have been a form of encephalitis. [...] There seems to have been a failure to realise how suggestible people are when they are ill or anxious.

In a letter to *The Times* entitled "Vapour or virus" Sir Francis Walshe stated: "Epidemics of mass hysteria have punctuated history and doubtless a few centuries ago were attributed to witchcraft or demoniacal possession on evidence not less than that now evoking the mystic chant of the word 'virus.' ..." Though the Royal Free outbreak was a sorry affair compared with dancing madness, the classic form of mass hysteria, ataxia, vertigo, fits and prostration were common to both. Nowadays the vapour or virus, or whatever the devil it is, seems to be most at home in nurses' homes (in "centres of excellence" particularly). Anyone who wants to know if Walshe's statement could be pertinent to the Royal Free epidemic should not be content with your leading article: he should study the evidence for himself.

H G Easton
Clinical Department of Infectious Diseases
Ruchill Hospital,
Glasgow

In extract 27 the 'hysteria version' is again being re-constructed and works to undermine the grounds for the claims made in the Leading article (extract 26). Dr Easton implies that the author of the article misrepresents the empirical evidence, which is otherwise there for anyone to 'study for himself'. He also makes use of a contingent repertoire to undermine the premises of the claims made in extract 26. That is, he claims that the term 'virus' is being misappropriated in a more or less superstitious way without any evidence to support the claim. This is constructed as being analogous to the way that attributions of witchcraft and possession were used as explanations of mass hysteria a few centuries ago.

On July 15, 1978 (p. 202) the following response to Easton's letter was published.

Extract 28: *Epidemic myalgic encephalomyelitis.*

Sir,- from Dr H G Easton's letter (24 June, p 1696), I can only conclude that he ignored all the evidence at the symposium on myalgic encephalomyelitis at the Royal Society of Medicine that did not fit in with his theories. If he had stayed to the end, when a vote was taken, he would have found himself the only person present still in favour of the "conversion hysteria" theory. [...] Dr Easton's "vapour and virus" remarks are hardly worth serious attention. Failure to isolate a virus does not rule out the possibility of a viral illness...[...] I would suggest that before putting pen to paper again he talks to some of the nurses (who have never been adequately followed up) permanently disabled as a result of the Royal Free Hospital outbreak. He might then discover how much unnecessary anguish the "conversion hysteria" theory had added to their mental and physical suffering. [...] Dr Peter Behan said at the symposium that he thought the disease was an immunological reaction triggered off by a virus. It would be helpful if more doctors, instead of pursuing outdated theories, seized the ample opportunities which study of this illness offers for research, a point which you rightly make in your leader. **Celia Wookey, Edgeware, Middlesex.**

In this extract, Celia Wookey employs a contingent repertoire to construct Dr Easton's account as motivated, misinformed, and prejudiced. On the basis of his comments in extract 27 she concludes that Dr Easton had a prior motive to ignore evidence "that did not fit in with his theories". Her grounds for making this claim are the observation that he did not even stay until the end of the symposium to listen to the evidence, so therefore he is *willfully* misinformed. He is in any case, the *only* one who still believes that "outdated theory", and so he cannot be taken seriously.²⁰ Wookey then moves to take the moral high ground vis the effect of such theories on sufferers. She puts Dr Easton on the wrong foot by formulating his 'ignorance' as "unnecessary" and therefore charging him with culpable negligence. She implies that he is not merely *clinging* to an outdated theory, but that he is actively "*pursuing* outdated theories" and setting his prior prejudices against all the available counter evidence. She suggests that he should take note of the anguish that this line of theorising has caused by talking to some of the victims, and perhaps contribute some *useful* research instead of wasting opportunities. Wookey's letter (extract 28) works to counter Dr Easton's earlier dismissal (extract 27) of the content of the Leading article (extract 26). In fact these three extracts appear to employ the same argumentative positions that were originally taken up earlier in the debate; particularly in extracts 5, 18, 19, 19a, 19b, 19c, and the responses to these in extracts 20, 21, 22, 23 and 25.

"Altered medical perception" and the social construction of epidemics

In 1980, an article by May et al in the 'Community Health' section of *The Lancet*, re-raised the question of "altered medical perception" as a factor in defining epidemics.

Extract 29: *Personality and Medical Perception in Benign Myalgic Encephalomyelitis.*

"In an outbreak of benign myalgic encephalomyelitis in a girls' school all the residential pupils, both those affected and those unaffected, were investigated. Special virological tests were essentially negative, but it seemed that a few girls had had a viral infection. Psychological testing showed that among younger girls the patients were more neurotic than the others. Girls with various disorders were found to have been classified as having the same disorder, because of what has been called altered medical perception."

May et al, *The Lancet*, November 22, 1980.

²⁰ "However, since the McEvedy & Beard papers were published, the standard psychiatric teaching, and indeed often the standard medical teaching, has been that ME is primarily a functional illness, namely hysteria." (Jenkins, 1991: 25)

This occasioned the following response in the correspondence section of the next edition:

Extract 30: *Was it Benign Myalgic Encephalomyelitis?*

"Sir,- The disease described by Dr May and others (Nov. 22, p.1122) is barely recognisable as myalgic encephalomyelitis. Although the symptoms were 'severe and recurrent, lasting up to 8 weeks' no girl had symptoms during the following term, which militates strongly against the diagnosis of myalgic encephalomyelitis (ME)...In 1969²¹, it was suggested that ME should only be diagnosed if neurological and muscle signs were found.[...] It is obviously essential to investigate mysterious diseases by psychological as well as physical tests, as May et al did. However, the diagnosis of myalgic encephalomyelitis should be restricted to patients with much more objective evidence of ME than was shown in the patients described. Two classic outbreaks of ME with many patients experiencing severe symptoms, and relapses were described in *The Lancet* in 1959."²²

C.S. Goodwin. *The Lancet*. Jan. 3, 1981.

Dr May and his colleagues replied to Dr Goodwin's letter as follows:

Extract 31

"Sir,- Dr Ramsay and Dr Goodwin believe that we are unjustified in describing the illness we reported (Nov. 22, p.1122) as benign myalgic encephalomyelitis. We would like to assert that the symptoms in the girls' school closely parallel those in all the main reported outbreaks.[...] We have not suggested that there have been no organic diseases in the outbreak we described, or in former outbreaks, but we have suggested, and do so again, that outbreaks or 'epidemics' are more than simple aggregates of cases of (benign) myalgic encephalomyelitis or epidemic neuromyasthenia, and so on, not least because "altered medical perception" causes a variety of disorders to be lumped together.[...] It may be idle to dispute over precise (or rather imprecise) nosological terminology; we maintain that we are describing the same phenomenon as Ramsay and others."

May et al. *The Lancet*. Jan.3, 1981.

This correspondence again²³ calls attention to the social processes by which medical categories are identified and agreed (or dismissed). An epidemic is defined in terms of medical agreement that individual cases are part of the same phenomenon; and in the case of M E, being part of the same phenomenon is what has allowed it to be easily identified as M E in the first place. It is *precisely* the circularity of this definition that makes sense of the claim that isolated, sporadic cases would be difficult for doctors to spot, and also that doctors are more likely to "lump different illnesses together" under

²¹ Adamson, J.R. (1969) Epidemic neuromyasthenia (cont). *New England Journal of Medicine*, 281: 789.

²² See extracts 13, and 14; the Durban and Athens outbreaks.

²³ See also extract 15.

epidemic conditions, where epidemic conditions are themselves constructed by that very process of ‘lumping together’. In extract 31, May *et al* call attention to the process by which M E, in this and other cases, might become an artefact of “altered medical perception”. Goodwin’s response to this (cited in extract 30) is to separate ME as a diagnostic entity from the phenomenon that May describes, and in a distancing manoeuvre Goodwin distinguishes between May’s outbreak and the “classic outbreaks” which are formulated here as severe and relapsing. So the accusation (that is refuted in extract 31) is that May is not describing the same phenomenon as the “classic outbreaks”. The social processes of “altered medical perception” are not being denied here, but the available implication is that there has been a fundamental misconstrual of what defines M E in the first place.

Taking the theoretical ‘high ground’

Over the next decade, there was an explosion of articles on M E that appeared in different journals all over the world.²⁴ However, I have selected just a few articles from the main medical journals that attend to the *debate* surrounding M E²⁵, as *itself* a participants’ concern. In other words I focus on those that have taken up a *metaposition* in documenting the progress of the debate, in the sense that they continue to formulate, re-formulate, and point up the issues (such as naming, diagnostic criteria, and the debate about the causes of the illness) that previous participants had constructed as being controversial in the first place.

For example, the following article appeared in the *British Medical Journal* in 1987:

²⁴ Over the next decade, Bids Embase listed 1,171 publications under the keywords ‘chronic fatigue syndromes’, which can be categorised in terms of their contributions to different disciplines such as microbiology, psychiatry, immunology, neurophysiology, epidemiology, virology, etcetera.

²⁵ Or CFS as it was increasingly referred to in the 1980’s. (see chapter 3 for a detailed discussion of the significance of diagnostic labels and their use.)

Extract 32: *Royal Free disease: perplexity continues.*

Epidemic neuromyasthenia, persistent myalgia following sore throat, Otago mystery disease, Icelandic disease, and myalgic encephalomyelitis are just some of the names used for a chronic debilitating illness presumed to be a sequel of viral infection. The medley of names reflects the protean nature and worldwide distribution of the condition whose cardinal feature is extreme exhaustion after exercise; this is usually accompanied by a range of somatic, psychological, and 'flitting' neurological symptoms. The Myalgic Encephalitis Study Group, formed in 1975, met last week at the Royal Society of Medicine to review the findings in the 70 or so suspected outbreaks and to discuss strategies for diagnosis and management. Postviral fatigue syndrome or myalgic encephalomyelitis are the currently favoured names for the illness, but in Britain a well known outbreak gave rise to the more familiar sobriquet, Royal Free Disease. [...] The division between those who believe that the outbreak was caused by an infection and those who favour a psychological explanation continues to echo down the years.[...] Until recently most cases of postviral fatigue syndrome have been epidemic. But since 1980 evidence that the illness may be endemic has accumulated.
Jane Dawson (Technical Editor, *British Heart Journal*) *British Medical Journal*, Feb 7, 1987.

The relevance of a division of opinion that "continues to echo down the ages" has been a central participants' concern. Organic versus psychological explanations, that can be traced right back to the start of this medical narrative²⁶, have been punctuated only by Gill's (1970) appeal for a less dualistic framework to understand the illness (extract 24). This appeal is expressed again in the following article that appeared in the *British Medical Journal* in 1988, where the author questions the assumptions on which the "acrimonious debate" is premised.

Extract 33: *Postviral fatigue syndrome: time for a new approach.*

"Myalgic encephalomyelitis continues to provoke strong opinions in the medical press and intense interest in the lay media, as it has for the past four decades. The condition, variously named epidemic neuromyasthenia, Icelandic disease, benign myalgic encephalomyelitis, is more appropriately referred to as the postviral fatigue syndrome. Clinical descriptions include a vast array of symptoms and signs but the two main features that emerge are fatigue and emotional disturbance. The condition may be epidemic or sporadic. In this paper we reconsider some of the arguments surrounding the postviral fatigue syndrome and suggest a starting point from which constructive knowledge may be gained.

The hysteria debate.

Published work has been dominated by acrimonious debate between those who view the postviral fatigue syndrome as a narrow "organic disease"---namely, physicians concerned in the Royal Free outbreak [see extract 8] and current sufferers---and those who follow the lead of McEvedy and Beard in viewing it as "mass hysteria"[see extracts 18, and 19]. This sterile argument continues to the present day, serving little purpose, based as it is on fundamental misunderstandings. [...] Present controversy rests on a false dualism and an outdated

²⁶ According to the author of extract 25 "The question of mass hysteria has been considered by the authors of most papers relating to this disease and in each instance has been discarded for a number of reasons..." Poskanzer (1970).

separation of mind and body, and the shortcomings of these approaches are emphasised by increasing knowledge of the biological abnormalities found in psychiatric disorders. Hysteria itself is an outmoded diagnosis and is being replaced by the concept of “abnormal illness behaviour.” This takes account of the interaction between “organic” illnesses and psychiatric symptoms and a more sensitive appreciation of how social factors govern the presentation and outcome of illness. It is a better description of the often fraught interplay between sufferers with the postviral syndrome and their doctors.”
David et al, *British Medical Journal*, March 1988.

David et al move to take up a metaposition by construing the other participants in the debate as having “outdated” ideas about the relationship between mind and body, and the nature of disease itself. The “sterile argument” of an “outdated separation of mind and body”, referred to in extract 33, is developed further by H.G. Kennedy in a letter to *The Lancet*, May 16, 1987: 1145, who points out the circularity of cause and effect arguments that themselves work to blur such a sharp distinction. These two articles can be seen as a move to transcend the “outdated” explanations and formulate one’s own contribution as premised on a more complex and sophisticated level of analysis and theoretical explanation.

A “circular argument”?

Extract 34: *Fatigue and Fatigability*.

“...The differential diagnosis of patients presenting to physicians with fatigue can be found in most medical texts, and to the usual list can be added the so-called “post-viral syndromes” of fatigue. Some of these have evidence of recent viral infection and some have not. Whether these cases should be classified with psychiatric disorders or with unusual immunological defects has become a circular argument; physical illness can cause fatigue and depression but depression can cause a wide variety of immunological defects which could in turn cause physical illness.

H G Kennedy, *The Lancet*, May 16, 1987: 1145.

The authors of extracts 32 and 33 have also drawn attention to the epidemic *or* endemic (sporadic) nature of the illness. According to the author of extract 32, evidence for the *endemic* nature of the illness (as well as its epidemic nature) has accumulated since 1980. One explanation that might be offered (if I felt inclined to enter the debate as a participant²⁷) is that in the light of more specific guidelines,

²⁷ My move to enter the debate as a participant is designed to call attention to the very distinction that is usually made between the analyst and participant in discourse, and conversation analytic work (see Schegloff, 1997). At this point in the text, I have adopted the ‘natural attitude’ and offered an

sporadic cases were becoming *easier* for doctors to classify, or that the debate surrounding this issue in the medical and popular press had called attention to the diagnostic possibility of sporadic cases, for both doctors *and* their patients.

This kind of “altered medical perception” argument was used originally by McEvedy and Beard (extract 19), except here I am applying it to how sporadic cases might have become more easily definable as M.E. For instance, in 1988 Lloyd et al drew on a “working case definition” of “Chronic fatigue syndrome” which gave detailed diagnostic criteria that any doctor could use as a guideline.²⁸ This kind of case definition typically consists of, what Aronowitz (1992) refers to as a “Chinese menu” style list of diagnostic criteria, outlining core signs and symptoms, and a lengthy catalogue of optional variations.

Extract 35: *What is Myalgic Encephalomyelitis?*

Sir,- To improve our knowledge of the pathophysiology of myalgic encephalomyelitis (ME), it is essential that only one name is used to describe the disorder and that reproducible diagnostic criteria are agreed. Having reviewed the clinical and laboratory features of over 200 patients with well characterised ME, we agree with the Centers for Disease Control (CDC) that the best term is chronic fatigue syndrome (CFS). We have developed and evaluated a set of diagnostic criteria after reviewing 100 patients with CFS diagnosed by a characteristic history (especially muscle fatigue), a normal physical examination (excluding the findings of lymphadenopathy, muscle tenderness, or pharyngitis), and negative investigations to exclude other chronic infectious or immuno-impairing diseases.[...] The CDC criteria require or recommend the exclusion of over thirty diseases by at least twenty laboratory investigations, before the complex clinical criteria may even be considered. Our criteria highlight the central positive features of the syndrome, supported where appropriate by laboratory investigations. Patients with CFS may well be heterogeneous, but we believe our criteria will define most of this population and that their disorder will have a common pathogenesis.

Lloyd et al. *The Lancet*. June 4, 1988.

explanation for why evidence for the endemic nature of M.E. has accumulated since 1980. There seems to be a blurring of the analyst/participant distinction in this case, since the social construction of a disease entity is a concern that is common to both.

²⁸ See also: Holmes et al. (1988). Chronic fatigue Syndrome: a working case definition. *Annals of Internal Medicine*. 108: 387-89.

Paradoxically the last sentence of extract 35 continues to point up how a heterogeneous group of patients can be legitimately ‘lumped together’ according to a set of criteria that define ‘chronic fatigue syndrome’ as a discrete diagnostic category. The following extract also emphasises the point that although fatigue itself can be a symptom of many medical conditions, the patient group who have been referred to as having chronic fatigue syndrome is “almost certainly aetiologically and prognostically heterogeneous”.

Extract 36: *Follow up of patients presenting with fatigue to an infectious diseases clinic.*
In recent years there has been renewed interest in the causes and management of the symptom of fatigue. Although fatigue is a symptom of many medical conditions, identifiable organic disease is rarely found in patients referred to hospital with fatigue as a major complaint. The fatigue is then considered to be “idiopathic.” Clinical concern has focused on patients whose fatigue is idiopathic, persistent, and associated with impaired physical and mental functioning, who have been referred to as having a “chronic fatigue syndrome” if the fatigue has been present for at least six months. The patient group thus defined is almost certainly aetiologically and prognostically heterogeneous. Several more specific syndromes have been proposed, including more restrictively defined chronic fatigue syndromes, postviral fatigue syndrome, and myalgic encephalomyelitis. Although each has its advocates, none of these specific syndromes has yet been shown to have a clinical utility.[...] In this report we present findings from a large consecutive series of patients who presented with a major complaint of fatigue to a single physician working in an infectious diseases clinic.[...] The functional impairment of patients with the chronic fatigue syndrome is severe, but our results suggest that the prognosis for functional recovery by two to four years after clinic assessment is good. Many patients remain symptomatic, however, and a significant minority remain chronically disabled.[...] Patients who are functionally impaired are more likely to have an emotional disorder, to believe in an infectious cause for their illness, to avoid alcohol, and to be members of a self-help organisation...”
Sharpe et al. *British Medical Journal*. July 18, 1992, 305: 147-152.

This article, suggesting a link between membership of a self-help association and poor prognosis, provoked a range of responses:

Self-help or “cherished beliefs”?

Extract 37.
Editor,- Michael Sharpe and colleagues’ paper confirms what many clinicians have long suspected- namely that the prognosis for those with a chronic fatigue syndrome who reach specialist care is poor. The paper also suggests that membership of a self help organisation is associated with a poor outcome. Although the authors emphasise that this association is not necessarily causal, I fear that the self-help organisations may interpret this as another attack on their credibility, which will further sour relations between the organisations and the profession. What are the possible explanations for these disturbing findings? Sharpe and colleagues suggest that patient’s beliefs are an important mediator of disability, a view I

share. An article written by a sufferer illustrates how this might happen: “These living viruses are erratic and unpredictable. The prickly-edged ones pierce their way into the body cells. If disturbed by the patient’s activity they become as aggressive as a disturbed wasps’ nest, and can be felt giving needle-like jabs (or stimulating the nerves to do so).” It is easy to understand how such beliefs, regardless of their scientific accuracy, amplify disability.

The situation is rendered more tragic as it now seems that the evidence on which these beliefs (that persistence of enteroviruses in muscles is the cause of undoubtedly genuine symptoms) is based is less than convincing.[...] Sharpe and colleagues’ findings of a poor prognosis should cause all those who advise patients with the chronic fatigue syndrome to pause for thought and perhaps discard cherished beliefs...

Simon Wessely, *British Medical Journal*, 8 August, 1992. 305: 365.

First, Wessely works to disalign himself from any further souring of “the relations between the [self-help] organisations and the profession”, that might have ensued from the statements in Sharpe’s article. But then he goes on to make available the implication that the link between functional impairment and membership of a self-help group (documented in Sharpe’s study, extract 36), might be due to ‘inappropriate beliefs’ based on scientifically inaccurate information that may be available to sufferers through “all those who advise patients with the chronic fatigue syndrome”. In other words, Wessely claims that patients are learning inappropriate illness behaviour through being supplied with ‘inaccurate explanations’ for their condition.

Charles Shepherd of the M E Association responded to Sharpe’s findings as follows:

Extract 38

Michael Sharpe and colleagues’ follow up study of 177 patients with chronic fatigue of uncertain origin raises several important unanswered questions, which require further investigation. Factors such as a belief that their illness followed an infection, intolerance to alcohol, and membership of a support group for patients with myalgic encephalomyelitis were all associated with an adverse prognosis. Could it be that the authors had identified patients belonging to a distinct postinfectious subgroup as many doctors maintain they do? [...] The problem with any kind of research into the chronic fatigue syndrome is that, like backache, it covers a large heterogeneous group of patients in whom physical, psychological, and social factors may be interacting. Researchers should therefore not be surprised to find that the outcome varies considerably when the aetiology is not more clearly defined.

Charles Shepherd, *British Medical Journal*, 8 August, 1992: 365.

Shepherd recruits Sharpe’s own findings to support the contention that M E is in fact a separate organic entity, and that this group of patients are after all “a distinct postinfectious sub-group”. Sharpe’s data is here being made sense of in terms of what the M E Association had been saying for years; that there is a real distinction between

M E and CFS. In other words, the outcome for this sub-group is poor precisely *because* it is a more serious condition that *does* follow an infectious disease.

Extract 39

Editor,- Michael Sharpe and colleagues report that most patients with the chronic fatigue syndrome rate contact with medical services as unhelpful or only slightly helpful. Many sufferers turn to alternative health care, again with varied success. Such dissatisfaction with medical care is well documented, and self-help organisations flourish to provide the support, advice, and education that is not, or cannot be, provided by the medical profession; they potentially fulfill an important role.

The authors conclude that for patients with the chronic fatigue syndrome membership of a self-help organisation is associated with a poorer outcome (although whether members were more functionally impaired at the outset is not known). Adopting coping strategies, particularly with regard to exercise and “stress”, and a belief in the persistence of a viral infection are also associated with continuing disability.

Unfortunately, such advice continues to be offered to patients with the syndrome, particularly by self-help organisations. It is to be hoped that all those caring for patients will take note of Sharpe and colleagues’ conclusions. Work with fatigued patients in primary care (E. McDonald *et al*, paper in preparation) suggests that general practitioners have a central role in preventing the longer term secondary disability described by the authors- by acknowledging the distress caused by fatigue, limiting investigations and referrals to specialist centres, prescribing antidepressants when appropriate, and encouraging maintenance of activities. The patients in Sharpe and colleagues’ study were receiving secondary care, and possibly by then beliefs and attitudes to physical symptoms are already engrained.

H Cope and A S David, *British Medical Journal*, 8 August 1992: 365.

Cope and David spell out the implications of Sharpe’s findings for the future policy of self-help organisations who are construed as currently contributing to the disability of their members by offering ‘unhelpful advice’ about the management of the illness.

Stake management - “No one gains...least of all us”

A representative of the M E Association responded to these letters as follows in the September issue of the *British Medical Journal*.

Extract 40: Self help organisation’s advice on myalgic encephalomyelitis

Editor,- I should like to assure Simon Wessely that neither the ME Association nor ME Action regards Michael Sharpe and colleagues’ findings in patients with chronic fatigue as another attack on its credibility. Nor do we see why the paper should “further sour relations between the organisations and the profession.”

As Wessely points out, the apparent relation between functional impairment and membership of a self-help organisation at follow up does not mean that membership of such an organisation is responsible for the impairment. Aside from the fact that the study did not focus on myalgic encephalomyelitis, or on the work the ME Association does, Sharpe

reassured us that there was no evidence of a causal relation between membership of a patient group and level of disability.

As regards the potential damage resulting from inaccurate information about myalgic encephalomyelitis, it is worth emphasising that the quote that illustrates this came from *Nursing Standard* and not from a magazine for patients. The British organisations have long been unhappy with the way the media have portrayed the illness and reviewed existing research, and it is often extremely difficult to get erroneous or biased information corrected. Sometimes we get a right of reply, but usually we don't.

Finally, I wish to make clear that our current advice on exercise and stress is based on sound scientific research, the recommendations of our medical advisors, and 50 years' experience. Since our aim is to help patients it would be ridiculous for us to ignore good research and to stick instead to outdated explanations, speculations, or even prejudice. No one gains from such a narrow minded approach, least of all us.

The main reason why our beliefs tend to differ from those of Wessely and H Cope and A S David is that the authors do not distinguish between myalgic encephalomyelitis and chronic fatigue and we do. We see myalgic encephalomyelitis as more than "mental and physical fatigue," and we have evidence that treatments that seem to help patients with chronic fatigue do not always benefit people with myalgic encephalomyelitis (C Hickie, conference "Unravelling the mystery," North Carolina, 17-18 November 1990).

Our cautious attitude may worry those who disagree with us, but a less critical approach may lead to mistakes and we are anxious to avoid this.

M. C. Hume (M E Association), *British Medical Journal*, 12 September 1992: 649.

First in extract 40, Hume works to formulate his response as *not* being a retaliation. He accomplishes this by saying that (contrary to Wessely's comments in extract 37) they (the M E Association) have not construed Sharpe's research as "another attack on their credibility". This works to set up Hume's comments as being merely a contribution to scientific debate rather than a response to what Wessely fears may be construed as a personal attack that "will further sour relations between the organisations and the profession.". Second, Hume distances the M E Association from the 'inaccurate information' quoted in Wessely's article (extract 37), which can be traced to a source other than the M E Association's magazine. Neither, he claims, is the M E Association responsible for the media images of the illness, which may be "erroneous" or "biased". The upshot is to portray the association's voice as being misrepresented by its critics, whose comments are thereby discounted. Third, Hume lays out the scientific grounds for the advice that the organisation gives to patients; that is, "our current advice on exercise and stress is based on sound scientific research, the recommendations of our medical advisors, and 50 years experience."

This scientific approach is set out as a three part list against his own similar three-part formulation of what the association stands accused by their critics. This he lists as;

- ‘ignoring good research’
- ‘sticking to outdated explanations’
- and “speculations, or even prejudice”

The imputation of prior motive is countered here by Hume. The association (which exists “to help patients”) surely could not wish to give unhelpful advice based on outdated science, guesswork, and prejudice. Hume is here responding to, and countering the inference, made available by Wessely in extract 37, that the association dispenses advice on the basis of “cherished beliefs” rather than solid evidence.

Finally, Hume moves to take the high ground by pointing out that the policy of the association is based on a fundamental difference of *scientific* opinion between themselves and their critics; “the authors do not distinguish between myalgic encephalomyelitis and we do”. Their critics are thus construed as being less discerning and precise than themselves; “a less critical approach may lead to mistakes and we are anxious to avoid this.”

A year later the following comments by Charles Shepherd of the M E Association, work to legitimate some of the prior claims made by Hume, recorded in extract 40.

Extract 41: Description of ME revised in disability handbook.

...the Disability Living Allowance Advisory Board has agreed to important changes to the clinical description of myalgic encephalomyelitis in its “disability handbook.” The next revision of this will make it clear that myalgic encephalomyelitis is a separate clinical entity from the chronic fatigue syndrome (although they have several features in common), is not hysterical in origin, and can result in severe and permanent disablement. In common with the tenth revision of the *International Classification of Diseases* the handbook will also refer to myalgic encephalomyelitis as a neurological disorder...

Charles Shepherd (M E Association) *British Medical Journal*. 2 October 1993: 869.

...which was replied to by two “disappointed” members of the *Disability Living Allowance Advisory Board*:

Extract 42: Description of ME in disability handbook.

Editor,- We were disappointed that Charles Shepherd considered that he was free to make an unauthorised disclosure of part of a draft revision of the *Disability Handbook's* chapter on

myalgic encephalomyelitis. [...] Shepherd's letter summarises selected parts of the draft's text, but lacking completeness, may have misled readers.

We hope that the final text of the section on myalgic encephalomyelitis will provide a balanced account of current knowledge about, and thinking on, the condition. It will probably conclude that myalgic encephalomyelitis is a separate entity within the group of disorders encompassed by the chronic fatigue syndromes and that some affected people remain disabled, make little or no progress, or even deteriorate over time. The revised chapter will also, however, provide information about the majority of people with myalgic encephalomyelitis, in whom disablement is neither severe nor permanent.

Rodney Grahame and Mansel Aylward, *British Medical Journal*, 23 October 1993: 1071.

This criticism displays a participant's concern with selective reporting, and also works to call Dr Shepherd's integrity into question. First, the authors point out that he has no authority to speak about a report that is only in draft form. The consequence of his premature "unauthorised disclosure" is that his claims are based on an incomplete, and therefore potentially misleading reading of the draft's text; "Shepherd's letter summarises selected parts of the draft's text, but lacking completeness, may have misled readers." Therefore, it follows that his comments can easily be discounted as being his own selective (and extreme) version, rather than an accurate representation of what will finally be written in the *Disability Handbook*. On the strength of this, Dr Shepherd stands accused of failing to give a "balanced account of current knowledge".

M E or CFS: Same or different?

The debate surrounding the definition of myalgic encephalomyelitis as a discrete diagnostic entity continues with an article by David and Wessely.

Extract 43: Chronic fatigue, ME and ICD-10.

The nosological status of fatigue syndromes continues to cause debate and controversy. The inclusion in the tenth revision of the International Classification of Diseases (ICD-10)²⁹ of benign myalgic encephalomyelitis as a synonym for postviral fatigue syndrome (G93.3) under Diseases of the Nervous System seems to represent an important moral victory for self-help groups in the UK³⁰ who promote the notion of myalgic encephalomyelitis (ME) despite almost universal scepticism of the appropriateness and accuracy of this term among neurologists. [...] It is regrettable that the term chronic fatigue syndrome (CFS) was not adopted since this avoids unsubstantiated pathophysiology implied by myalgic encephalomyelitis and is neutral regarding aetiology. CFS avoids artificial separation between mental and physical symptoms and treats them both as inherent to the syndrome...

²⁹ World Health Organisation. *International statistical classification of diseases and related health problems*, tenth revision, Vol 1. Geneva: WHO, 1992.

³⁰ Shepherd, C. Description of ME revised in disability handbook. *BMJ* 1993; 307: 869. (see Extract 40)

Anthony David and Simon Wessely, *British Medical Journal*, 13 November 1993.

This worked to marginalise “people who promote the notion of myalgic encephalomyelitis” (such as M C Hume and Charles Shepherd of the M E Association) from a consensus of “almost universal scepticism”. David and Wessely’s move to take the scientific and theoretical high ground in recommending the “neutral” term CFS which “avoids artificial separation between mental and physical symptoms” was then challenged by two representatives of the *International Federation of ME Associations* as follows:

Extract 44: *Chronic fatigue syndrome or myalgic encephalomyelitis.*

Sir,- Although we agree with David and Wessely (Nov 13, p.1247) that the term benign myalgic encephalomyelitis (ME) is no longer accurate, we do not share their enthusiasm for the suggested replacement, chronic fatigue syndrome (CFS). CFS means different things in different countries. In Australia, it is synonymous with ME; in America, it covers several disorders, including ME, chronic fatigue and immune dysfunction syndrome, giardiasis, fibromyalgia, and masked depression, whereas in the UK it has become a dustbin diagnosis for all cases of unexplained chronic fatigue.

In a sense, ME is to CFS what migraine is to headaches: it is much more disabling, it is aetiologically more complex, and it is often more difficult to treat. The confusion between ME and CFS has persisted because too much of the published information is incomplete and unbalanced. For instance, many commentators have discussed the similarities between ME and depression, but have failed to point out the differences.

A growing number of scientists feel that the term CFS is so misleading that its adoption will hamper research, rather than help it...

Martin Arber & Anne Macintyre, *British Medical Journal*. 22 January 1994: 243.

In a similar move to the one employed by the authors of extract 42, who accused Dr Shepherd’s version of the description of M E in the *Disability handbook* of “lacking completeness”, Arber and Macintyre counter argue that the confusion and blurring of M E with CFS is an artefact of “incomplete and unbalanced” published work which fails to “point out the differences” between these two separate categories. The usefulness of the term CFS is also called into question on the grounds of ambiguity, on the grounds that its Australian, American, and UK counterparts do not use the same definitional criteria. This argument effectively undermines David and Wessely’s adoption of the ‘neutral’ term CFS as based on incompetent science. In the same issue Sandra Howes points out that M E and CFS are distinguishable *even* by the criteria of David and Wessely’s *own* research!

Extract 45.

Sir,- David and Wessely assert that ME and CFS are identical, but their own research has clearly shown that they are not. David and colleagues have reported that of 77 patients with chronic fatigue, 17 satisfied the Oxford criteria for CFS. Of these, only 4 (24%) people had, or believed they had, ME. Another 2 so-called ME patients did not fulfill the criteria for CFS.[...] Other research has also shown differences between ME and CFS (Oxford criteria). For instance, ME is associated with more pronounced cognitive deficits, more evidence of immune system abnormalities and a different pattern of cerebral hypoperfusion.

With respect to diagnosis, the new London criteria for ME might be more specific than the Oxford guidelines, but they too avoid “artificial separation between mental and physical symptoms”. [...] Finally, I challenge David and Wessely’s statement that the Oxford criteria have “proven reliability”. I am not aware of any research that supports this view, and, indeed, the only published report on the subject concluded that it had relatively poor predictive validity.

We may not know much about ME, but we seem to know even less about CFS.

Sandra Howes, *British Medical Journal*, 22 January 1994: 243.

Dr. Charles Shepherd responds to his critics...**Extract 46**

Sir,- I disagree with David and Wessely’s view that the “important moral victory” in having myalgic encephalomyelitis (ME) classified under diseases of the nervous system by the world Health Organisation (WHO) will undermine the progress in understanding the complex pathoaetiology of this syndrome. In fact, official recognition will probably now stimulate original research, which should include studies into the virology, immunology, neurology, and psychiatric components of the illness.[...] Patients with ME strongly welcome this decision. Their perception is that this classification will allow them to persuade sceptical doctors, employers, and educational authorities that the illness is genuine. Medical insurance payments might become more easy to obtain...

Charles Shepherd, *The Lancet*, 22 January 1994: 243.

Dr Shepherd formulates the consequences of having official recognition of ME as a separate clinical entity as being the stimulation of original research of all kinds, and as being beneficial to patients who might have had difficulty in persuading the authorities that they have a legitimate illness. His formulation works to counter the implication made available in David and Wessely’s article (extract 43), that “the important moral victory for self-help groups in the UK” represents the vindication of a partisan and marginal position which does nothing to address the complex relationship between mind and body.

“Scientific constructs...the catalogue of official sounds”

In the next issue of the *British Medical Journal* there were several articles on the topic of M E. These were introduced by the following comments in the *Editor's Choice*, which reflexively attend to the constructive practices involved in defining disease and arguing about M E, in the press, and in and through the practice of medicine.

Extract 47: *Fighting not against but over disease.*

Only the naivest medical students think that diseases have some independent, objective reality. Rather they are social and scientific constructs, and as such they can be fought over. This week's journal provides us a ringside seat from which to watch the struggle over myalgic encephalomyelitis. [...] Tony Delamothe reports on a study undertaken by the organisation Action for ME on how the condition is reported in the British medical press (p 798). The organisation detects a bias against a physical aetiology for the disease. Two medical authors have undertaken a longer term study of how the condition is reported in the medical trade press, national newspapers, and women's magazines; they find a bias in the lay media towards a physical aetiology. [...] We should try to keep an open mind on the condition. Richard Asher, the English doctor and writer, warned 30 years ago that “we shut our eyes to observations which do not agree with the conclusions we wish to reach. We close our ears to bits of history which seems out of place, or to noises coming down our stethoscopes which are not included in the catalogue of official sounds we have been taught to recognise.”

***British Medical Journal*, Editor's Choice, 19 March 1994:**

In particular Tony Delamothe's paper (referred to in extract 47) had made the following wry observations:

Extract 48: *Look at M E*

The supporters of myalgic encephalomyelitis as a discrete entity with an organic cause have brought off some spectacular coups. They have landed a Myalgic Encephalomyelitis Act on to the British statute books, requiring an annual report to be made to parliament on its causes, effects and treatment. And they succeeded in getting the latest revision of the *International Classification of Diseases* to include myalgic encephalomyelitis under diseases of the nervous system. Only doctors now remain sceptical about the condition and wary of accepting “encephalomyelitis” as the cause of symptoms without evidence of inflammation of the brain and spinal cord.

Doctors sometimes believe what they read in medical journals. Could the journals be partly to blame for their doubts? Action for ME, a patient support group, thinks so. After reviewing the coverage in the *BMJ*, *Lancet*, and three weekly newspapers sent to British general practitioners for the 18 months up to August 1993, it concluded that “medical journals keep doctors in the dark” with their “biased reporting”. The main complaints were that journals confused the chronic fatigue syndrome, myalgic encephalomyelitis, and the postviral fatigue syndrome and that they preferred psychological explanations of patient's symptoms “despite growing evidence of abnormal brain and immune function.”

The report is best understood as part of a marketing exercise to separate myalgic encephalomyelitis from a rag bag of chronic fatigue syndromes and to “brand” it as the one

with the organic cause.[...] Having defined the condition myalgic encephalomyelitis, its proponents now want doctors to diagnose it- a previous study by Action for ME suggested that they are reluctant to do so. Hence the need to police the coverage of the condition in medical publications, particularly those read by general practitioners.[...] If winning over doctors is important then the effort should go into proving beyond reasonable doubt that myalgic encephalomyelitis exists separate from the chronic fatigue syndrome and that it has an organic cause. Attempting to censor the encephalomyelically incorrect is more likely to alienate than convert.

Tony Delamothe, *British Medical Journal*, 19 March 1994: 798.

The first thing to notice about this report by Delamothe is the way that he describes the activities of the “supporters of M E as a discrete entity”, as having “brought off some spectacular coups”. The use of the term “coups” is suggestive of an organised movement that is politically motivated to make changes in favour of their own interests. He goes on to list the ways that they have accomplished this: First, by act of parliament,³¹ second by a revision of the *ICD*, and finally his three-part list³² is completed by the recent report of ‘Action for M E’ which dealt with ‘biased reporting’ in the medical press. This is described by Delamothe as a “marketing exercise”, where policing the coverage of M E in the medical press is construed by him as an attempt at censorship. His comments construct the research activities of ‘Action for M E’ as politically motivated. In other words, ‘Action for M E’ have a stake and interest in policing the kind of press coverage by which doctors “who sometimes believe what they read in the medical press”, might be influenced. The irony of his claim that “only doctors now remain sceptical” is brought into sharp contrast with the rhetorical certainty bestowed by the endorsement of two official and legitimating institutions (parliament, and an official classification of diseases). The scepticism of doctors who want to rely on scientific evidence is here sharply contrasted with the definition of disease as a *legal* accomplishment by a lobby of interested “supporters”.

³¹ ME is the *only* disease that has been legitimated by Act of Parliament, through a Private Member's Bill in 1987.

³² Gail Jefferson (1990) (discussed in Potter, 1996: 195-7) pointed out how three-part lists are used to construct the listed items as being instances of a more general class of things. In this case, Delamothe's use of the three-part list constructs a set of separate instances of political action, as part of a “spectacular coup” to get ME recognised as an discrete entity with an organic cause.

This vitreolic attack was followed up in a later issue of the *British Medical Journal* by a letter from the Director of the Information Unit, *International Federation of M E Associations*, who moves to take the high ground by offering a scientist's point of view.

Extract 49: Distinguish between syndromes...

Editor,- I note that several people writing in the *BMJ* are still confusing myalgic encephalomyelitis with the chronic fatigue syndrome. I wish to clarify matters. From a scientist's point of view, the main problem is not the term chronic fatigue syndrome but the various diagnostic criteria that go with it. For instance, the strict Australian definition adopted by Wilson *et al* is similar to that for myalgic encephalomyelitis. As a result, it is reasonably certain that in this article the two names probably refer to the same disease.

The "Oxford" criteria used in Britain, however, are far broader, covering all patients whose severe, unexplained fatigue has been present for at least half of the time and for at least six months. The only other requirements are that the fatigue must have had a definite onset and that it affects both physical and mental functioning. [...] Most patients who fulfill the Oxford criteria suffer not from myalgic encephalomyelitis but from more common conditions, notably *depression, anxiety states, sleep disorders, and fibromyalgia*. None of these disorders occur in epidemics, and most are not associated with the neurological and immunological abnormalities found in myalgic encephalomyelitis.

Does the distinction between the chronic fatigue syndrome and myalgic encephalomyelitis matter? It depends. According to recent research, treatments such as graded exercise which are helpful for the chronic fatigue syndrome do not generally benefit those with myalgic encephalomyelitis. On the other hand, combining all the fatigue syndromes together, implying that they share a common aetiology, and treating them in the same way would probably save the NHS and Medical Research Council some much needed money...

Ellen M Goudsmit, *British Medical Journal*, 14 May 1994:1297-8.

Goudsmit attempts to reinstate the scientific grounds for the claims of the M E Associations, and implies that the use of CFS as a catch-all term might potentially be used as a money-saving device. This makes available the suggestion that there are some participants in the debate who might have an interest (other than a purely scientific one) in wanting to resist the separate definition of M E as a disease entity.

A matter of methodology and definitions?

The Director of 'Action for M E' spells out precisely the implications of the different methodologies and definitions that "inevitably lead to different findings on the degree to which depression is a perpetuating agent in these conditions."

Extract 50: ...and study them separately.

The struggle over myalgic encephalomyelitis and the chronic fatigue syndrome is not, as S M Lawrie and A J Pelosi suggest, whether they are physical or mental illnesses. Both sides in this debate accept that most illnesses combine organic and psychological factors. The struggle is about methodology and definition and, in particular, how different methodologies and definitions inevitably lead to different findings on the degree to which depression is a perpetuating agent in these conditions.

One side favours studying the chronic fatigue syndrome as a single entity, arguing that there is insufficient knowledge at present to differentiate between different chronic fatigue syndromes. This side prefers Sharpe *et al*'s broad definition of the syndrome, which includes depressive illness, anxiety disorders, and the hyperventilation syndrome. Unsurprisingly, studies that use these criteria find higher levels of depression (or "psychosocial disorders"- yet another woolly term).

The other side argues that there is sufficient knowledge to distinguish specific chronic fatigue syndromes, particularly the much studied myalgic encephalomyelitis, and that it must be better science in these cases to study such syndromes in their own right. Furthermore, it argues that the study groups based on broadbrush criteria will have been so aetiologically heterogeneous as to invalidate the findings. This side, which includes the national patient organisations, equates myalgic encephalomyelitis with Holmes *et al*'s tighter definition of the chronic fatigue syndrome, which focuses more on organic symptoms and, again unsurprisingly, finds lower levels of depression similar to those found in patients with cancer and multiple sclerosis- that is, the levels that might be predicted in any chronic illness.

Until the various chronic fatigue syndromes are each studied in their own right rather than as one huge "dustbin" syndrome we shall make little progress...

Nick Anderson, *British Medical Journal*, 14 May 1994: 1298.

Thus, it is the different disease definitions *themselves* that promote the categorisation of collections of symptoms into CFS or M E; Sharpe's broad definition that is associated with higher levels of depression and psychosocial disorders, or Holme's tighter definition "which focuses more on organic symptoms" and is associated unsurprisingly with lower levels of depression, "levels that might be predicted in any chronic illness". This process can be described as an example of the 'documentary method'. The categories of M E or CFS have themselves been defined by reference to two 'chinese menu' style collections of symptoms that differ in certain ways from one another (notably, in the extent to which they include, or exclude psychiatric symptomology). In the literature, the details of individual cases (outbreaks and so forth) were demonstrated in this chapter to be diagnosed as conforming to a particular kind of illness-category, where the details of the cases/outbreaks, and the illness-categories themselves are ongoingly co-constituted alongside one other.

In the case of a medical controversy there is (of course) more than one explanation being worked up by different authors. Therefore, the details of individual cases/outbreaks are worked up as either belonging to, or being excluded from a particular category, depending on who is giving the account and which case definition they are using and constructing as resource. This lack of consensus over definitions and categorisation has remained a participant's concern right up until the present day, as this final contribution from the *Medical Director* of the *ME Association* makes clear...

Extract 51: *Disagreements still exist over the chronic fatigue syndrome.*

Editor- Although the ME Association welcomes the royal college's unequivocal conclusion that the chronic fatigue syndrome is a genuine and disabling condition³³, we also agree that their report will "engender disagreement on both sides of the Atlantic."³⁴ We have no problem in accepting that the alternative name for the condition- myalgic encephalomyelitis (ME)- is pathologically incorrect, and this is a matter that we now intend to address. However, labels are important to patients as well as doctors, and support groups throughout the world are unanimous in their view that "chronic fatigue syndrome" is a totally inadequate way of describing the symptomology and associated disability. The chronic fatigue syndrome may well become a dustbin diagnosis for anyone with chronic fatigue, and a new name that is acceptable to both doctors and patients clearly needs to be found.[...] Our main disagreement with the report concerns its undue bias towards psychological explanations and treatments. Taking into account the fact that some studies have failed to concentrate on a strict definition of the chronic fatigue syndrome and that others have used questionnaires that "perform poorly as screeners for psychiatric morbidity in chronic fatigue syndrome", we cannot agree that the published literature can be used to justify the conclusion that about three quarters of patients have a co-existent psychiatric illness. Equally, we are surprised that no mention is made of the view that when depression co-exists it is possibly a combination of neurobiological changes and the psychological distress that so commonly affects these patients.[...] Many of these disagreements could have been resolved if the working party had consulted more widely during its preparation of the report. Sadly, an opportunity to create consensus has not materialised.

Charles Shepherd (*Medical Director, ME Association*), *British Medical Journal*, 314. January 11, 1997.

³³ Joint Working Group of the Royal Colleges of Physicians, Psychiatrists, and General Practitioners. *Chronic Fatigue Syndrome*. London: Royal College of Physicians, 1996.

³⁴ Straus S.E. Chronic Fatigue Syndrome. *British Medical Journal*, 1996; 313: 831-2. (5 October.)

Participants' concerns (as an analyst's narrative device).

One of my aims for this chapter has been to show how M E has been constructed as a medical controversy by the participants who have written about it, and as pointed out by the last contributor, "consensus has not materialised". However, the context of ongoing uncertainty surrounding the 'M E debate' has provided an ideal forum to show how medical practitioners and research scientists set about the process of both defining and challenging the idea of a new disease entity in and through scientific argumentation in research literature and correspondence. What the M E controversy amounts to has been constituted by the participants as the juxtapositioning of two (or three) alternative versions or explanations for the 'mystery illness', such that its nature can be formulated in terms of mind, or body, or a more integrated combination of the two.

An important feature of any scientific controversy is the threat that competing versions and interpretations pose to the 'canonical script' of an objective, scientific, and discoverable truth. This possible breach or 'reality disjuncture' is managed by the participants here as a practical discursive accomplishment, in just the same way as the biochemists in Gilbert and Mulkay's (1984) study made use of the empiricist and contingent repertoires in talk about the everyday practice of science. The empiricist repertoire has been used by some participants to establish the factuality of the claim that there is no organic disease mechanism. For example, there are no objective clinical signs; hysteria is a well documented condition that can explain the symptoms; and no virus has been isolated. On the other hand, the contingent repertoire has been used to undermine such claims. For example, studies have been badly designed; the people who make those claims want to avoid being accountable for the lack of medical knowledge; they cling to outdated theories; they are prejudiced against theories that do not agree with their own, and evidence that does not fit their theories is ignored; their theories are based on a fundamental misconstrual of what M E is, and their work is confused by heterogeneity in their research samples.

A further strategy in this controversy has been to challenge the utility of dualistic reasoning in medical explanation. This is often referred to as the ‘post-modern turn’ in medicine, and is glossed as a more sophisticated and complex way to explain disease processes. It challenges the entire epistemological basis on which medical thinking around this controversy has been based, and represents a move to take the theoretical ‘high ground’ in advocating a new conceptualisation of disease process that will be more useful to explain this and *any* medical phenomenon. This approach makes use of the ‘Truth Will Out’ device, whereby science will eventually be able to provide rational explanations, even in the face of apparent disagreement and uncertainty.

The second accomplishment of this chapter has been to construct the author’s grounds for what will follow in the rest of the thesis. In other words, it works as a narrative ‘scene-setting device’. Specifically, this refers to my later analysis of participants’ concerns that have been identified in and through the pages of this ‘dialogue’. For example:

- . The management of ‘reality disjunctures’ in accounting for illness.
- Diagnostic labels and categorisation as a central issue.
- The use of different models of medicine.
- The categories of mind and body, and the relationship between them.

The next chapter takes the issue of diagnostic labels as its topic, exploring how participants both *deploy* different labels in their discourse, and also talk *about* the significance of meaning.

CHAPTER THREE: Labels and Things

“...taxonomic items themselves, if considered in contexts of use, will always be part of whatever action such discourse performs, invoking all the norm-referenced accountability that pervades the analysis of discourse and conversation...”

(Derek Edwards, 1997: 235)

The issue of diagnostic labels has been a central concern to researchers, medical practitioners, and patient organisations, as participants in the M E controversy. Two recent ‘official’ reports have both problematised issues of definition and nomenclature; a theme that has also been repeated in various review articles (eg. Richmond, 1989; Wessely, 1990; Archer, 1987; Straus, 1991) in which the authors have attempted to define (and problematise) their terms of reference. There are complexities inherent in any discussion of definitions and labels, that relate to, and emerge from, various different theoretical approaches to the relationship between language and reality that can be explicitly deployed (or assumed) by both participants and analysts.

As a prelude to my analysis in this chapter, it is useful to distinguish between some broadly different approaches to the relationship between language and reality. This provides a *background* to the analysis of how *participants* themselves talk *about* labeling and what it does; and also as a way to indexically display my own theoretical approach to the analysis of ‘talk *about* labeling’ and also to the analysis of discourse in which labels are (merely) *used*.¹

Language and Reality.

Traditional notions of word meaning and reference, assume that language is merely a code for the representation of thoughts and ideas, and a means of describing objects and events in the world. From this view words stand for things that exist in the world independently of the way people describe them, so diagnostic labels *name*

¹ My analysis does not set out to make any claims about whether any particular label is, or is not, more or less appropriate than any other. This issue is analysed here as a participant’s concern.

diseases/illness phenomena, such as measles, heart disease, cancer, M E, PVFS, etcetera, that pre-exist the label. This implies a realist assumption that diseases/illness phenomena are natural sets of things that are 'out there' waiting to be discovered and given appropriately descriptive names by scientists.

A second approach, that is relevant to participant's discourse in this chapter, is the 'labeling perspective', which derives from the interactionist school in the sociology of deviance and social problems. This approach is a critique of traditional positivist sociology, which treats the notion of 'deviance' as a category which simply describes an aspect of 'social reality' that exists 'out-there' and which can be measured and explained in terms of causal analysis. In contrast to this the 'labeling' approach argues that deviance (or social problems) is a matter of social definition. "it [deviance] is created by society (...) social groups create deviance by making rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. (...) The deviant is one to whom that label has successfully been applied; deviant behaviour is behaviour that people so label." (Becker, 1963: 8-9).

This perspective was popularised by Howard Becker, but the same kind of claims were being made by others² (Kitsuse, 1962; Erikson, 1962), and also by Lemert (1951, 1967), who developed the notion of 'secondary deviance' to refer to a process where people who are labeled as deviant (or a social problem) *react* in some way to that label; "the secondary deviant (...) is a person whose life and identity are organised around the facts of deviance" (Lemert, 1967: 5,7), to the extent that 'psychic structure', 'social roles', and 'self-regarding attitudes' are altered. The relevance of the labeling perspective to this chapter is in its application to medical discourse, and therefore its availability to be used as a resource by both analyst and participants (including researchers in the field of M E).

² My gloss on the labeling perspective in sociology seems to represent it as a more or less theoretically homogenous approach. To conceptualise it in this way is to oversimplify the subtle and important theoretical differences between the various contributors to the labeling approach which is beyond the scope of this chapter. I draw on it here as a background to my analytic interest in the structure of arguments in historical reviews of M E in particular.

A third approach to the relationship between language and reality is the radical relativist position, which argues that in naming things we *constitute* their essence (Edwards, Ashmore, & Potter, 1995; Edwards & Potter, 1992a; Woolgar 1985; Edwards, 1997). This is the position that I am taking to analysing the discourse of interviewees and participants in the 'M E controversy'. But the other approaches are not displayed here merely as a debunking exercise. They are important because they are available to be used as resources by participants when they talk *about* labels and labeling. There is a complex interplay between participant's *use* of labels, labels as a participant's *topic of talk*, and the different *theoretical* approaches to language and reality which are available as explanatory *resources* for analyst and participants alike, in the context of discourse about a medical controversy.

The "Report from The National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (M E)" (hereafter Westcare, 1994), has provided a useful starting point to show how the development of different diagnostic labels has been summarised, along with an account of the research that defined their criteria.

Summary of Definitions (Extract taken from Westcare Report, 1994, pp.88-89)

"Definitions and descriptions for the following terms have been proposed by the following authors or groups.

Benign Myalgic Encephalomyelitis,	Acheson, 1959.
Myalgic Encephalomyelitis (ME),	Ramsay, 1988.
Post-viral Fatigue Syndrome (PVFS),	Behan and Bakheit, 1991.
Chronic Fatigue Syndrome (CFS)	Holmes et al, 1988. (CDC) ³
CFS (NIAID) ⁴	Schluederberg et al, 1992.
CFS (Australian)	Lloyd et al, 1990.
CFS (Oxford)	Sharpe et al, 1991.
Post Infectious Fatigue Syndrome (PIFS)	Sharpe et al, 1991.
ME/PVFS ('London')	International Federation of ME
	Associations (IFMEA) et al, 1993.

"The different names, descriptions and definitions arose in response to different circumstances...Benign M E was the name given to the Royal Free Hospital outbreak in 1955 and to similar endemic cases that appeared at the same period (Acheson, 1959.) Ramsay

³ This abbreviation stands for the 'Center for Diseases Control' in the USA.

⁴ National Institute for Allergy and Infectious Disease.

(1988) provided a broader description of M E, describing the cardinal features of the illness as he observed it. Following in the same tradition, Behan and others preferred the term “PVFS”, for which an initial viral infection was essential. In the USA the path was mainly via a chronic mononucleosis-like syndrome which was given the name of “chronic Epstein-Barr virus syndrome” in 1986.

Dissatisfaction with the idea that the EB virus was indeed the cause of the syndrome led Holmes and colleagues at the Center for Disease Control (CDC), in the USA (1988), to propose the name of Chronic Fatigue Syndrome (CFS) and to offer specific criteria for its use. The criteria given have since been criticised as being too restrictive. Schluederberg et al (1992) proposed a relaxation of the criteria at a workshop organised by the National Institute for Allergy and Infectious Disease (NIAID) and the National Institute for Mental Health (NIMH).⁵

A further meeting was held at the CDC in September 1993. The term “CFIDS”, which stands for Chronic Fatigue Immune Dysfunction Syndrome, is an alternative name, one which is much preferred by patient groups in the USA. Meanwhile a wider definition of CFS had been formulated by Lloyd et al (1990), in Australia. Also in the UK, Sharpe et al produced a definition of CFS which included a sub-category, PIFS (Post Infectious Fatigue Syndrome) where the condition followed a definite viral infection. Recently IFMEA, Action for M E, and the M E Association have proposed ‘London criteria’ for M E/PVFS...”

The rhetorical style of this summary is notably empiricist; the absence of agency allowing labeling to *reflect* rather than construct events. “The different names, descriptions and definitions *arose in response to different circumstances*” (my emphasis). In this account, the events just happened, and names *arose* in response to them, rather than maybe in the process of constructing a ‘retrospective discovery account’ (Woolgar, 1980).

The process of distinguishing between diagnostic labels is premised on a participant’s concern with causality in two related senses; one being the label and its causes, the question of how a label ‘arose’ as a reflection of findings rather than being constitutive of reality; and another being the question of the disease and its causes. On the one hand, “...the M E patient organisations, believe that M E is a separate and recognisable disease of the central nervous system. It is classified as such by the World Health Organisation (International Classification of Diseases No 10, re. G93.3)...” (ibid. p.3); further “...The commonest initiating factor [in post-viral fatigue syndrome] was a severe viral infection, presenting as sore throat, acute gastro-enteritis, acute

⁵ It was proposed that the criteria should no longer exclude psychiatric disease, apart from the major psychoses and substance abuse. This meant that depression, panic disorder, and somatoform disorder were now not excluded for purposes of diagnosing CFS. In other words they were now considered to be *part* of CFS.

labyrinthitis or myocarditis. This initial illness was usually so severe as to confine the patient to bed.” (*ibid*, p.92) But on the other hand, “Over 20 studies have been published concerning the role of psychiatric disorder in CFS, of which 11 used direct interviews to diagnose psychiatric disorders.” (R.C.P., 1996)

The discursive construction of the disease therefore involves the conflation of two levels of causality; the disease and its causes, and the label and its causes. Discussions about the label and its causes arise as a way to deal with problems and variations about the disease and its causes.

These variations are here considered in the context of the mundane management of ‘reality disjunctures’ (Pollner, 1987). Pollner borrows the term from R.D. Laing (1967: 35-6) to describe people’s contradictory experiences of the world. Given the mundane (and positivist science) view of the world as simply existing ‘out-there’, then reality disjunctures pose a problem for mundane (and scientific) reason to resolve, especially if the notion of an objective reality is to survive. Pollner argues that this problem is resolved as a matter of routine by mundane reasoners as follows: “reality disjunctures are potentially explainable by formulating one or another (and perhaps both) of the competing versions of reality as the product of an exceptional method of observation, experience or reportage.” (*ibid*: 69).

The misalignments to be resolved by mundane reasoners are of a similar type to those that are at issue for participants in the ‘M E controversy’. Reality disjunctures about the nature of the disease and what to call it, if indeed it exists as a discrete entity, are threatening to the notion of an objective reality. These are the issues at stake for the authors of the summary of definitions taken from the Westcare report. They (as scientists) are in the business of ‘merely’ describing how names ‘arose’ in response to the objective circumstances of medical research.

The fuzziness surrounding the researchers’ definitions of their terms of reference, and the kinds of phenomena that can be included in their categories, have typically been

managed in the literature (see chapter two, above) in various ways that work to dissolve or defuse the notion of a 'reality disjuncture', thereby preserving the notion of an objective reality discoverable by research. This is also evident in the Westcare extract (above). There are three analytic moves that have systematically worked to accomplish such business. For example, scientists can argue that they are labeling different things (eg. different diseases, different criteria for inclusion in a disease category, incomparable samples, etc.); or they can argue (as some do in review articles) that different labels have been used to describe the same thing, or by claiming that some labels are wrong (eg. chronic Epstein-Barr virus syndrome). In the following three sections I shall examine the rationale of these different analytic moves as they are deployed in the literature and official reports.

Heterogeneity, Inconsistency, and Fuzzy Boundaries.

As pointed out above, one way that a 'reality disjuncture' has been managed is by the argument that they might be labeling different things. The following three extracts illustrate this kind of analytic move, using arguments about the heterogeneity of the disease phenomena, a possible overlap with other kinds of syndromes and diseases, different selection criteria in research studies that make comparisons difficult, and the inconsistencies of findings, which have often been related to the latter point about non-comparability of research populations.

"As far as symptoms are concerned, people with chronic fatigue syndromes generally experience both physical and psychological symptoms. What is less clear is whether or not the causes, in all cases, are similarly a mixture of physical and psychological factors. Objective physical abnormalities have been demonstrated in some patients with chronic fatigue syndromes and psychosocial stress has been shown to play a part in some individuals. There is evidence of heterogeneity; in other words, all cases are *not* the same" (Westcare, 1994:18).

"In the account which follows we describe the syndrome of CFS(ME) because this is severe and is central to the wider group. We recognise that there are in addition some patients who do not exactly fit this description but who are nevertheless severely and genuinely disabled by chronic fatigue and associated symptoms. Furthermore, there are other syndromes which overlap with CFS and which may in some cases be impossible to distinguish clearly, such as depression, fibromyalgia, irritable bowel syndrome and chronic pain" (Westcare, 1994: 25).

“Some researchers have studied patients who fall into the broader category of “idiopathic chronic severe fatigue”. Others have focused their attention on the sub-group of CFS(ME), but even amongst these, differing selection criteria have been used [...]

A further block to our understanding of the chronic fatigue syndromes is that though many abnormalities have been reported, findings have not been confirmed. The one finding which seems to be consistent is that a significant number of patients with CFS also meet the criteria for depression. But even here there are differences of opinion over the frequency and aetiological significance of depression in this situation” (Westcare, 1994: 35).

By the rationale used in these extracts from the Westcare report, it is possible for the notion of an objective reality to be retained and to make available the upshot that there is really no disjuncture at all. If CFS(M E) is being used as an umbrella term for a set of problems that are in fact different categories, or which have fuzzy boundaries and actually blur into one another, then that works to diffuse the notion of a ‘reality disjuncture’, and mitigates the lack of consistent research findings. This kind of ambiguity can be heard as a way for participants in discourse about a medical controversy to manage dilemmas of fact and accountability, rather than being ‘merely’ a problem for analysts to resolve.⁶

Historical Reviews and ‘Ontological Gerrymandering’.

This next section deals with the second analytic move described above; that different labels have been used to refer to the same thing. Here are some extracts from journal articles that attempt to give a historical perspective/review of ‘M E’, ‘CFS’, and ‘PVFS’. Many such reviews take the position that there have been different names/diagnostic labels given to what is treated as the same condition in different socio-historic contexts. The following extracts illustrate how this kind of analytic move is accomplished:

“ Myalgic encephalomyelitis is a new name for an old disease with an impressive history of synonyms.” (Richmond, 1989, p.1295)

“ The thesis of this essay is that the origins of ‘ME’ lie not in 1955 or 1934, but in the last century, and in the condition known as neurasthenia.” (Wessely, 1990)

“ Post-Viral Syndrome is the current name for an illness with almost as many names as symptoms. It is also referred to as myalgic encephalomyelitis and as epidemic

⁶ According to MacMillan & Edwards (in press) talk of ‘fuzziness’ and ‘overlaps’ in the content categorisation of newspapers may have a systematic importance with regard to how the newspaper journalists accomplish the business of managing fact and accountability.

neuromyasthenia, and has been called Akureyri disease, Iceland disease and Royal Free disease in the past.” (Archer, 1987, p.212)

“ It is my goal to review briefly the history of CFS. In so doing, it becomes apparent that CFS is not of recent origin. Physicians struggled to define it for centuries in the context of their own comprehension of human pathophysiology. Many names have been given to it, each reflecting a particular concept of the syndrome’s etiology and epidemiology. Most evident throughout the history of this syndrome is the debate about the relative contribution of organic and psychological factors to the disease process of CFS.” (Straus, 1991)

Straus goes on to document the list of diagnostic labels that have recently been compared with CFS. For example; febricula (Manningham, 1750), neurasthenia (Beard, 1869), Da Costa’s (Effort) syndrome (1871), chronic brucellosis (Evans, 1947), Total Allergy Syndrome (Brodsky, 1983), chronic candidiasis (Truss, 1981) chronic Epstein-Barr virus infection (Jones et al, 1985), fibrositis/fibromyalgia (Yunus, 1988) and benign myalgic encephalitis (Acheson, 1959). Many of these diagnoses have *in common that they have been discredited* and re-interpreted in terms of psychiatric explanations.

Straus concludes;

“ By whatever name one chooses to describe this syndrome, careful reading of the older literature cited here reveals that it is not new and probably no more prevalent now than it had been...”

The structure of the arguments in these review articles are reminiscent of the ‘selective relativism’, that was characteristic of the labeling approach to deviance and social problems (Becker, 1963; Kitsuse, 1962; Erikson, 1962; Lemert, 1951, 1967), that has since been criticised by Woolgar and Pawluch (1985). They used the example of Pfohl’s (1977) analysis on ‘child abuse’(amongst others) to outline an analytic strategy that Woolgar and Pawluch refer to as ‘ontological gerrymandering’. A phenomenon, X, is presented as a constant object throughout history, and Y as the changing definitions or labels that have been applied to X in different socio-historic contexts. They describe the structure of Pfohl’s argument as follows;

“despite X for a long time, Y is only recent”

They claim that, in the context of Pfohl’s analysis, the category X (child-beating) is taken as fixed and constant throughout the ages. It is treated as referring to a

description of behaviour, which has been defined or constructed as the category Y ('child-abuse') in the context of specific socio-historic circumstances.⁷

Woolgar and Pawluch argue that, in this type of argument, the phenomenon X has been 'backgrounded' by a realist assumption that it had always existed, whereas the phenomenon Y has been selected for a constructivist analysis.⁸ They point out that the analyst's realist definition "despite X for a long time" is essential to the constructivist account, but fades into the background (like the cheshire cat). So it may not be immediately obvious that the constructivist analysis is contingent on a realist assumption. This analytic move is what Woolgar calls 'selective relativism', in that some definitions are considered to be ontologically given, while others are treated as relative to the social context. This accomplishes boundary-work between assumptions that are to be taken as problematic and those that are not.

If we now return and take another look at the extracts from review articles on 'ME/CFS/PVFS' (etcetera), the structure of the authors' arguments are identifiably similar to those which Woolgar refers to as 'ontological gerrymandering'. The kinds of accounts provided by Richmond (1989), Wessely (1990), Archer (1987), and Straus

⁷ Pfohl cites these circumstances as serving the professional interests of three marginal specialties; paediatric radiology, paediatrics, and psychiatry.

⁸ In response to the criticisms of Woolgar & Pawluch, Pfohl (1985: 230) has argued, "my point was not that there really was something, which we today call child abuse, and that certain things prevented it from being seen before 1960". He refutes it by quoting a sentence from his original paper, "Despite documentary evidence of child beating through the ages, the 'discovery' of child abuse as deviance and its subsequent criminalisation are recent phenomena" (1977: 310), and he makes his repair as follows (1985: 230): "In actuality, I had chosen the word "documentary" as reference to the ethnomethodological concept of "documentary interpretation" (Garfinkel, 1967:78) to qualify the term "evidence". My intent, although implicit, was to suggest what Woolgar and Pawluch make explicit - that historical evidence of all sorts is itself a social construction". Schneider (1985:232) has also made the point that the examples of alleged gerrymandered research cited by Woolgar & Pawluch are more plausibly formulated as examples of careless talk: "mistakes in applying the definitional perspective". He points out that, "many who describe their research as constructionist or definitional do have trouble keeping the study of claim-makers' activities separate from their own sociological definitions of troublesome conditions." In other words, social scientists often conflate two levels of constructs - the interpretative work of participants, and their own theoretical constructions. However Woolgar & Pawluch offer a reading of their critique of the labeling approach that allows for epistemological inconsistencies to be an inevitable feature both of social problems arguments, and more generally of the same style of sociological argument as it applies to other areas (including say the historical reviews of ME in which there is a similar blurring of members' /claims-makers' reasoning and social science theorising.

(1991), all resonate with the following short extract taken from an interview with a General Practitioner.

Extract 1 (MHS/Dr Smith/ 8-10)

1. MHS when did you first become aware of- of the illness known as M E?
2. (3.0)
3. Dr Smith in the form of M E? (.) or (.) in what we used to know it as?

The phenomenon X, is backgrounded as something that has always existed, or “what we used to know it as”(line 3). The interviewer’s category ‘the illness’, is constructed here as shared knowledge, whereas Dr Smith’s question at line 3, “in the form of M E?” implies that there are other ‘forms’ or diagnostic labels for the same thing. This response can be heard as an uptake of the phrase, “the illness known as M E” in the interviewer’s question at line 1, where “the illness” seems to be offered as a ‘given’ category, but the name is indexed as being problematic. This is accomplished by MHS saying, “the illness known as M E” rather than just M E, and also by the three second pause at line 2 (Pomerantz, 1984; Sacks, 1987). The category X (the illness) has been neatly backgrounded by both participants. It is assumed that X has been around for a long time. Doctors have always seen this particular group of medically unexplained symptoms, which although were labelled as Y at the time, they turned out to be the same category, X.

The analytic move of ‘selective relativism’ functions discursively in this kind of exchange, and that of review articles, to background any potentially contentious questions (or reality disjunctures) surrounding the generic categorisation of a group of patients with medically unexplained symptoms and chronic debilitating fatigue. From a historical view, it is difficult to see how any such claims could be made about this category with any pretensions to objectivity, so this form of gerrymandering helps to manage some of the tensions and fuzziness inherent in categorising current medically unexplained conditions in terms of the unexplained conditions of previous eras.

Selective relativism functions here both to make implicit claims about the category X, the illness phenomenon, and also to undermine definitional claims about the category Y - the label. In other words, realist assumptions are backgrounded in the implicit claim that there really is a phenomenon that has existed over time, that is, a medically unexplained syndrome; whereas the constructionist argument functions to undermine the claims inherent in different definitions of that phenomenon as being contingent on social context.

Of course, in Extract 1 this could just be seen as a way of talking that functions to manage issues of fact and accountability that arise from the participants' engagement in discourse about a controversial topic; the form of the interviewer's question signalling acknowledgement of M E as a controversial category, and the doctor's response as establishing his footing for making any kind of comment about it. In other words the participants are indexically displaying the potential for confusion by attending to questions such as, 'Are we talking about the same illness? Is this the same illness with a different name?'. This display of fuzziness paradoxically functions here as an inoculation against being heard as confused or gullible.

The following analysis of 'official' definitional-work continues to build on the notion that realist and constructionist arguments can be variably deployed by participants themselves, in making and dismissing claims about labels.

'Official' Definitional-Work.

The following extracts, are taken from a statement made in the most recent "Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists, and General Practitioners" (hereafter, RCP, 1996), and represent a 'policy statement' on the topic of which name is currently claimed to be the most appropriate and which is not. These claims have been grounded by the authors in two different models of medicine, the biomedical model, and the biopsychosocial model, which in a later chapter I have referred to as two 'medical repertoires' that can be drawn on variably in discourse.

Also included are extracts from the Westcare report, a news item that followed the publication of the RCP report, and an extract of data from an M E Self-Help Group discussion.

Extract 2

The joint working group's report firmly dismisses the term ME on three grounds. First 'encephalomyelitis' [inflammation of the brain and spinal cord] describes a distinct pathological process absent from the conditions included within the term ME. Second, the term ME implies a single diagnostic entity, which is unlikely and unproved. Third, it ignores the psychological dimension.

(RCP Report, October 1996, p.44)

In this extract the authors draw variably on the discourse of realism and constructivism to warrant their dismissal of the term M E. The first thing to notice is that it makes use of a realist interpretation of language to make the claim that M E is not the correct name. In realist discourse the correct word is assigned to the thing that has the appropriate characteristics. Language is taken to be a 'mirror of reality', so that names are claimed to *reflect* the properties of things/entities. So by this rationale, if the name does *not* reflect the properties of the thing (in this case the conditions included within the term M E), then it must be the wrong name.

The authors of extract 2 also deploy a constructivist account of how 'entities' are constituted as such by the terms that name them. They point out that the term M E implies that there is a "single diagnostic entity" that exists as something separate called M E. The entity can be dismissed therefore by dismissing the term that constructs it. This use of a constructivist analysis neatly manages the "unlikely and unproven" (and even contradictory) nature of current biomedical research claims which focus on the search for a discrete organic causal pathogen.

The authors then revert to a realist interpretation of the relationship between words and reality in making the claim that the term M E does not reflect the properties of "the psychological dimension", which is here constructed as *given* or *known* and has been discursively 'blackboxed'⁹ by the use of the definite article. It is not construed as 'a psychological dimension', or 'a *possible* psychological dimension', but "*the*

⁹ Latour, 1987; Latour & Woolgar, 1979; Woolgar, 1988.

psychological dimension” (my emphasis). This packaging of a contentious claim as ‘given’ information is a common feature of discourse in such settings as law courts, advertising, journalism and propaganda, as well as in mundane conversation (Edwards, 1997). It functions here in the context of medical scientific discourse as a conflation of knowledge and reality that can counter a possible alternative explanation¹⁰, since what is *known* about is taken in positivist science as equivalent to what is *real*.

Extract 3.

The Daily Express printed this next extract on Thursday October 3, 1996, following the publication of the RCP report. Dr Robert Kendall, a representative of the Royal College of Psychiatrists (joint authors of the document), was quoted as saying:

People who use the term [ME] are unshakeably convinced that its a physical disease. That’s not just wrong, *it is meaningless. ME (Myalgic encephalomyelitis) is not an appropriate term* because there’s no evidence of any inflammation of the brain or spinal cord...nor is there any reliable evidence that chronic fatigue syndrome is linked to common viral conditions...

There are various things accomplished by this statement. First, Kendall implies that the term M E is used exclusively by people who hold a particular set of convictions that

M E is a physical disease. These are convictions (sets of beliefs) that are “unshakeable” even in the face of a lack of supporting evidence. Second, his claim that this conviction is “not just wrong, but meaningless” is bolstered by his construction of M E ‘believers’ as irrational dogmatists, who continue to hold unsupported beliefs. This formulation of “people who use the term M E” functions to discredit them, and to undermine their accounts and their research activities. (Some organisations which currently use the term M E, for example The M E Association, and M E Action, also carry out research.)

Again we can see how a contingent repertoire is being used in formulating an account of error or doubt. Kendall claims that it is particular *kinds* of people who use the term

¹⁰ I am thinking here of the counter criticisms that have been made about research that identifies a ‘psychological dimension’ as a causal explanation for M E/CFS.

M E - those who have “unshakeable” beliefs about the nature of the illness. This notion of ‘illness beliefs’ is being constructed in opposition to a more scientific, empirical way of talking about illness labels, in which terms (and their implications) are chosen on the basis of “reliable evidence” rather than ‘unshakeable convictions’.

A third aspect of this extract is the way that Dr Kendall establishes his categorisation of the preferred term CFS. The notion of a physical disease is dismissed again in the case of the term CFS, “nor is there any reliable evidence that chronic fatigue syndrome is linked to common viral conditions”. Thus any available research evidence into the organic pathogens associated with the illness is dismissed as unreliable. The rhetorical force of this statement by Dr Kendall works both to undermine “people who use the term M E”, and the research that has been done on organic aetiology. His comments work to bolster up the alternative implication that CFS should be treated as a psychiatric disorder, whilst avoiding the contingency that any counter evidence he might use to support this implication, would be vulnerable to the same kind of critique. Rather than making a direct formulation of CFS as a psychiatric disorder, which might make the psychiatrist’s account vulnerable to accusations of having a stake in constructing a psychiatric category, the account focuses on the reasons why CFS/M E cannot be considered a *physical* disease. The rhetorical power of the argument therefore lies in what is ignored or taken as ‘given’ or unproblematic, and can be interpreted as an example of what Jonathan Potter (1996: 184) calls the “extended sense of ontological gerrymandering; one realm of entities is constituted in the description while another is avoided.”

The following two extracts, from RCP and Westcare, have in common that the authors formulate reasons for CFS being a preferred term.

Extract 4

The most appropriate term for this syndrome is chronic fatigue syndrome (CFS), which is accurate and free from unproven aetiological claims. CFS can be operationally defined, which will aid future research and clarify aspects of clinical practice...
(RCP report, p.5, paragraph 3.1.)

Extract 5

The main merits of the term ‘CFS’ are that it focuses on a major feature of the condition, namely fatigue, and that it is aetiological neutral.

(Westcare, 1994, p.15)

First, CFS is claimed to be “accurate” (line 2, extract 3). It describes a syndrome- a collection of symptoms for which no medical explanation has been found, where the central feature is chronic idiopathic¹¹ fatigue which lasts for six months or longer. The term claims to represent the symptoms accurately and neutrally, in a way that is “free from unproven aetiological claims”. In other words it does not implicate causality. Further, CFS can be “operationally defined”, which means that CFS can be diagnosed by reference to the presence of symptom combinations from a ‘symptom-pool’ which are the criteria for defining CFS.¹² Thus CFS is an “accurate” description of the symptoms that define it; in other words the concept being defined is part of the definition itself.¹³

Furthermore, the symptoms that form the criteria to define CFS turn out to be a collection of symptoms for which no medical explanation has been found, plus chronic idiopathic fatigue. On page two (paragraph 2.1) of the RCP report it is pointed out that, “Patients presenting with physical symptoms for which it is not possible to give a clear medical explanation are not new...”¹⁴ Aetiology and classification of these symptoms and syndromes is controversial. *The Royal Colleges have stressed that approaches to these patients should not be based on simple biomedical models. Rather, they advocate a combined biological, psychological, and social approach in formulating what predisposes to, what precipitates, and what perpetuates the symptoms.*” However, the biological component of the model is played down in the case of CFS. See extract 3, “ people who use the term[M E] are unshakeably convinced that its a physical disease. That’s not just wrong, it is meaningless...nor is there any reliable evidence that chronic fatigue syndrome is linked to common viral conditions”. This dismissal of possible physical pathogens rhetorically situates CFS in the arena of psychosomatic illness and emphasises the role of psychosocial explanations. The claim that CFS is a “neutral”, “accurate” term can therefore be seen

¹¹ The term ‘idiopathic’ refers to symptoms which have no known cause.

¹² Two case definitions for chronic fatigue syndrome appear on page 43 of the RCP report, Appendix 3.

¹³ This is rather like the way that operational definitions of intelligence work. “intelligence is what intelligence tests measure” (Boring, 1929).

¹⁴ For an overview of this the RCP refer to Creed F, Mayou R, Hopkins A. (1992).

as a discursive device which functions as a move to take the scientific ‘high-ground’ , and also to manage a potentially hostile response from a lobby of patient organisations which have ‘bought-into’ the term M E and its aetiological implications of organic disease.

The following two extracts resonate with one another in that they both position CFS rhetorically against M E. Extract 6 is taken from the Westcare report, and extract 7 is taken from a discussion at an M E self-help group meeting.

Extract 6

‘M E’ carries the implication of organic rather than of psychogenic disorder, whereas the term ‘CFS’ is aetiologically neutral. .
(Westcare, 1994, p.16)

Extract 7

(MHS/ MEPSYCH/ 45-135)

1. FM M E was used a lot initially (.) a lot of writers are changing over to the
2. term Chronic Fatigue Syndrome (.) because M E implies a particular
3. cause (.) something to do with the nerves and the muscles (.) and
4. because there’s no clear cut cause been fo:und (.) then people are
5. saying “well let’s not give it a label that implies a cause (.) when we
6. don’t actually know what it is yet (.) let’s have a general label that
7. implies the symptoms”(.) so most of the articles in the professional
8. journals (.) appear under the name ‘Chronic Fatigue Syndrome’(.) you
9. don’t usually get an article under the name of M E anymore.

The last extract provides an analytic link with the positioning of CFS against M E that we have also seen in extracts 1-5. In extract 7, FM is a clinical psychologist who is leading a discussion with members of an M E self-help group. FM has come to the group to talk to members about CFS, so in this case he is working to justify his resistance to their use of the term M E. He makes the claim (line 4) that since no cause has yet been identified that can justify the use of the term M E, then “let’s not give it a label that implies a cause”(line 5). FM argues that this warrants the use of chronic fatigue syndrome in professional journals as a “general label that implies the symptoms”(lines 6-7).

FM is here constructing a distinction between the two labels M E and CFS which is based on the notion that some terms can be *merely* descriptive, whereas other labels

are doing some attributional work in naming causes. Rhetorically, this positioning of CFS against M E works to undermine the attributional work accomplished by the term M E (and people who use it), that it is a physical illness with an organic cause, and to imply that the term CFS is neutrally descriptive and therefore performs no such attributional work.

FM, and the authors of the Westcare Report and the RCP Report are claiming to be neutral and merely descriptive of the symptoms of the illness in their choice of CFS as a preferred label. However, in extracts 6 and 7 an asymmetrical analysis of naming draws on a constructivist account of language¹⁵, as a device to resist the claim that ME is an appropriate term, and a realist account of language is a useful device to make an 'unambiguous' claim about the appropriateness of the term CFS as being 'merely descriptive' of 'what is going on'. In other words, *participants can deploy either realist or constructivist notions of the relationship between language and reality in a flexible way; realist commonsense to bolster claims of objectivity and neutrality, and constructivism to undermine that claim in others*. Latour (1987) refers to this feature of scientific discourse as the "two faced Janus character of science". Truth claims are bolstered by an empiricist (realist) repertoire, whereas doubt or error can be managed or constructed by deploying a contingent (constructivist) repertoire (Gilbert and Mulkay, 1984). These kinds of repertoire can be deployed as resources in both scientific and ordinary discourse¹⁶.

¹⁵ From this view language is not taken as a neutral system for conveying information; words chosen to describe everyday things carry powerful implications for the causal explanation of events or states (Edwards & Potter, 1992).

¹⁶ Including mine! Apparently by avoiding reflexivity, in this chapter, my analysis seems to 'tell it like it is' concerning *their* discourse being full of gerrymandering devices. Derek Edwards tells me that rather than being defeated by a 'tuquoque' of this kind, I should be reassured that the devices I am analysing (and using) are so discursively robust as to be unavoidable. Alternatively, I *could* use Jonathan Potter's rhetorical 'opt-out clause' (1996: 84), "This largely unreflexive voice helps to keep the text as simple as possible..." (And in any case, he assures us that discourse analysis *is* an inherently reflexive form of analysis.) Or perhaps I should choose to be reassured by the poetic comments of MacMillan's textual therapist (Sybil Sleepstone) who advises that "*Reflexivity, like hypnotherapy, has various levels. Some dabble near the surface, dipping into reflexive moments, flirting with the images evoked in the reflection, before returning to the safety of the mundane.*" (MacMillan, 1996: 29).

The ‘action-orientation’¹⁷ of the descriptions which have been analysed in this section can be summarised as follows: First, categorisations can work to exclude potentially relevant considerations, for example, calling an illness M E can work to exclude a psychological aspect, whereas calling the illness CFS can work to ‘blackbox’ psychological explanations and downplay organic considerations as being of minimal importance. This effectively draws boundaries around what is important, and is usable as a form of ‘ontological gerrymandering’. Second, the empiricist repertoire is used to claim the ‘scientific high-ground’ for those who use the term CFS. Claims of neutrality, accuracy, and objectivity are made in opposition to the “unshakeable beliefs” of ‘people who use the term M E’. Third, a contingent repertoire is used to construct error by formulating such people as fanatics who hold irrational beliefs.

‘Unofficial’ Definitional-Work.

The next section takes a look at the way that General Practitioners have not just deployed, but talked *about* names and labels and what they do, in the context of interviews. This kind of data represents a more informal context, in which medical practitioners are responding to a researcher’s questions about their own experiences with patients, rather than in the more formal context of ‘official’ reports or statements to the press. The analysis in this section focuses on the use of explanatory repertoires, a point which was applied earlier to extract 3, representing part of a psychiatrist’s statement to the Daily Express.

In the following extracts the doctors refer to a diagnosis of M E as a category that patients might be motivated to choose.

Extract 8 (MHS/Dr Brown/150-162)

1. Dr. Brown ye:s (.) yes (.) you see I think the thing is heh I mean obviously when
2. we don’t fe:el well and we try to make sense of it (.) and we want a
3. name for it (.) u::m (.) because if you’ve got a name for it (.) it makes
4. us feel safer (.) that we’re not at the whims of some random (.)
5. whatever (.) or we’re going mad or (.) so I think we desperately want a
6. name (.) and if it is a name whereby somebody else is going to have to
7. get us better (.) as opposed to sort of saying (.) “yeah I’m running my

¹⁷ This refers to a feature of discursive psychology where discourse is taken to be primarily a social activity.

8. lifestyle (.) or I'm running my marriage or (.) my job (.) in a way that is
9. wearing me out and exhausting me" (.) then the onus is then on me to
10. fix it (.) and it's far easier if somebody else can fix it for me (.) y'know
11. so I think alot of people want the diagnosis of M E because they then
12. think that that's going to (.) either make it easier or somebody else will
13. be able to cure it (.) u::m

Extract 9 (MHS/Dr Smith/100-106)

1. Dr Smith it's a new fad for patients because it's a way of (.) avoiding
2. responsibility for (.) psychological illness(.) if you've got a physical
3. label (.) then it's not your fault (.) nor can you do anything about
4. it (.) whereas the people who we labelled (.) neurasthenia (.) or weak
5. personalities y'know going back in the old psychiatric textbooks
6. (.) those at least you could confront (.) so it's a useful label for
7. avoiding (.) in some patients (.) er (.) for avoiding er (.) internal
8. conflict

Extract 10 (MHS/ Dr Kelly/ 72-111)

1. Dr Kelly I think they like to find something that they are happy to accept the
2. title thereof
3. MHS = mm
4. (.)
5. Dr Kelly now whether the title
6. (2.7)
7. Dr Kelly I suppose you've got to say 'well why do they like the title
8. (1.9)
9. Dr Kelly of M E rather than depression?'
10. (1.5)
11. Dr. Kelly I thi:nk that there is a (.) a social class element to it as well
12. (2.5)
13. Dr. Kelly that prefers the title of M E (.) that dislikes the title of depression
14. MHS = what sort of group would you say preferred to be ?
15. Dr Kelly = I think the middle classes prefer to be labelled M E rather than
16. depression

All of these extracts have in common that they use a contingent account to formulate the label M E as a category which is used by patients as an avoidance device. That is, certain types of patients might want to use the diagnosis of M E to avoid an alternative explanation for their problems. The label of M E is being constructed by these doctors as an error, a dubious category, or at least a category that is open to abuse. They each formulate certain types of patients who might want a diagnosis of M E. Dr Brown works up an account of the social context and stressful lifestyles of patients who

would rather not have to get themselves better by changing their lives, Dr Smith formulates M E as “a new fad” (extract 9, line 1) - a physical label for a psychological illness - used by patients to avoid having to face up to their problems, and Dr Kelly uses the notion of social class to categorise people who prefer the label M E rather than depression. With this group of extracts, a contingent repertoire is being used by the doctors to construct M E as error, by categorising a group of people who might want to use the diagnosis as a device to avoid psychosocial interpretations of their problems.

In the following three extracts, Dr Walker is making available a range of concerns relating to his own choice of label, in the context of a story about a particular patient.

Extract 11 (MHS/Dr Walker/ 511-518)

1. Dr Walker I think this post-viral fatigue is a medically more popular name (.) in
2. the sense that it implies that you know what's causing it (.) I'm not
3. sure that's necessarily true (.) but it's (.) y'know it's something that I
4. think doctors are sometimes more comfortable with (.) they can say
5. 'well this is a bit like glandular fever (.) it's the aftermath of an
6. infection' (.) and it's a working model if you like (.) which gives some
7. sort of reassurance that it isn't in the mind (.) there is something
8. (.) there's a possible explanation

Extract 12 (MHS/Dr Walker/512-523)

1. Dr Walker yeah (.) I mean (.) I'm trying to think what we actually () said to this
2. case (.) because (.) he had problems over the school (.) being
3. off (.) obviously and having sick notes (.) and I think we
4. agreed to put post-viral fatigue (.) syndrome (.) or just post-viral
5. fatigue (.) rather than actually putting M E (.) on the grounds that there
6. was a lot of emotive feeling about it (.) whether y'know you took the
7. tack that he was trying it on or something like that

Extract 13 (MHS/Dr Walker/608-616)

1. Dr Walker it's something that (.) certainly (.) seen by patients (.) and I think to
2. some extent (.) would be (.) y'know (.) by doctors as well (.) is this
3. business of whether physical and mental things equate with real and
4. imagined (.) do you know what I mean?
5. MHS = yes
6. (.)
7. Dr Walker and I think that's (.) that's the danger of it (.) y'know (.) that you
8. equate stress related things as being imaginary (.) and you equate
9. physical things with being real (.) do you see what I mean?

First, in extract 11, Dr Walker gives an account of why PVFS is a preferred term for doctors to use. In formulating this account he constructs two categories in opposition to one another. The category that “doctors are sometimes more comfortable with” (line 4) is construed as “the aftermath of an infection” (lines 5-6). Such biomedical explanations are construed here as the *bona fide* business of medicine, and this category is used here by Dr Walker to manage his accountability as a GP in his choice of a particular term. But that is not the whole story. As a GP, he needs to be sensitive to the patient’s needs as publicly accountable, so this biomedical category is being contrasted with an alternative implied category that is less reassuring: That is, there isn’t anything medically explainable. He formulates his choice of PVFS as “something we agreed to put”(line 4, extract 12), to avoid the alternative formulations that might be associated with a diagnosis of M E (which he attends to at line 7 by his reference to the possibility that the patient might have been “trying it on”). He goes on to provide a further warrant for using a diagnostic label that implicates a physical cause (PVFS), by referring to “this business of whether physical and mental things equate with real and imagined” (extract 13, lines 3-4). Thus, in a narrative formulation of his patient, Dr Walker gives an account of why he chose to use the term PVFS rather than M E, which he attributes here to both the doctor’s and patient’s need to manage a range of accountabilities relating to the factual nature of the patient’s illness.

The participants in these extracts are making relevant two culturally related constructions. First, as the research literature points out (eg. Wessely, 1990), psychiatric illness is still associated with a stigma which many patients would prefer to avoid. Second, one of the central problems or tensions in the ‘M E controversy’ relates to the popular (and sometimes medical) categorisation of psychological illness as ‘not real’, when contrasted to physical illness as ‘real’. Westcare (1994: 18) have also pointed out that our common understanding and management of diseases takes place within a cultural context that traditionally distinguishes between physical and psychological illnesses. “We live in a society which is used to thinking of illness as ‘physical’ or ‘psychological’ and which harbours different attitudes towards these.” (*ibid*:18)

The report further points out that the popular notion that psychological illness is not 'real', has its bureaucratic corollary: "a person whose condition is judged to be 'psychological' is debarred from being awarded the higher mobility component of the Disability Living Allowance. Such an award can only be made if the person's complaint is 'physical'." (ibid:16). Thus, policing the boundaries between 'physical' illness and 'psychological' illness is also built into the way that social welfare benefits are distributed. In view of this, participants might be expected to orient to these kind of constructions and their practical consequences, when accounting for themselves, or their patients in both formal and informal talk about illness.

Labels, Categories and 'Boundary-Work'

The next section looks further at this notion of medical 'boundary-work', focusing in particular on the kind of categorisation that is being done by two General Practitioners in the following three extracts, and what that accomplishes.¹⁸

Extract 14 (MHS/Walker/595-616)

1. Dr Walker heh er yes we were going down this road of physical things
2. and mental things (.) I mean (.) I think it's something doctors are
3. particularly bad at (.) we tend to like to put illnesses into
4. categories (.) and label them (.) there's this scientific thing of
5. y'know (.) attaching labels to things (.) and you tend to go down (.) the
6. mental illness sort of route or a physical illness sort of route (.) a::nd (.)
7. I think people aren't sure which route to go down (.) and that maybe (.)
8. it may be because the model is wrong (.) do you see what I mean? (.)
9. the model of putting peo-illnesses into these different boxes is wrong

Extract 15 (MHS/ Dr Turner/ 229-244)

1. Dr Turner chronic fatigue syndrome (.) or post-viral fatigue syndrome (.) I
2. don't-I never really liked the idea of syndromes I have to say (.) I
3. canna do with syndromes (.) I prefer disease labels I think
4. MHS = why? what's wrong with syndromes?
5. Dr Turner = well syndromes (.) I think technically a syndrome is (.) a group of
6. symptoms that nobody's found a reason for (.) technically that might
7. be more appropriate for this particular disease (.) because nobody's
8. found an underlying cause for it (.) er but I think M E and what it

¹⁸ I would like to thank Derek Edwards, Jonathan Potter, Kevin McKenzie, and Claudia Puchta, for their helpful analytic comments on extracts 14, 15, and 16.

9. stands for (.) is making a more definite statement about it (.) is
 10. recognising it more as a disease entity rather than (.) yeah (.) than as I
 11. say a syndrome (.) and y'know there are quite a lot of
 12. syndromes (.) basically what they are a collection of symptoms that are
 13. recognised as belonging together in certain people (.) er (.) a sort of
 14. repeated pattern of symptoms but nobody's found a cause for it yet (.)
 15. er as I say I prefer what seems to be rather a definite (.) with M E it
 16. seems a little more specific (.) a little less nebulous

Extract 16 (MHS/Walker/698-742)

1. MHS do you- do you think that M E's a (.) a new illness? because there's
 2. been so much about it in recent years(.) do you think it's a new illness
 3. or ?
 4. (.)
 5. Dr Walker I think it probably isn't (.) er I mean it's (.) I-y'know a lot of people
 6. have probably had other diagnoses made (.) I mean there's certainly
 7. over the years there are various
 8. (1.0)
 9. that we've had (.) things put down as I say to glandular fever (.) or to
 10. one sort of illness or another (.) who haven't fitted into diagnostic
 11. categories (.) or have tended to be rather sort of ignored because
 12. people don't want anything to do with them (.) which is something
 13. medicine's really quite good at doing (.) if they don't understand
 14. something (.) you go down two routes (.) you either say 'well
 15. this is something to really find out about' or people tend to rather
 16. ignore it and hope it will go away (.) and I think that's happened over
 17. the centuries
 18. (.)
 19. MHS do you think the kind of ignore it and it'll go away kind of equates to
 20. saying 'well (.) there's nothing really wrong is there?'
 21. Dr Walker = yeah
 22. MHS = it's sort of stress related thing ?
 23. (.)
 24. Dr Walker that's right yeah (.) that's been a- an (.) attitude about things that
 25. haven't been understood (.) or haven't fitted in (.) with what (.)
 26. certainly in the last couple of hundred years
 27. MHS = so the biomedical model really (.) sort of looking down the (.)
 28. physical lens if you like
 29. Dr Walker = yeah (.) and that's I suppose particularly the last hundred
 30. years (.) because I mean y'know sort of (.) particularly sort of scientific
 31. model of medicine (.) developed in the nineteenth century
 32. (2.0)
 33. became the dominant sort of model in the first part of the twentieth
 34. century (.) rather to the exclusion (.) of anything that didn't fit into that
 35. model (.) and I think the changing attitudes-the attitudes are changing
 36. (.) but it's still er (.) it's still (.) er (.) part of the doctor's model in a
 37. sense (.) things that don't fit in (.) either need explaining (.) or if you

38. can't think of a logical explanation for them (.) they get put into a sort
 39. of rag bag of funny illnesses that you can't explain (.) probably stress
 40. related y'know

In extract 14, Dr Walker is formulating a critique of an explanatory model in which illness is categorised as *either* mental, *or* physical. This is worked up as “this scientific thing” (line 4); something that science has set up by putting illnesses into categories and labelling them. This is marked as something for which doctors are notorious: “particularly bad at” (line 3). If the doctor isn't sure which route to go down, the mental or the physical, then that's an indication that this kind of exclusive model is wrong (line 8-9). This makes available the notion that the uncertainties in medicine, things that medicine fails to explain, such as the controversial category of M E, might be an artefact of using the wrong model, rather than necessarily unexplainable by *any* criteria. By implication, there might be another explanatory model that would be more appropriate to solving the problem of categorising unexplained illness phenomena.¹⁹

This linking of uncertainty with an inappropriate model functions here to manage a tension between on the one hand, the concern of medical science to can categorise diseases according to the facts of their existence, and on the other hand, the fuzziness of unexplained illness in the context of medical practice. Dr Walker is *distancing* himself from the notion of scientific labelling and dualistic categorisation. The model is *derived* from science and ‘merely’ *used* by medical practitioners. But at the same time he is *part* of the medical world that deals with uncertainty and can make mistakes. There are also a broader set of people allied to the medical world, who are in the business of explaining and categorising illnesses, therefore the categories are not *invented* as such by medical practitioners. However, Dr Walker has to formulate himself both as a practitioner who is knowledgeable and professional, rather than *merely* a technician who *applies* ready made models to sort out patient's problems. At

¹⁹ This implication again serves a similar function to a ‘truth will out’ device. To re-cap, the notion of a ‘TWOD’ was introduced by Gilbert & Mulkay (1984) in their study of the discourse of biochemists. It was used to reconcile two inconsistent repertoires where they occurred together in the context of informal interview talk. Specifically a TWOD is used as a way of holding on to a scientific position when there is not yet unambiguous grounds for it. Here it functions to manage the tension between the demands of science-based medicine and the uncertainty of medical practice.

the same time he deploys this notion of 'scientific models as resource' to distance himself, as a practitioner, from personal accountability for the model being wrong.

In extract 15, Dr Turner formulates the category of 'syndromes' (lines 1-3) against the category of 'disease labels' (line 3), for which he expresses a preference. His preference orients to the concern that medicine is set up to deal with definite, specific, recognisable 'disease entities', and causal stories. M E and "what it stands for" (lines 8-9) does that work. It makes a "definite statement" that you are dealing with a disease entity (lines 9-10). Dr Turner claims that he would *rather* use the term M E to be more definite, "a little more specific (.) a little less nebulous" (line 16). This is contrasted with the notion that syndromes are associated with uncertainty: There is no causal story, no disease entity, but just a group of unexplained symptoms.

He also appears to be formulating syndromes as an interim category, in which knowledge is not yet solid, "a sort of repeated pattern of symptoms but nobody's found a cause for it yet" (13-14) which allows for the possibility that syndromes may *become* ontologically solid *as* disease entities, when medicine finds out what they are. So in *this* context, calling something a syndrome is a way of talking that formulates medical uncertainty as an *interim state* which could eventually be replaced by a body of solid knowledge. And in lines 8-10, and 15-16, he seems to be moving towards the idea that there might be enough solidity to move out of the syndrome category and into the disease category and call it M E, even though here he seems to treat this process as a *decision* based on clinical judgement, rather than 'solid fact'. This categorisation of an interim state of knowledge functions here as 'boundary-work' to delineate the *bona fide* concerns of "definite statements" (line 9) and "recognising it more as a disease entity" (line 10), as mainstream medicine, and anything else, more nebulous, as marginal to it. The fuzziness of this interim state of knowledge also appears to be the point at which various tensions are being managed, for instance between medical science and medical practice, and between labels and reality.

Extract 16 occurs a little further on in the interview with Dr Walker, occasioned by the interviewer's question about whether M E is a new illness. The question orients to the recent high profile of M E in the media, and also the literature which has defined M E as an old illness with a new name.²⁰ This question provides the occasion for him to do some categorisation and 'boundary-work'.

Dr Walker formulates two generic categories in opposition to one another. These are "diagnostic categories" (lines 10-11), and "the rag bag of funny illnesses that you can't explain" (line 39). These two categories implicate the notion of the all-inclusiveness of medicine. They cover everything that a GP might ever need to deal with in practice. Diagnostic categories are here given as unproblematic, clear cut medical business, in contrast to "the rag bag" which is being constructed here as *marginal* to that, and routinely functioning to manage uncertainty "if you can't think of a logical explanation" (line 38).

At lines 10-16, Dr Walker starts to offer a binary formulation of how medicine deals with uncertainty. Either medicine is knowledge-based, "something to really find out about", or things that aren't understood are dismissed in an "ignore it and hope it will go away" style. The interviewer's question at lines 19-20 offers a formulation of the dismissal strategy, that 'ignoring' is equivalent to saying there's nothing for medicine to find out, apart from stress-related things. 'Stress-related' and 'nothing really wrong' are therefore offered here as equivalent categories by the interviewer, and this appears at first glance like a contradiction- after all, stress is not 'nothing'.

However, in terms of the context of medical talk, stress can be used as a vague universal sort of category. If something is stress-related, it could be a physical illness (such as heart disease or ulcers), it could be psychological (such as anxiety disorders), or it could be more like *social* hassles; part of the ordinary business of living life, like financial worries, domestic problems, housing and unemployment, bereavement, and all the things that make life difficult for people.

²⁰ See for example, Richmond, 1989; Wessely, 1990; Archer, 1987; Straus, 1991.

Therefore, if something is stress-related, then maybe it's a borderline case for medicine to deal with, or possibly just outside the jurisdiction of medical intervention. If stress-related is taken to mean the consequence of a difficult life, just normal 'wear and tear', then in terms of mainstream medical business, that could be equated with "nothing really wrong". The interviewer's formulation at lines 19-22 offers him that kind of boundary between stress and medical concerns, which he takes up at line 24, "that's been an attitude". From line 27-36, this "attitude", or way of looking at things, is worked up as a model of medicine in relation to which things get defined. Thus unexplained illness becomes an artefact of a particular way of categorising illness. In other words, it is *constructed* in opposition to the biomedical and scientific, which is currently still dominant, and exclusive of things that don't fit.

At this point it is useful to identify the issues that seem to be 'at stake' for the doctors in the last three extracts. There are contradictions between the working up of scientific knowledge-based medicine as an ideal model, and the routine of dealing with things that are controversial or not that well understood. These are common themes in all three extracts. They are therefore attending to two potentially conflicting demands. The GP's *identity* as a professional medical practitioner whose job it is to apply knowledge-based medical science in trying to advise, treat, and refer patients appropriately, and also the doctor's accountability for a system of medicine that can fail to provide clear-cut explanations. This is a contradiction that has been managed in the discourse in a variety of ways.

Scientific, 'knowledge-based' medicine (by definition) *excludes* things that are not understood, or that no-one has yet found a cause for. It is deployed in the talk to accomplish 'boundary-work'. 'Syndromes', 'the rag bag', or 'stress-related' are categories that can be used as a medical safety-net to 'catch-all' the excluded items. But these might also be formulated as 'interim categories', which implies that have the potential to become disease labels either when a cause has been found, or when they are picked up at the point of physical or psychological crisis, as they might be with a

heart attack, an ulcer, or a nervous breakdown. Labels, in this context, are to do with categorising things according to what is known and is medically explainable. Illness phenomena get identified as entities and given a disease label, which means they are real, or at least known about within the jurisdiction of scientific knowledge-based medicine.

The uncertainty of things that are, in practice, not well understood or controversial, is managed in the talk by two related devices that allow the doctors to reaffirm the scientific legitimacy of medicine, which pivots on a delicate balance between science, medical practice, and clinical judgement. First, in extract 14, the uncertainty is managed by attributing it to the use of the wrong model; in other words, its *science* that got it wrong in the first place. Second, in the other two extracts, Dr Turner and Dr Walker both use a ‘truth will out’ device as a reconciliation device that allows medical science, to finally provide sound explanations.

For example, Dr Turner implies that syndromes are an interim category that could become disease labels when they have found a cause, and has the potential to become assimilated into knowledge-based medicine. Dr Walker claims that “attitudes are changing” towards a model of medicine which fails to explain such a lot. He works up his account of historical time, tying a particular medical “attitude” to a specific historical time and a particular kind of model. This notion of a ‘changing attitude’ orients to a more enlightened approach that will replace the old attitudes in due course, and hints that this will provide a solution to the current state of confusion which surrounds the “rag bag of funny illnesses that you can’t explain”. What is interesting here is that it’s medical science itself that is being given a historical basis, and it functions here almost like a contingency account for doctors who still use the empiricist repertoire. In other words, labels and diagnostic categorisation are contingent on empiricist medical models, which are themselves contingent on the historical context of medicine.

To summarise, this chapter has focused on the controversial issue of diagnostic labels. My analysis has shown how authors and speakers have attempted to define and problematise their terms of reference. I have examined labels and their meanings as the topic of discourse as well as being deployed as part of that discourse. Three different kinds of models of the relationship between language and reality were identified as part of participants' resources in talk about labels: these were the representational model, the labeling approach, and a constructivist model. I have demonstrated how authors and speakers have appropriated these different assumptions about language in making particular kinds of analytic moves that work to resolve 'reality disjunctures' and preserve the notion of an objective medical reality. For example, participants have argued that

- they are labeling different things
- they have used different labels for the same thing
- or that some labels are simply not appropriate, since they do not provide an accurate description of the illness

The chapter has also shown how speakers make use of empiricist and contingent repertoires to argue that one label (CFS) is more appropriate than others, and that it is certain kinds of people who are motivated to use labels such as M E.

Finally, the chapter has looked at labels, categorisation, and the kinds of medical boundary-work that can be accomplished, particularly with reference to the construction of a division between mental and physical illness categories. Physical diagnostic categories are equated with clear-cut medical business, and everything else is marginal to that; part of a 'rag-bag' and probably stress-related. Similarly to the talk in the medical literature analysed in chapter two, different kinds of medical model are deployed in GPs talk, as an explanatory device. Uncertainty is constructed as being a product of the biomedical model that explains and categorises illness, and is exclusive of things that don't fit into its categories. From this view, 'mystery illness' would be explainable only in terms of a new model of disease that will eventually allow medical science to provide complex biopsychosocial explanations for all illnesses. This is again reminiscent of the 'truth will out device' that was deployed by the authors of

some extracts in chapter two (for example, David *et al*, 1988; Gill, 1970; Jenkins, 1991) as a way to overcome the ‘fruitless dichotomy’ of dualistic explanations.

In the next chapter, I shall further examine the participants’ concern with the relationship between mind and body that has been central to the debate about the existence and naming of a mystery illness. As I have just pointed out, some authors have drawn on the idea that there are different models of medicine that might be used to explain illness. The next chapter explores the background to these different kinds of models, and analyses the way that they can provide the discursive resources not only for categorising illness as either physical or mental, but also for accomplishing illness talk as a realm of moral accountability.

CHAPTER FOUR

Repertoires of Mind and Body

One of the focal participants' concerns in the dialogue of chapter two was an orientation to the different possible kinds of explanations for the 'mystery illness'. Specifically, participants in the 'M E controversy' worked to position their claims against possible alternative explanations. Three broad groups emerged as the major participants constructing the controversy. There were those who constructed the phenomena as an organic disease called M E, and worked to dismiss the alternative suggestion that the illness was hysterical in nature (Ramsay & O'Sullivan, 1956; Galpine & Brady, 1957; The Medical Staff of the Royal Free Hospital, 1957; Poskanzer, 1970; Shepherd, 1992; Hume, 1992). Those who adopted the alternative position worked, on the other hand, to show that there was a lack of reliable evidence for an organic explanation and proposed a different way to interpret the available clinical data in terms of a psychosomatic explanation; that is, the reported symptoms were claimed to be 'conversion symptoms', the somatic presentation of an underlying psychological disorder (McEvedy & Beard, 1970; Easton, 1978). The third group of participants took a metaposition in the debate, pointing out the dualistic nature of such 'either/or' arguments, which they claimed derive from an unhelpful and "outdated separation of mind and body". In other words, the third group of participants claim that the other participants in the controversy have formulated their arguments by stressing *either* organic *or* psychological causes for the illness. *They*, on the other hand, take the scientific 'high ground' and propose what they consider to be a more complex "multi-axial framework" for thinking about and explaining disease processes (Jenkins, 1991; Gill, 1970; David *et al*, 1988).

The relationship between mind and body is taken up here, in this chapter, as a *participants'* concern in the 'M E controversy', and *also* as a central and abiding concern in medical discourse. This chapter therefore aims to examine the rhetoric of mind and body by looking at the different kinds of 'models of medicine' that have been written about by practitioners and researchers in the fields of medicine, social

science, and psychiatry. Rather than being conceptualised here as explanatory models that have provided a framework to guide doctors' diagnostic thinking and practice, these are reformulated as explanatory repertoires¹ that can be deployed variably by both lay and professional participants in the rhetorical context of their accounting practices to accomplish particular kinds of discursive business.

The Legacy of the 'Biomedical Model'

George Engel (1977: 591) has used the language of cognitivist social science to define the term 'model' as a "belief system".²

broadly defined, a model is nothing more than a belief system utilized to explain natural phenomena, to make sense out of what is puzzling or disturbing. The more socially disruptive or individually upsetting the phenomenon, the more pressing the need of humans to devise explanatory systems.[...] Disease par excellence exemplifies a category of natural phenomena urgently demanding explanation

In his 1977 paper, Engel claimed that the dominant model of disease in Western society is biomedical and rooted in both philosophical reductionism and Cartesian mind-body dualism.

The biomedical model reduces disease to disorders that are located in the *physical* body, and which can be explained using a language derived from physics and chemistry. The aim of this approach was therefore to isolate the single smallest biochemical or neurophysiological factor as the cause of disease. Engel points out that the biomedical model is a *scientific* model which embodies a set of assumptions and rules based on the rationale of the scientific method. On the other hand, explanatory models, he claims, can also be popular '*folk models*' or belief systems which he refers to as "efforts at social adaptation" rather than scientific investigation. He makes this distinction to call attention to the possibility of cultural differences in the kinds of

¹ The term 'repertoire' is used here in the same sense as conceived by Gilbert & Mulkay (1984) and developed by Potter & Wetherell (1987).

² His reference to a "belief system [...] utilized to explain natural phenomena" implies a cognitive process, where 'beliefs' are formed as a result of our cognitive-perceptual experience, and thereafter guide or influence our thinking. The terms "natural phenomena" also imply an objective reality that exists independently of our constructive practices.

‘folk models’ that lay people might use to explain illness.³ He goes on to make the claim that not only has the biomedical model become the dominant *folk* model⁴, in modern Western societies, but also in *medicine* it has acquired the status of a *dogma*, demanding that anomalies should either be forced to fit the model, or else be excluded entirely. In other words, all disease should be explainable in terms of physical mechanisms, otherwise it should not be included in the category ‘disease’.

The biomedical model is also inherently dualistic, in the sense that it distinguishes between a physical body and a mental sphere, excluding the latter from its explanations of disease mechanism. The origin of this dualism is usually attributed to the philosopher Descartes who (in line with the Christian church’s doctrines) distinguished between the *material* body as a vessel for the *spiritual* soul that inhabits it. In Descartes time, the human mind therefore came within the domain of the spiritual, which was conceptualised as an entirely different kind of substance from the material and, as such, could not (and should not) be investigated and explained in the language of scientific investigation. Engel points out that “the Church’s permission to study the human body included a tacit interdiction against corresponding scientific investigation of man’s mind and behaviour”(ibid: 593).

An historical legacy of this restriction (coupled with the Enlightenment endeavour towards scientific rational explanation) was that the biomedical model tended to focus on the physical body to the exclusion of the psychosocial. This is not to say that the spiritual, or psychosocial had previously been considered unimportant as an influence on people’s state of health (see Ackerknecht, 1982), but rather that the Enlightenment project aimed “to ‘disenchant’ nature and see ‘God’s world’ as a mechanism, composed of physical matter obeying natural mechanistic laws rather than spiritual ones” (Gordon, 1988: 24).

³ In so doing he constitutes the very duality of folk versus scientific models, where these are construed as having a differential ontological status.

⁴ Which implies that the epistemology/ontology divide dissolves or, rather, that lay people have internalised the biomedical model to the extent that it informs and blends with their commonsense ‘way of knowing’. (Of course, from the perspective of ethnomethodology, scientists and social scientists frequently take members commonsense practices and work them up as theoretical constructs in the first place, therefore the degree of resonance between commonsense and theory is likely to reflect that.)

Engel's Critique of the Biomedical Model

The main focus of Engel's contribution was to call into question the adequacy of the biomedical model. He accomplished this by challenging the grounds of both the reductionist and exclusionist positions - that disease does not exist as such unless some biochemical evidence can be identified to explicate a phenomenon in terms of cause and effect. In other words, all phenomena not meeting these criteria should be excluded from the category of disease.

He uses the examples of diabetes mellitus and schizophrenia to demonstrate how biomedical reductionism and the exclusion of the psychosocial can "distort perspectives" and even "interferes with patient care". As Kety (1974:957) points out Both are symptom clusters or syndromes, one [diabetes] described by somatic and biochemical abnormalities, the other [schizophrenia] by psychological. Each may have many etiologies and shows a range of intensity from severe and disabling to latent or borderline. There is also evidence that genetic and environmental influences operate in the development of both.

In both of these disorders, it is considered possible to have a biochemical defect which provides the potential for the disease, without actually *experiencing* the illness. "Diabetes and schizophrenia have in common the fact that conditions of life and living constitute significant variables influencing the time of reported onset of the manifest disease as well as of variations in its course." (Engel, 1977).

In other circumstances, (say, for example, in the case of M E) someone may continue to complain of *feeling* ill when biomedical investigations have failed to identify any biochemical abnormalities that can explain the reported symptoms as disease. Engel points out that by focusing exclusively on the measurement of clinical signs and laboratory testing, the biomedical model fails to take into account the cultural, social and psychological context that he considers necessary to analyse the meaning of the patient's verbal account of illness experience. The relationship between the doctor and the patient is also argued to have a powerful influence in the process of treatment and healing, and it is claimed that an appreciation of psychosocial contingencies can facilitate a positive therapeutic outcome. For example, "...insulin requirements of a

diabetic patient may fluctuate significantly depending on how the patient perceives his relationship with his doctor.” (Engel, 1977). In other words, the biomedical model does not provide a basis for understanding the complexity of disease, its causation and treatment.

“The crippling flaw of the model is that it does not include the patient and his attributes as a person, a human being. Yet in the everyday work of the physician the prime object of study is a person, and many of the data necessary for hypothesis development and testing are gathered within the framework of an ongoing human relationship and appear in behavioural and psychological forms, namely, how the patient behaves and what he reports about himself and his life. The biomedical model can make provision neither for the person as a whole nor for data of a psychological or social nature, for the reductionism and mind-body dualism on which the model is predicated requires that these must first be reduced to physico-chemical terms before they can have meaning.” (Engel, 1980: 536)

The Clinical Application of Systems Theory: A Biopsychosocial Model

Engel therefore proposed that a new kind of model should be introduced into clinical practice to address the deficiencies of the biomedical model, and this he derived from the rationale of systems theory. General Systems Theory was developed by the biologists Paul Weiss (1959, 1969) and Ludwig von Bertalanffy (1968, 1969).

According to Engel, systems theory overcomes the limitations of the biomedical model by “providing a conceptual framework within which both organised wholes and component parts can be studied” (*ibid*: 536). More specifically, the natural world is understood as a “hierarchically arranged continuum” which ranges from subatomic particles, upwards through atoms, molecules, organelles, cells, tissues, organs/organ systems, the nervous system, the experience and behaviour of the person, within two person relationships, family, community, culture-subculture, and in the context of society-nation, and biosphere. Each level of the hierarchy has its own distinctive properties and characteristics, and therefore requires particular kinds of study and explanation; on the other hand each of these systems is also a component of higher systems. As Engel formulates it, “Nothing exists in isolation. Whether a cell or a person, every system is influenced by the configuration of the systems of which each is a part, that is, by its environment.” (*ibid*: 537).

A criticism of reductionist biomedicine is that the physician’s exclusive focus on the body and disease has resulted in a neglect of the patient as a whole person within the

social context. It was for this reason that Engel proposed the adoption of a new conceptual model, the biopsychosocial model, to take into account the complex interplay between the biological, psychological and social environments in the explanation of disorders and the treatment of patients.

As we have seen, this approach takes a process, or systemic understanding, rather than a linear causal explanation of disease as previously taken in the biomedical model. The upshot of this kind of explanatory model is that *all* illness/disease process is potentially explicable in terms of the interplay of multifactors, which are biological, psychological, and also social.⁵ The psychosocial aspects of this process have been investigated by the application of social science theories to medicine and to the study of health and illness.

Social and Psychological Factors and Health

Any textbook on the sociology or social psychology of health and illness informs us that there has been an enormous amount of research into the social and psychological aspects of health. Sociologists and social psychologists have identified a wide variety of factors that can have a potential influence on people's health. For example, Scambler (1991) identifies three broad types as (i) socio-environmental, (ii) behavioural, and (iii) psychological; "Socio-environmental factors include poverty, social support and relationships with others, work and unemployment; behavioural factors include smoking, exercise and dietary practices; and psychological factors include personality type, coping capacities and health beliefs." (*ibid*: 21)

The first category, socio-environmental factors, represents a whole set of influences on people's health whose causes cannot be directly addressed by health practitioners, even though their effects are generally understood as 'stressors' with which the patient has to cope. The second category, behavioural factors, represent a set of influences

⁵ The biopsychosocial model is thus 'multifactorial', which is to say that two more kinds of factors/variables (the psycho-social) have been added to biological factors to explain disease. This is fundamentally different from the way that the *social* is conceived of in *constructionism* where the social is *constituted* rather than being treated as a variable. From this view the biological and the psychological are also social constructs. There is nothing that stands outside of the socially constructed world.

that *can* be addressed by medical practitioners in practical ways, to the extent that they are able to educate people about the likely consequences of their habits and lifestyle. For example, they might try to persuade patients to give up harmful habits, such as smoking, and adopt healthier ones, such as taking appropriate amounts of exercise. Doctors might wish to convince their patients to cooperate with a plan for a healthier lifestyle, especially as this relates to a presenting medical problem, say for example, heart disease.

The third category, psychological factors, represents a set of influences that are deemed to be *internal* to the individual and are drawn on to explain a *causal* relationship between disposition (personality), perception, and experience of pain⁶, stress, or susceptibility to disease; or between cognitive health beliefs (explanatory models), illness attributions, and illness behaviour.

Also, as pointed out before, the factors described in the first (socio-environmental) category, such as poverty, lack of social support, difficult relationships, and problems with work and unemployment, all represent '*stressors*' that the *individual* has to find the resources with which to cope. The extent to which people are able to manage stress has become a major focus for cognitivist social psychology research, which has investigated the dimensions of people's 'coping styles' as a potential means to identify styles that are typically more or less effective at coping with stress (e.g. Folkman & Lazarus, 1980; Folkman *et al*, 1986a, 1986b; Amirkhan, 1990; Endler & Parker, 1990; and Rohde *et al*, 1990).

Dialogue Box ⁷

DE: *Of course, the identification of factors and variables and their subdivision is itself a feature of members practices and is analysable as such. Being able to distinguish between socio-environmental, behavioural and psychological can be a way of not having to comment*

⁶ See, for example, Ogden's (1997) discussion of the role of perceptions and interpretations in the 'gate theory' of pain, and transactional theory.

⁷ This dialogue is based on a tape recorded discussion between the author (MHS) and her supervisor, (DE) in the context of discussing an earlier draft of this chapter (October 8th, 1997). As I pointed out in the synopsis outlined in chapter one (page 23), I have used an 'alternative literary form' to *perform* the construction of parts of my text as a dialogic and intertextual practice, rather than simply presenting the *product* of such practices. This activity mirrors a rhetorical move I made in chapter two, where I chose to call attention to the constructive processes that are normally obscured in the craft of writing a review.

on the socio-environmental if you're a doctor. And yet there may be a blurring of this distinction, to the extent that the socio-environmental can be made relevant via the mechanism of psychology (in, for example, the relationship between stress, coping and personality). Categories can start to merge and interfere with one another. If that's the case, then this raises the question 'What are the categories there for in the first place?' Are they categories, not so much that describe the world 'out-there', but conceptual resources for saying what doctors are able to deal with. In other words, they're indexical⁸ categories for the practice of medicine rather than descriptive categories for the etiology of disease.

MHS: Yes- that's the route I was going down. I want to say that the models- reformulate them as repertoires that do things- they function in particular ways. Especially the psychological aspects- including things like health beliefs, disposition of the patient, coping style etcetera. And the behavioural ones are things like smoking, exercise diet, lifestyle, and illness behaviour- all things for which the patient can be held accountable.

DE: So this does moral categories as well- being held to account is more mind and body isn't it? You can only be held accountable for something if you have a choice -free-will.

MHS: Yeah, that issue comes up in the next section- where Kirmayer uses a case study of conversion disorder (hysteria) to illustrate psychosomatic theory and practice. One of the categories he describes is 'biological psychiatry', where you get this collapsing of mind and body into... the same substance.

DE: It's the brain!

MHS: Yeah- and so they (the patients) aren't accountable, and yet they are!

DE: That's the kind of flexibility for which you would require flexible concepts- medical concepts that are designed to cover every aspect of accountability.

MHS: Exactly!

The Influence of Psychosomatic Medicine

Another way that the influence of psychosocial factors on people's health has been constructed has been in and through the discourse of psychosomatic medicine.

Ackerknecht (1982:17) introduces his "history of psychosomatic medicine" thus:

Psychosomatic medicine begins with the Greeks. It finds a place in Galen's system as diseases of passion, a concept current until the middle of the nineteenth century. The great French and German clinicians of the nineteenth century were all familiar with psychosomatic diseases. During the twentieth century the field was for a while monopolized by

⁸ 'Indexicality' is a feature of discourse in which the meaning of an utterance depends on its context of use. "Descriptions...are not to be regarded as disembodied commentaries on states of affairs. Rather, in the ways in which they (1) make reference to states of affairs and (2) occur in particular interactional and situational contexts, they will unavoidably be understood as actions which are chosen and *consequential*. Like other actions, descriptions are 'indexical' and are to be understood by reference to where and when etc. they occur." (Heritage, 1984a: 140, emphasis added)

psychoanalysts. The psychosomatic specialist is essentially the doctor who listens to the patient.

He points out that psychosomatics has been around for 1700 years, under the label of 'passions' (products of the vital soul that could both produce and also cure disease), and which were included in the six non-natural causes of disease in the Galenic system (Galen, 1821). The 'passions' were also discussed by philosophers such as Plato⁹ who criticised Greek physicians for treating the body whilst neglecting the 'fair words' for the soul that were deemed necessary for a cure (in Hermann, 1919). It was not until 1929 that the term 'passion' was replaced by the term 'emotion' in the Index catalogue of the Library of the Surgeon General.

Despite evidence to the contrary¹⁰, Ackerknecht claims that the emergence of psychosomatic medicine is commonly dated to around 1900, and was at that time dominated by the Freudian concepts of psychogenic neurosis, and symptom conversion.¹¹ In 1978, Shepherd commented about Dunbar's (1943) writings in his text, *Psychosomatic Diagnosis*; "much of what passed for psychosomatic medicine was little more than a scientifically naive attempt to impose psychoanalytical theorising on physical illness in an attempt to demonstrate psychological causation."

However, the most recent 'official' emergence of the psychosomatic movement in Britain was marked by the appearance in 1956 of the *Journal of Psychosomatic Research*.¹² Despite the current existence of many different theories about the genesis of psychosomatic disease, and different techniques of psychotherapy, Ackerknecht claims that a consensus appears to have emerged at least on the following point the basic element of psychosomatic medicine represents a dialogue between doctor and patient, their cooperation, the rediscovery of Dunbar's 'gentle art of listening' and the notion of the 'doctor as placebo' (Lain Entralgo, 1956, p. 173). In this way the gap created by the progressive mechanization of medicine may be filled. Our own age, which tends to solve all problems through the creation of new specialities, has reinstated this basic element of

⁹ And of course later by Descartes whose treatise on '*The Passions of the Soul*' was published in 1656.

¹⁰ He claims that medieval psychogenic explanations of plague survived into the 17th century, and continued into the 18th century, (Ackerknecht, 1973; 1981) as did psychogenic explanations of pulmonary tuberculosis, fever, consumption, gout, scurvy, as well as hysteria and hypochondriasis.

¹¹ One of the explanations offered in chapter two (McEvedy & Beard, 1970, extract 18, page 41) is based on the Freudian notion of hysterical symptom conversion.

¹² Although the *Journal of Psychosomatic Medicine* had been published in the USA in 1939.

medicine by creating a new speciality. The psychosomaticist seems above all to be the physician who specializes in listening to the patient (*ibid*: 23).

On the other hand, Kirmayer (1988) argues that, in practice, psychosomatic medicine has had little impact on the fundamental organisation of biomedicine. Rather than seeing all disease as psychosomatic, in the sense that the disease process involves both mind *and* body, a view supported by the World Health Organization (1964), he claims that psychosomatics has been marginalised as a category of ‘not quite legitimate illnesses’ that are equated with the imaginary and ‘best handled by mental health practitioners’ (Kirmayer, 1988: 64).

To illustrate his claim he uses the case history of a patient who had two overlapping episodes of illness; the first which was diagnosed as a CVA¹³, where there was “a satisfying fit between history, physical findings, and a specific neurological diagnosis” (*ibid*: 68), and the second, where the patient experienced symptoms that resembled her initial stroke, but was later diagnosed as suffering from a conversion disorder (hysteria).

she had symptoms that followed the conventional lay person’s representation of the body rather than established neuroanatomical pathways. Thus it appeared that the problem involved Mrs. D’s mind rather than her brain. Of course, the neurologists, if questioned, would state that her mental symptoms were ultimately caused by the brain. But hers was a disorder in brain function not structure, akin to learning bad habits, and of little neurological interest except as a difficult diagnosis to make.

Mrs. D’s body was seen by the doctors as alternately suffering from a disease of the imagination or no disease at all. Depending on what level of self-awareness the physicians attributed to her, she was then viewed as pitiable and incompetent or as foolish and histrionic. Either way her sense of self was challenged and she perceived rightly when she thought that some of the housestaff physicians were laughing at her (*ibid*: 68).

Kirmayer describes the way that the ‘real’ disease of the first episode held the interest of the biomedical practitioners, who treated the patient with care and attention. In contrast, during the second episode, he claims that the illness was not treated as legitimate; since there was no identifiable disease, the biomedical practitioners lost interest and the patient felt as though her distress was not being taken seriously.

¹³ Cerebrovascular accident (Stroke).

Kirmayer identifies three different models of psychosomatic illness that were eventually used by psychiatrists in this case, to explain the patient's second episode of illness. The first model; 'biological psychiatry', explains her illness as being the result of organic vulnerability following the CVA. From this view, the conversion symptoms were either a consequence of reduced ability to cope due to brain damage, or hysteria associated with biologically determined personal traits. In this account, the dichotomy of mind and body are eliminated to the extent that both neurological disease, *and* psychological disorder, are reduced to the activity of the central nervous system and are therefore construed as being the same *material* substance. However, the contrast between mind and body is preserved in this account, to the extent that reason and emotion are mapped onto brain structures; the cerebral cortex being responsible for the co-ordination of higher mental function such as rational thought, whereas the more primitive brain structures being the origin of bodily responses such as emotion, arousal, and motivation. This anatomical hierarchy of the brain is argued, by proponents of this approach, to parallel the ascent of man from mammals driven by passion and aggression, to civilised beings capable of rational thought and reflection.

From this view, psychosomatic symptoms such as conversion symptoms are therefore attributable to irrationality; "an infantile expression of distress" taking the form of somatic symptoms rather than rational verbal expression. Kirmayer points out how the organic explanation of biological psychiatry implicates the patient in a lack of social competence, whilst managing to avoid the construal of psychological distress as a form of social protest, thereby implicating a moral dimension which would otherwise suggest the possibility of a blameworthy victim. However, in this case, access to the 'sick role' *does* implicate the patient in a tacit agreement that their *competence* is diminished due to a disordered or malfunctioning brain.¹⁴

The 'psychodynamic approach' explains hysterical conversion symptoms as the result of conflicting desires that are not directly accessible to the conscious mind.¹⁵ The

¹⁴ See earlier comments in the dialogue between DE and MHS (page 110), this chapter.

¹⁵ DE: *I see you've included 'hysteria' in the category 'psychosomatic' here. Some perspectives in medicine would want to distinguish psychosomatic disease from hysteria- psychosomatic can be*

rational/irrational split is relocated from the structure of the brain, to the division between the conscious and unconscious mind. Treatment aims to overcome the 'self-destructive irrationality' of the unconscious urges in terms of rational conscious control by the development of self-knowledge. In other words, emotions are to be controlled by verbal description and scientific explanation, rather than by suppression and symptom conversion. Kirmayer describes how one of the psychiatrists interpreted an angry outburst by the patient, as further evidence of her psychodynamic problem rather than as anger and frustration at the prospect of yet another psychiatric evaluation of her illness. He points out how the clinician's account is privileged over the patient's in interpreting the 'symptom'. Since the psychological conflict is not deemed to be accessible to the patient's conscious mind, the clinician must therefore claim 'authorship' of the meaning of the patient's symptoms in terms of an underlying psychodynamic disorder.

Dialogue Box

DE: *Psychodynamic explanations sort of mess up attribution theory don't they? There's a kind of crude notion of external and internal causes and it's like you're accountable for internal causes but not external ones. But the trouble is- you can't help it if it's the way your brain is, or the way your unconscious is- after all your unconscious isn't accountable! This makes rather flexible, what in attribution theory is meant to be clear-cut - internal/ external.*

MHS: *So...the question of accountability becomes dependent on the willingness of the patient to co-operate (or not) with the doctor's therapeutic intervention...*

The third approach to psychosomatics, described by Kirmayer, is 'behavioural medicine', which derives from learning theory in academic psychology (Skinner,

described as stress-induced breakdown of the autonomic nervous system that led to actual physical diseases that needed treating but the causes were psychological (eg. skin rashes, and hypertension), whereas hysteria refers to false physical syndromes- like paralysis with no physical basis. You seem to be using it (the term psychosomatic) as any kind of presenting symptom that a GP might come across that has a psychological cause.

MHS: *I think it depends who you read as to how these things get categorised.*

DE: *But it's of interest in your project that someone might want to include things like ulcers and skin rashes in the same category as hysteria: why put them in same category? It's to adopt the approach that the mental/physical causation is so important as to obliterate differences. From one perspective in medicine someone wouldn't want to have them in the same category!*

MHS: *I think it relates to whether you wanna talk about things being real or imaginary. I think Kirmayer wants to call attention to the distinction that's often made between 'real' as physical and psychosomatic as 'it's all in your mind'. But there's no neutral way to list/categorise things is there? However I choose to categorise things I'm doing some business!*

1971; Seligman, 1975). From this view, the psychosomatic symptoms of the patient's second episode of illness are interpreted as a result of learning that illness elicits care-giving from other people. This is *not* seen as happening at the level of the individual's awareness, but as having been acquired by means of the normal psychological processes of learning, and maintained by external environmental contingencies.

'Stress' is also formulated as the demands of the environment to which people can be more or less vulnerable. Stress is seen as related to lifestyle, as determined by economic necessity, character, or moral choice. In other words, individuals may choose to subject themselves to stress in pursuit of goals that can be judged either morally good or questionable. As pointed out earlier, many of the *social* origins of stress are taken as 'givens' (which cannot be directly addressed by medical practitioners), therefore the treatment emphasis is on individual lifestyle change and psychological coping.

Kirmayer argues that the three models of psychosomatic illness used by the psychiatrists to explain the patient's second episode of illness *clearly* occupy a *moral* realm of *accountability*. In Western culture, where it is claimed that the biomedical model has become the dominant 'folk model' (Fabrega, 1975), 'real' disease is equated with things that 'just happen to us', for which we are not responsible and cannot be held accountable. The unexplained phenomena of an illness that has no clinical signs and therefore cannot be categorised as disease in terms of the biomedical model, can, on the other hand, be accounted for in terms of *psychogenic explanation* as illustrated by the three types of psychosomatic explanation outlined here.

The diagnosis of a psychosomatic condition transforms the real into the imaginary, the innocent into the culpable. This is well brought out in the range of informal terms used to label psychosomatic patients and their conditions.[...] They range from causal dismissal of the problem as not real ("It's all in your head," "imaginary," "pseudoseizures," "pseudoangina," and so on) to frankly moralistic labels. [such as "malingerer", "Green poultice syndrome,"¹⁶, "fake" etcetera]
(Kirmayer, 1988: 66)

¹⁶ "symptoms that are relieved when paper money is applied directly to the affected region" (Kirmayer, 1988: 66).

The responsibility is thereby shifted to the patient, rather than being a reflection on the skills of the physician who has been unable to supply a biomedical, scientific explanation for their disorder. This observation has led to the accusation that the speciality of psychosomatics functions to protect the legitimacy of the biomedical model by “siphoning off cases with which it is unsuccessful”(Lock & Gordon, 1988: 11).

The main thrust of Kirmayer’s argument is that the speciality of psychosomatics *reproduces* the dualistic relationship between mind and body that is central to biomedical explanation. He claims that “psychosomatics expresses its holistic perspective in dualistic terms that ultimately invoke the same values of rational control and distance from passion and bodily-felt meaning that are part of the mechanistic world view of biomedicine.” (Kirmayer, 1988: 58)

This formulation also reproduces the distinction between ‘objective’ scientific evidence, and ‘subjective’ personal experience, as two ways of knowing, where in the tradition of empiricist biomedical science the medical ‘reality’ of disease is ontologically definable by means of the identification of ‘objective’ clinical evidence, whereas the patient’s subjective *feelings of illness* are symptoms that need to be interpreted within that framework in order to be legitimated as the symptoms of ‘*real*’ *disease*. This kind of distinction between subject and object is of course itself a construction that has its origins in the broader empiricist and scientific rationale of the Enlightenment project, where a distinction is made between ontology and epistemology or between scientific evidence and personal experience. The mind-body dichotomy, re-worked as a kind of epistemological dualism, (rather than the Cartesian dualism of two different substances for mind and body) is a variant of that same rationale (DiGiacomo, 1992).

This kind of epistemological dualism of two different ‘ways of knowing’, is manifest in the distinction that is often made between disease and illness (Eisenberg, 1977), where disease refers to pathological changes in the body (or at least, the physician’s

biomedical interpretation of those changes), and illness refers to the patient's personal experience of distress. As pointed out earlier, these two are attributed a different ontological status in biomedicine which is discursively accomplished using the empiricist and contingent repertoires in order to construct one as factual, and the other as a construction, with reference to illness attributions, personal beliefs, disposition etcetera.

If we return to the biopsychosocial model that was described earlier as being a challenge to the biomedical model, we can see that the bio-psycho-social components of this model roughly correspond to the categories of disease, illness, and sickness¹⁷ where the latter term, sickness, refers to a social condition, status, or role that is adopted or attributed to the person suffering from a disease or illness.¹⁸ Of course the distinction between these three categories is very central to the way that people talk about disorders in general, and especially a controversial disorder such as M E. In chapter two, we saw how the patients' symptoms of illness, as manifested in the reported outbreaks, was variously interpreted as being either an example of physical disease or a case of psychiatric illness such as hysterical conversion. Thus, symptom reporting (of the illness experience itself) is not necessarily equated with the incidence of disease, and this whole question of whether or not the mystery *illness* could be defined as a new *disease* entity was seen to have a bearing on the legitimacy of the patient's *illness* and consequently on the status of the patient as a 'sick' person.¹⁹ In other words, in the context of the dominant biomedical model, accounting for oneself as *legitimately* 'sick' appears to involve the definition of one's *illness* experience in

¹⁷ See chapter one, pp 2-6 (above) for a discussion of these categories.

¹⁸ DE: What's at stake in your thesis is what is the extent of the domain of the social? Why don't you just discuss social factors in M E? Why don't you be the second and third variables?

MHS: Whereas what I want to do is say, 'What are the second and third variables doing? What have they been constructed to do?

DE: But you have to look at how all of the variables (including the biological) are constructed and what they do.

MHS: I tried to do that in chapter two.

DE: But it's worth spelling out that you aren't the second and third variables- given that there's such a thing, in your topic, as the social (or the psychological), you have to state that you're not actually investigating that or using that as your resource, but you're studying the whole 'ball game'.

¹⁹ See also chapter 6, Angela and Joe's illness narrative, where the discursive processes of accounting for oneself (or one's relative) as legitimately 'sick' are analysed in more detail.

terms of the category of *disease*. Or at least it involves the patient in a tacit agreement that their psychological competence is diminished, and therefore that their subjective experience of illness symptoms has a dubious status.

This argument provides the grounds to support a claim that there may be a *cultural* basis for somatisation²⁰, which has been constructed as an “idiom of distress” (Katon, Reis and Kleinman, 1984: 208), whereby a psychological disorder can be presented in terms of bodily symptoms. It has been claimed that approximately 60% of primary health care involves psychosocial distress which is presented to the physician as physical symptoms (*ibid*: 209). The *psychological* dimensions of illness are often felt by patients to be addressed by doctors most commonly in the context of ‘dismissive rhetoric’, so that patients may become anxious about presenting such problems to the doctor. This could be formulated as an *interactional* basis for somatisation:

the presentation of disorder in bodily narrative [...] precludes discussion of the psychological dimensions of illness except when in reference to the moral or mental ineptitude of the patient. Such cultural values may be reflected in medical discourse in a dismissive rhetoric that labels the person as ‘a crackpot’, a ‘neurotic female’, a ‘hypochondriac’. (Parsons & Wakeley, 1991: 127).

This kind of observation is supported in the literature by a survey of general practitioners’ categorisations of “‘*Trouble*’ and *Types of Patients*”, in which Stimson (1976: 50) noted that “whereas references to physical illness were likely to be made in the context of least trouble, references to psychiatric illness and psychological problems were made, with the exception of one doctor, entirely with reference to patients who cause the most trouble.” Stimson goes on to point out that

Some patients are seen to be ‘genuinely ill’, or are ‘really ill’. A real illness is a physical or organic illness. The ‘real’ patients are ‘medical patients, that is, with real pathology’. From the point of view of doctors one advantage with a physical illness is that it can be diagnosed because it is a ‘definite clinical disease’. Psychiatric illness is not so genuine, may not be medical, and is often hard to diagnose.[...] For doctors the trouble with vaguer illness, and especially psychiatric, is that people very often will not accommodate to their illness. Indeed the attitude of the patient to the illness may be seen to be part of the illness: ‘Patients who cause the most trouble are patients complaining of vague ill health or symptoms who after intensive investigations with negative findings, cannot come to terms with their symptoms,

²⁰ White (1982) discusses the link between cultural explanations of illness and ‘somatisation’ and ‘psychologisation’. He points out the differences between the Chinese and Americans in making interpretations of symptoms of depression; the Chinese using somatic or situational explanations, compared with the Americans being more likely to use psychological explanations.

and fail to respond to reassurance or medication'. Finally in the context of 'trouble' there is the matter of time: Patients with psychiatric illness are seen to take up much more of the doctor's time. They are more demanding and they have to be seen more often. (Patients who cause most trouble are) 'People who are basically depressive and not prepared to see it, who deny any psychogenic factors in their illness, who feel that they have an exclusive right to take as much time as they want to talk about themselves and their ailments' (*ibid*: 51-2).

The Psychologisation of Illness

On the other hand, some researchers have complained that physicians all too readily attribute patients' symptoms to a psychological disorder. Goudsmit and Gadd (1991: 449) give the following definition of psychologisation,

Psychologisation, i.e. the exaggeration of the role of psychological factors when considering the aetiology and treatment of illness...". They go on to give a range of examples in which they argue that health-care professionals have, "shown a clear preference for psychological explanations [...] where the available evidence does not justify such an emphasis; where alternative explanations are ignored or dismissed, or not even sought.

For example, they describe a study of patients with subacute encephalitis, where "The bizarre behaviour induced physicians to ignore neurological findings, to overlook evidence of organic syndromes (such as intermittent lucidity and markedly abnormal electroencephalograms) and to make functional diagnoses." (Himmelhoch *et al*, 1970). They point out how in the early history of AIDS, "Doctors frequently missed the damage to the central nervous system, writing off the often vague symptoms of dementia as related to stress or depression" (Shilts, 1988: 207). Other illnesses that are often mistaken for a psychiatric disorder are myasthenia gravis (Nicholson *et al*, 1986), and multiple sclerosis (Easton, 1989), where in the latter case "its early symptoms- fatigue, loss of sensation, weakness and visual changes- are frequently misdiagnosed as psychoneurosis or even a more severe psychiatric disorder, such as hysteria, particularly in women." And, as Robinson (1988) has observed from his study with MS patients "the disclosure of the diagnosis gave back to many respondents their credibility and legitimised their strange behaviours which had previously been labelled as neurotic, hypochondria, malingering or drunk".

ME/CFS and Repetitive Strain Injury (RSI) are two more conditions in which the patient's symptoms are often interpreted as an indication of an underlying psychological disorder. In her study of CFS sufferers, medical anthropologist Norma

Ware (1992) formulated their illness experience as “delegitimation” because their subjective experience of illness had been disconfirmed, trivialised and “defined as either non-existent or psychosomatic” (*ibid*: 347). “Thus, the absence of observable evidence of pathology, together with the ambiguous status of the illness in professional medicine, precluded the possibility of a physical diagnosis for many chronic fatigue syndrome sufferers. And if the illness is not physical, it must, it follows, be mental.” (*ibid*: 351). In chapter two of this thesis, I constructed a ‘plausible history of M E’, where hysterical conversion was one of three types of explanation that were positioned against one another in the controversy about the status of the mystery illness. Similarly in RSI (“a non-specific and controversial constellation of work-related hand arm and neck symptoms”) there have been different schools of opinion about its status, ranging from work related injury, compensation neurosis, normal fatigue, a form of conversion disorder, or a complaint of malingerers (Reid, Ewan & Lowy, 1991).

Moreover, it has been argued that the practice of psychogenic dismissal, has itself led to iatrogenic injury²¹ (Rippere, 1991). In other words, when doctors dismiss people’s symptoms as being ‘all in the mind’ there can be serious consequences that include lack of treatment, or inappropriate treatment, delegitimation of the patient’s illness experience, stigma and loss of credibility, disaffection from medical care, and damage to social functioning, to name but a few. Rippere has even referred to psychogenic dismissal as “a significant threat to public health and safety”, and “the ultimate health fraud” (*ibid*: 146). On the other hand, Woods & Goldberg (1991: 908-18) have warned physicians against “iatrogenically perpetuating disability” by colluding with “patient’s attempts to avoid the psychological aspects of their illness”.

Legitimacy and the Subject-Object Dichotomy

The question of the relationship between the *nature* of illness and its *legitimacy* (and inextricably also the legitimacy of *medical practice*, and the *credibility* of diagnosis)

²¹ Iatrogenic injury refers to injury “caused by the process of medical examination or treatment” (Concise Oxford Dictionary, seventh edition, 1983).

are very clearly issues that are at *stake* for doctors, patients, and those participants who engage in discourse about illness/disease. The research on 'somatisation' has claimed that there may be a tacit mutual orientation on the part of doctors and patients to the notion that 'real' disease corresponds to bodily signs. On the other hand, other research on 'psychologisation' has suggested that in certain circumstances health-care professionals have a "clear preference for psychological explanations", especially in cases of uncertainty where symptoms are vague and confusing. This sounds somewhat similar to Kirmayer's earlier claim that psychosomatic explanations function to "protect the legitimacy of medicine".

The question of what is *legitimate* and what is *not* is worked up (and made relevant) in the distinction that is made between object-subject, where legitimacy is warrantable in terms of objective empirical evidence, and lack of legitimacy is construed as based on the subjective, and contingent on personal experience, internal attributions and beliefs, and needing to be evaluated in relationship to the findings of empirical science.

That's been my experience [with doctors] over and over again. They really try. They really listen. And then they try a whole bunch of things that they think might turn something up, and when everything fails, they just think you're nuts. And then they get sort of angry [...] 'you can't be experiencing what you are experiencing. You need to see a psychologist. you're not as sick as you think you are' [...] 'there's nothing wrong on your X-ray' (Quotation from CFS patient, cited in Ware, 1992: 351).

Subject and Object as Discursive Accomplishments

Discursive psychology construes both objectivity and subjectivity as *discursive* accomplishments. The 'objective as factual' is constructed by means of an empiricist repertoire, which works to delete agency; whereas the 'subjective as a personal construction' (that is likely to be inaccurate or biased) is constructed by means of a contingent repertoire, which works to construct error in terms of social processes and the disposition and cognitions of the agent. In *this* context (of illness talk) the 'subjective' dimension could be made relevant by drawing on a range of psychological concepts such as: personality, or the notion of health beliefs, and illness attributions, otherwise referred to in the literature as lay explanatory models.

Lay Explanatory Models/ Illness Attributions

The work on illness attributions and explanatory models in health and illness studies is derived from the rationale of attribution theory in social psychology (Heider, 1958).

The rationale for this is based on a cognitive-perceptual approach that explains how human beings try to understand their experiences and perceptions by assigning causes to them (Shaver, 1975). According to Stoeckle and Barsky (1981: 230) illness attribution refers to both the cognitive processes by which a patient arrives at an explanatory belief, and *also* to the explanation itself.

Their specific content, then, is shaped by the person's personality, prior knowledge and experience, cultural beliefs and characteristic defense mechanisms. A clue to a patient's predominant defenses may be suggested by his attributions. For example, persons who tend to blame themselves when things go wrong also view illness as their own fault as something they have brought upon themselves; those who typically see themselves as helpless and at the mercy of their environment tend to see illness as something externally inflicted upon them.

This is a type of analysis which places patient's illness attributions as a centrally important concern for the doctor's work, precisely because they *reveal* the *meanings* that patients attach to symptoms, disabilities or bodily signs that they bring to the medical consultation.²² These *meanings* are considered to be important because they help to determine the patient's illness behaviours, coping responses and emotional reactions (Lipowski, 1969; 1974). When a patient's illness attributions are taken into account (by acknowledgement, interpretation, or redefinition) this is supposed to facilitate the caring tasks of the doctor. For example, it is argued that a patient's attribution *itself* "may produce an anxiety state more discomforting than the bodily distress itself. In many instances, the patient only seeks help because of his worry over his own diagnosis" [...] "Doctor, I want to know if it's my nerves or my heart." (Stoeckle & Barsky, 1981: 228).

The 'illness attribution' literature is distributed throughout both social science and clinical literature, often under headings other than attribution. For example, sociologists have written about '*lay knowledge of illness*'. Mabry (1964) has

²² See Edwards (1997) for a discussion of three types of analysis that can be performed on discourse. Edwards refers to 'type 2' analyses as being based on a fundamentally *cognitivist* rationale, where participants' accounts are treated as evidence of what is going on in the mind. Illness attribution studies, of the type described by Stoeckle and Barsky (1981), fall into this 'type 2' category.

documented typical causal attributions as exposure to elements, germs, being run down, nerves, and diet; Samoral (1962) investigated the public knowledge about heart disease and cancer; Monteiro (1979) contributed to the literature on heart disease. Generally, such studies report the degree of congruence between lay explanations and those held by doctors, and any incongruence has been used to explain why the public's health practices may diverge from doctor's recommendations and also provide grounds for improving the education of the public.

The *beliefs* of patients with specific diseases have also been studied. For example, Elder (1973) identified etiological explanations of rheumatoid arthritis that were related to ageing, climate, working conditions, and exposure to the elements; Markson (1971) showed how arthritic patients commonly offered similar kinds of explanations of their joint disease, using a combination of vulnerability (things that lower resistance and increase susceptibility) plus external causal agents, to explain their condition; Bard and Dyk (1956) noted how attributions of *blame* were directed at either themselves or at an external force. For example, internal attributions of blame included acts, habits or thoughts for which the patient held themselves accountable, or external occurrences such as interpersonal friction, hostility of others, or supernatural, or environmental events. Similarly, Abrams and Finesinger's (1953) work on the attributions of cancer patients showed that the attribution of blame to self or others was common to many accounts.

Medical anthropologists document the 'health and illness beliefs' of other cultures, and clinicians give accounts to their colleagues in the form of patients' case studies on the 'personal meanings of illness' (e.g. King, 1962; Fabrega, 1973; Kleinman, 1973). It is claimed that a patient's particular illness attribution is often embedded in older culturally determined systems of belief about health and illness. In addition to a scientific belief system that assumes biomedical causes for disease, it is claimed that both primitive (supernatural) and also folk beliefs persist in the attributions of modern 'well educated' patients. Herzlich (1973) found that illness attributions were either exogenous forces such as; way of life, crowded cities, bad air and food, or endogenous

individual factors such as temperament, constitution, or disposition. Such studies on the 'personal meaning of illness' claim that meaning is the basis for the patient's affective, cognitive, and behavioural response to illness. Lipowski (1979) identifies five of the most prevalent categories of personal meanings as: illness as enemy, as weakness, as punishment, loss or damage, or a challenge. Each of these meanings is taken to have psychological and behavioural consequences, ranging from anxiety, anger, denial, resignation, hostility and depression, or appropriate adjustment and coping.

A number of studies have looked *specifically* at the relationship between patient's illness attributions and the Chronic Fatigue Syndrome. Susan Abbey (1993) examines the relevance of illness attributions, personality characteristics or styles, somatisation and illness behaviour to the initiation, maintenance and perpetuation of CFS. She cites Wessely and Powell's (1989) findings; that 86% of a group of 21 patients with post-viral syndrome attribute their illness to physical factors, and further, that this is associated with a poor outcome in a Cognitive Behavioural Therapy treatment programme. (Wessely, *et al*, 1991; Butler, *et al*, 1991). Also Sharpe *et al*, (1992)²³ studied a group of M E patients in an infectious diseases clinic and found that patients who attributed their ongoing symptoms to physical causes (and also belong to a support group) were more likely to remain disabled at two-year follow up. A caveat points out the ambiguous interpretations of this data; that is, the attributions and advice of support groups may be linked to a perpetuation of disability, or, as argued by Charles Shepherd in chapter two, extract 38, the results may indicate that a more *severely* ill group of people (who might have M E rather than CFS) are seeking the support of other sufferers in the absence of effective medical treatment. Powell *et al*, (1990) have also warned that (given the uncertain ontological *status* of CFS) "one cannot overemphasise that it is impossible to judge the 'correctness' of the attributional style found in CFS".

²³ See chapter two, page 57, for an outline of this study.

Nonetheless, (and regardless of the circularity of the argument) the ‘evidence’ on the role of patients’ illness attributions (their ‘dysfunctional cognitive distortions’) in the prognosis of CFS, have been used by clinicians as the basis for prescribing cognitive behaviour therapy. Wessely *et al*, (1991) describes how the attributions that CFS patients make about the causes of their ongoing illness, (eg. all symptoms are the result of a virus, physical activity is harmful and likely to result in a set back, etcetera) are linked to behavioural avoidance (of activity) and physical deconditioning. Treatment by a CBT programme is designed to specifically change the way that patients *think* about their illness and how to *manage* it. The rationale of this programme is *not* based on the assumption that a patient’s disorder necessarily has a psychological *origin*, but seeks merely to “optimize patients’ level of physical and psychosocial functioning” (Abbey, 1993: 243). *Control* over symptoms is taken to be an important factor in the rehabilitation process and the concept of ‘learned helplessness’ (Seligman, 1975) has been appropriated to construct patient’s problems as a downward spiral of events in which the patient has learned to expect to be unable to control the symptoms of their illness, and CBT is designed to help them to regain a sense of self-efficacy and control. Where the programme *fails* to help patients, “six out of the seven patients who attributed their illness to exclusively physical causes having a poor outcome”(Abbey, 1993: 243), this is attributed by the authors to ‘the strength of physical illness convictions’ and untreated depression.

The rhetorical force of this last statement functions in the same way as the psychoanalytic concept of ‘resistance’ that was mentioned earlier in this chapter (page 114) in the context of the psychosomatic repertoire and the CVA patient. That is, the patient’s *accountability* for being sick depends on the extent of their co-operation with the medical ‘authorship’ of their illness and *therapeutic intervention*. In the case I have described *here* (cognitive behavioural therapy with CFS patients) the patient’s physical illness attributions (like the CVA patient’s ‘angry outburst’) are interpreted as constituting part of the illness cycle itself by working to guide the patient into ‘abnormal and dysfunctional’ illness behaviour patterns. The failure of CBT is attributed by the authors to the *resistance* of the patient to therapeutic intervention - an

unwillingness to change their illness attributions and behaviour, rather than to any doubt about the *legitimacy* of the treatment itself. This is regardless of the controversial nature of CFS, and the claims of other researchers in the field who have *emphasised* the need for *rest* and moderating activity in managing the illness (e.g. Dawes, 1991; Gantz & Holmes, 1989; Jenkins, 1989; Spracklen, 1988). Ho-Yen (1990: 38) has argued that chronically ill patients read their symptoms of fatigue on exertion as a *warning light*, and “far from being maladaptive, their behaviour shows that they have some insight into their illness”.

From the claims made by the researchers in the above studies, there is clearly more than a degree of *uncertainty* and disagreement about the appropriate balance of rest and activity in CFS, which means that the patient’s illness behaviour and level of activity is likely to be made relevant as an *accountable* issue by researchers, medical practitioners, and patients alike. The following quotation from a patient (cited in Ray *et al*, 1993: 385) displays an *orientation* to that accountability, “...it’s the whole thing of how far to push yourself to keep that level of fitness, and how far you push yourself because you’re pushing yourself over the limit and consequently making yourself feel worse again.”.

Moral Accountability and ‘Type 3’ Analysis

At this point, I should again like to emphasise the difference in rationale between the type of analysis that takes as its analytic topic the perceptions and cognitions of ‘minds at work’, and discursive psychology (a ‘type three’ analysis²⁴) that takes as its analytic topic discourse as social action (Edwards and Potter, 1992). In the former analytical framework, the illness attributions of patients reflect their cognitive sense-making practices, which are derived from stable beliefs and models that guide their thinking. In the latter analytical framework, people’s illness attributions are made in the social and rhetorical context of accounting for themselves or other people. Attributions from this view are therefore not seen as linked to stable beliefs, but rather they are discursive resources that are drawn on to accomplish some interactional business.

²⁴ See Edwards, 1997: 271, for an outline of three types of analysis that can be performed on discourse.

Similarly to the claims made by Kirmayer about theories of psychosomatic illness, illness-attribution talk (and diagnostic talk) clearly occupies the realm of *moral accountability*. Nonetheless, many of the general conclusions made by cognitive-perceptual theorists *ignore* the *rhetorical* context in which attributions are made, defining them as stable and internal cognitions that can explain people's responses, coping, and illness behaviour, rather than analysing the discursive actions that such attributions perform in an interactive context.

Repertoires of Mind and Body (A Summary)

In this chapter, the participants' concern with the relationship between mind and body in explanations of illness, have been brought forward from chapter two where they were central in the 'M E controversy'. Here, my concern (as analyst) has been to look at how the rhetoric of mind and body is constructed in and through professional and lay explanatory models of disease/illness: but also to look at how authors have drawn attention to the potential for these models to be *used to accomplish certain kinds of* business.

First, the biomedical model was introduced as being 'the dominant model of disease in Western society', and rooted in reductionist and dualist philosophies. Engel's critique construes this model as being inadequate to explain the complexities of disease processes. He offers an alternative model for clinical practice; the biopsychosocial model, which derives its rationale from systems theory in biology. This new conceptual model promises to take into account the complex interplay between the biological, psychological and social environments in the explanation of disorders, and indicates that *all* disease is potentially explainable (and treatable) in multifactoral terms.

The psychosocial elements of this new model are addressed by social science research in, for example, the sociology of medicine, the social psychology of health and illness, *and* in the application of psychosomatic medicine. Three types of social scientific endeavour were identified from the textbooks as socio-environmental, behavioural,

and psychological. The latter two are individual, that is, things for which the patient can be made accountable. The first (socio-environmental) category cannot be directly addressed by medical practitioners, but can be made relevant under the psychological category of 'coping' with stressors. The second category includes illness behaviour, which is also construed by cognitive psychology as being related to people's internal beliefs. Therefore, for the purposes of medical practice, the clinical application of the biopsychosocial model boils down to a concern with the interplay of body and mind in the explanation and treatment of disease/illness.

It was also argued that although psychosomatic medicine can be traced back (in some form) around 1700 years, it has had little impact on the recent move to re-organise biomedicine, but rather, it has been marginalised into the category of 'not quite legitimate'. Thus, rather than *all* disease being conceptualised as psychosomatic, only *certain* disorders have attracted this kind of explanation. Three kinds of model are described, all of which occupy the realm of moral accountability, whereby the responsibility for illness can be shifted to the patient by using internal psychological explanations. It was argued that psychosomatic explanations function to protect the legitimacy of biomedicine by "siphoning off" cases of uncertainty, where a biomedical explanation for illness cannot be identified.

The notions of dualism and the object-subject distinction remain central to the kind of arguments that derive their rationale from psychosomatics, *and* the biopsychosocial model. I am referring here to an epistemological distinction that has been constructed between two ways of knowing (objective and subjective) that are attributed a differential ontological status within the discourse of empirical scientific investigation. These different ways of knowing correspond to the distinction that has been made between the terms 'disease' and 'illness', and are implicated in the task of accounting for oneself as legitimately sick, where legitimacy corresponds to one's illness being 'objectively' definable in terms of the biomedical category of disease, or is dependent on accepting a view of one's own experience as having a diminished relevance and currency.

This notion of a realm of moral accountability is one of the grounds that has been drawn on to construct and explain 'somatisation', which is constructed by authors as a phenomenon where psychological problems are presented as physical ailments. This explanatory model works particularly well alongside the claim that psychology is addressed by medical practitioners in a 'dismissive rhetoric'. In other words, the claim that psychological disorders have been marginalised as 'not quite legitimate' in mainstream medicine works to explain why patients' might want to avoid having their ailments construed in this way. On the other hand, some have argued that physicians use psychological explanations far too readily (e.g. Goudsmit & Gadd, 1991). Psychologisation (as this has been called) is construed as a way to delegitimise illness in the context of uncertainty, and the question of whose account can be taken as correct is played out in the subject/object distinction between empirical evidence and subjective experience.

Both of these categories (subject/object) can be re-worked by discursive psychology as discursive accomplishments that are constructed by means of empiricist and contingent repertoires. An empiricist repertoire is used to construct factuality, and a contingent repertoire is commonly used to construct or account for doubt, error or bias. One example of the way the 'subjective' dimension has been constructed in terms of the contingent repertoire would be through the cognitive psychology notion of the link between patients' illness attributions and personal health beliefs that may be construed as inaccurate. An outline review of three realms of attribution studies has indicated a range of exogenous forces, (including those that can 'invade' the body, such as germs) and endogenous individual factors, that are commonly drawn on to explain disease or illness in general, and also to explain specific kinds of diseases or illnesses. This kind of study has also been applied to the field of CFS and M E where patient's illness attributions and related illness behaviour have been made an accountable issue in the perpetuation of disability. The theoretical concepts of health beliefs and illness attributions can be made relevant by medical practitioners to formulate contingent

accounts of error (or non-legitimacy) based on the notion of inappropriate cognitions, and this can function discursively to psychologise illness²⁵.

A critique of the cognitivist approach, from the viewpoint of discursive psychology, links such attributional discourse to moral accountability in the rhetorical context of interactions (such as interviews or medical consultations). Throughout the following analyses of *both* lay and professional discourse on the topic of M E, I shall be concerned to examine the following aspects of participants' discourse:

- The next chapter looks specifically at how the categories of mind and body and the relationship between them is ongoingly constituted in and through the activity of talking about M E and CFS.
- Chapter 6 examines the relationship between attributional discourse and moral accountability in the context of an illness narrative²⁶.
- Finally, chapter seven focuses on how psychosocial issues are made relevant in patients' stories and doctors' case constructions.

²⁵ See 'Labels' chapter, where doctors make use of the contingent repertoire in their talk about patients' who use illness labels such as M E to avoid the definition of their illness in psychological terms.

²⁶ See chapter 6, where I analyse Angela and Joe's story.

CHAPTER FIVE

The Authorship of Meaning in ‘Mind and Body Talk’

“When *I* use a word”, Humpty Dumpty said in rather a scornful tone, “it means just what I choose it to mean - neither more nor less!”

“The question is”, said Alice, “whether you *can* make words mean different things!”

“The question is”, said Humpty Dumpty, “which is to be the master - that’s all!”

(‘Alice Through the Looking Glass’, Lewis Carroll, reprinted 1962, p.75.)¹

The previous chapter looked at the rhetoric of mind and body as it has been worked up in the way that different kinds of ‘medical models’ have been formulated and justified. I showed how psychosomatic, and psychosocial repertoires, from within the disciplines of medicine, psychiatry, and the social sciences, are explanatory resources that can be used by both lay and professional participants to make people’s actions accountable in the context of explaining, and treating illness. In this chapter, rather than address the distinction that is made between mind and body as an analyst’s concern, to be taken up and potentially resolved, I shall analyse how the *categories* of mind and body and the relationship between them is *ongoingly* constituted in and through the activity of talking about M E and CFS.

In the previous chapter I referred to a concern expressed by Kirmayer (1988), that the specialty of psychosomatics *reproduces* the model of a dualistic relationship between mind and body that he claims is also central to the biomedical model. Jane Ogden (1997) has recently extended that observation to include “psychosocial theories of health” in health psychology and medical sociology, where she questions their effectiveness in developing an alternative way of thinking about the causes of disease. She argues that although the disciplines of health psychology and medical sociology *describe* themselves as presenting a challenge to biomedical dualism, there has in fact been a fundamental failure to do so. She locates this failure in the underlying assumptions of the model of *etiology* (the science of the causes of disease), where psychological and social factors are treated as both contributing to, and mediating

¹ See also Fromkin & Rodman (1988) for further appropriation of this quotation.

bodily processes. Such a model essentially *prioritises* the physical, regarding the mind and body as separate rather than integrated categories. In other words, “The physical body is presented as the essential hardware to be moderated by the optional psychosocial software.” (*ibid*: 26).

For example, the Gate Control Theory of pain only points towards an inter-action of mind and body, not an integration of these components of the individual. Likewise, the transactional theory of stress examines how perceptions may impact on the body, but the mind and body are defined as separate entities which interact: they are not one. The mind/body boundary remains intact. In its call for a disintegration of this boundary, health psychology contextualises its analysis of a need for an holistic individual alongside philosophers such as Plato and Descartes who are seen as the enemy to be challenged and Aquinas and St.Paul who are cited to reflect the golden age of holistic medicine (Hippocrates appears to have an ambiguous relationship with the mind/body problem as he is frequently cited as belonging to both camps). This retrospective construction of a time of both dualism and holism provides health psychology theorists with an object to be challenged and a faith that this challenge is possible. In addition, this construction creates a separation between the discipline of health psychology and the problem of mind/body dualism. However, perhaps the mind/body divide is not a reflection of a biomedical perspective to be challenged by health psychology but a problem created by the very existence of these two disciplinary frameworks (*ibid*: 27)

Here, Ogden is claiming that the mind-body divide might be an artefact of different ways to conceptualise the ‘object’ of study, and the model of etiology used to explain the significance of these ‘objects’. Therefore, it could be argued that psychosocial theories of health ongoingly help to constitute the very ‘problem’ that they purport to solve. This is reminiscent of Alan Radley’s argument² that the separateness of the categories of ‘disease’, ‘illness’ and ‘sickness’, has itself been constructed to “justify the different interests of social science as compared with medicine” (1994: 5). In other words, the physical body, individual experience, and the social context, constitute the focal analytic concerns of the separate disciplines of biomedicine, psychology, and sociology.

I would like to suggest that it is the very separateness of these kinds of categories that *itself* signifies their general indexical usefulness as discursive resources. The so called ‘failure to challenge dualism’ that has been identified by authors such as Kirmayer

² Alan Radley’s discussion of the social constructionist approach to health and illness is referred to in chapter one of this thesis.

(1988) and Ogden (1997), might therefore be re-interpreted as evidence that indicates the robust discursive *utility* of the separate categories of mind and body to accomplish rhetorical work.³ By this rationale, it is *not* so much that “present controversy [about, say, M E] rests on a false dualism and an outdated separation of mind and body” that will eventually be overcome by a more sophisticated way of explaining disease processes (David *et al.*, 1988)⁴, but rather that categories of mind and body are used as discursive *resources* to manage sickness as a practical realm of moral accountability. In other words, if being sick (or treating the sick) is a morally accountable issue, as has been claimed by Parsons (1951a), then explanations of sickness and its appropriate management and treatment are always (and *have* always been) worked up in that context.

Parsons’ concept of the ‘sick-role’ (1951a) is frequently cited to explain health and illness in terms of its social, as well as its biological dimensions (see, for example, Radley, 1994).⁵ The ‘sick-role’ describes a ‘bargain’ that is struck between the sick

³ Harvey Sacks (1989: 280-1) has argued that “formulating in terms of two-class sets is a method of doing things”. It is not just that there are two classes of things; for example, male, female; young, old; rich, poor; mind, body; etcetera. The important point is that these are binary oppositions, and therefore lend themselves to the situated production of comparisons and contrasts. As Derek Edwards points out, contrast structures are not “simply a built-in feature of cognitive sense-making, nor a reflection of how the world itself happens to fall naturally into two-set classes. Rather, it is a powerful, general-purpose discursive device for constructing the world *as such*. That makes it ideally suited to ideological, dilemmatic, and rhetorical discourse (Billig *et al.*, 1988), and to the mundane, situated production of contrasts and alternatives (Atkinson and Drew, 1979; Smith, 1978)” (Edwards, 1997: 237)

⁴ See extract 33, chapter two (above), where David *et al.* (in their article entitled “Post-Viral Syndrome: Time for a new approach”) make such a claim. In doing this they take up a metaposition and claim for themselves a transcendent view that is a more sophisticated, complex level of analysis that takes account of both mind and body explanations. (See Pels, 1996: 282, for a discussion of “analytic third positions”, where it is claimed that “a symmetrical approach invariably subverts the dominant view, and strengthens the side of the weak and the marginal. Symmetry is often a ‘cool’ and detached way of siding with the oppressed. In this fashion, it still conspires with the established authority of value-free science, even while moving to attack it.”) The case represented here is not quite the same as the kind of ‘third position’ that Pels has in mind, where analysts of scientific controversies claim for themselves a position of methodological relativism (as I do in chapter two!). Rather, David *et al.* themselves *enter* the controversy as participants and move to take the ‘theoretical high ground’, conceptually re-working previous arguments by means of a ‘paradigm-shift’. This is a move to retain the idea of scientific truth and knowledge, by postulating a new model, in the face of a controversy that threatens the basis of medical and scientific reality. As I pointed out in chapter two, this parallels Gilbert and Mulkay’s ‘truth will out device’ (TWOD).

⁵ Parsons (1951a) developed a functionalist perspective on society as a social system. This view appropriates the rationale of systems theory in biology to explain how the social system is made up of interrelated parts that function to maintain the society as a whole. One of the central concerns in functionalist theory was therefore to explain the nature of *social order*, since that was seen as crucial in the survival of the social system. This can be explored further by defining the concepts of *norms*, *roles*,

person and society, where sickness is treated as a form of deviance from the social norm. If one's health status affects one's ability to carry out normal social duties, then the adoption of the 'sick-role' is a way to *legitimate* that deviance. The 'sick-role' therefore implicates a moral dimension of accountability, in which sick persons have both rights and obligations (for example, the right to be excused from the social duties of their normal roles, and not to be held personally responsible for their illness). In return, they are expected to seek out medical help, adopt the status of a patient, and comply with the doctor's advice or treatment. Frank (1997) has recently argued that in Parsons' account the patient's agency is *reduced* to such compliance, whereas the physician is construed as the *active agent*, both 'policing' access to the 'sick-role', and providing suitable advice and treatment that will help patients to return to their normal roles as soon as possible.

The concept of the 'sick-role' has been criticised for its *lack of explanatory power* in cases of ambiguity, such as with chronic, psychological, or lifestyle related illness (for example, Blackwell, 1967; Segall, 1976; Twaddle, 1969). In the case of chronic or psychological illness, people do not always withdraw from their normal duties, whilst the latter case of lifestyle related illness calls into question the accountability of the patient for their own condition. The categories of psychological illness, psychosomatic illness, and psychosocial factors can *also* be used as a way to make patients accountable for their own illness, as we have seen from my analysis in earlier chapters.

and values. From a functionalist view, the *norms* of any given society are the rules/guidelines that specify appropriate actions. These norms are taken to be enforced by sanctions that are either *informal*, such as approval and disapproval, or *formal*, such as official legislation. The *norms* of a given society are said to be defined in terms of underlying *values*; or in other words, beliefs about what is important, worthwhile and desirable. Values therefore occupy a *moral* category which defines what is good and what is not. The idea is that a social system cannot operate successfully without shared values and norms, and that the absence of these would threaten the social order. Each member of a society is taken to occupy a number of social positions, for example, an occupational status, a family status, a gender status, etcetera. These different social positions are related to the social *roles* that people are expected to play in relationship to others. Thus, the social position/status of a doctor is accompanied by their role in relationship to patients, and vice-versa. The role of a doctor or a patient can be defined by a set of norms (informed by underlying values) that specify the appropriate actions for a person who occupies that social position/status. The idea is that people who have been socialised into a common culture share the same kinds of values, follow the same norms, and adopt the appropriate kind of behaviour for each role that they play. People also have shared knowledge of one another's roles, and are therefore able to understand and predict the behaviour of others. According to functionalist theory, all this makes for the perpetuation of a well ordered and stable society.

In effect, accountability is built into the assumptions that inform psychosocial explanations for illness, along with the kind of medical interventions deemed appropriate for its successful management. These matters inform questions such as: ‘Could the illness have been avoided by making changes to lifestyle?’, ‘Has the sick person been instrumental in their own misfortune?’, ‘Could they be coping better with the stressful circumstances of their lives and their illness?’, and ‘Is their illness behaviour informed by a set of misattributions and false beliefs about the nature of their illness?’. Such questions, that help to define mental illness as a form of personal weakness, or social and mental incompetence, indicate why mental illnesses have been commonly associated with the sort of social stigma that people work to avoid.

The kind of anomalies created by the concept of the ‘sick-role’, can be re-considered in the light of an objection to the assumption that norms or rules are something that specify people’s actions (Wittgenstein, 1958; 1967; 1978). An ethnomethodological treatment of this matter would work along the lines that the norms of the ‘sick-role’ operate *not* as a set of rules that *govern* conduct, but rather as a resource to make patient’s actions ‘account-able’ in relation to health and illness issues.⁶ Therefore, rather than seeing the separate categories of mind and body as *merely* artefacts that emerge from different kinds of repertoires that have been constructed to serve the interests of different disciplinary frameworks, perhaps it would be more useful (and empirically tractable) to conceptualise them as *indexical* categories⁷ that are primarily constituted in and through the activity of everyday accounting practices, and in the *second* place are an analyst’s distillation of those commonsense categories that have been re-formulated as philosophical dualisms and psychosocial theories of health. Such theoretical distillations have been dealt with in the previous chapter by

⁶ I am using the term ‘account-able’ (Garfinkel, 1967) here in the sense that people’s actions are made both *describable* and *morally sanctionable* (by participants). The Wittgensteinian sense of rule-following is that norms are something that people can *appeal* to in making justifications, and explanations for their actions. Rule-following, for ethnomethodology, is therefore a feature of common-sense reasoning, by which people constitute the *sense* of their actions.

⁷ Indexicality is one of the fundamental precepts of ethnomethodology, whereby descriptions “are to be understood by reference to where and when etc. they occur.” (Heritage, 1984a: 140) In other words, the meaning of an expression alters with its context of use.

examining various forms of medical repertoire, whereas accounting practices can be analysed here in the context of participants' talk about M E.

The first analytic task of this chapter is to examine a collection of extracts from the talk of doctors in interviews and participants at self-help group meetings. My analytic focus will be to identify a variety of possible ways that the categories of mind and body, and the relationship between them, can be constituted in talk. I am interested in how participants' categorisations of mind and body work variably either to make relevant or to obviate agency, and thereby either to avoid the implications of personal accountability or to provide for its relevance. This is *not*, however, to imply that there is likely to be a one to one correspondence between the category of 'mind' and personal agency; but that (as topics) both the mind and the body are indexical categories that are constituted *in situ*, where meaning and its implications for personal responsibility are worked up on and for the specific occasion of use.

[At this point, there is a rude interruption from one of the fictional characters in the quotation at the beginning of the chapter.]⁸

- ALICE: Ah! but the question *is* whether you *can* make words mean different things!
- MHS: We:ll...I was just thinking of the way that an ethnomethodologist would theorise the *in situ* constitution of meaning...did you *read* my footnote 7...or what ?
- DA: Yes...we:ll the trouble *is* of course...if you just take the ethnomethodological insistence on indexicality, it's not clear *how* meaning is possible! It can't be *just* indexical otherwise it wouldn't matter *which* word you used. To take the argument to its *extreme* would reveal an absurdity...we'd only need *one* word and we'd just have to say it all the time and it would take its meaning entirely from its context! This word is 'flug' ...so... "flu↑g, flu↓g, flug, flu::g, flug! flug?"
- [*sound of suppressed sniggering from Alice and MHS*]
- ALICE: It's kind of *obvious* that we need different words!
- DA: Well my point *is* that the mind and the body are concepts that are *somewhat* ready-made...as well as indexical
- MHS: Now *I* want to clarify this...in *what* sense can we say that categories such as mind and body are ready-made?

⁸ The following textual dialogue takes place between Lewis Carroll's fictional character, Alice, MHS (the author), DA (a discourse analyst), and HD (Humpty Dumpty). It is based on (but not identical to) a similar conversation that the author had with her supervisor, after he had commented on the first draft of this chapter. Any resemblance to real or fictitious characters is ...constructed here in the text!

- DA: We'll...if you look mind up in a dictionary, you're going to find something to do with, say, 'things in your head'. After all, there *is* still the dictionary! But we have to re-theorise what 'ready-made' *means*...
...it doesn't mean classical categories, or logical categories, or ready-made cognitive packages. You've got to have an awareness of a whole range of semiotic affordances, as well as the actual situated use...there and then...The point about situated use is... that the word 'mind' is useful *because* you're going to use it to say that something's mind and *not* body...or something's mind and *not* real...that's what it's *for*! The word 'mind' enables you to do all kinds of descriptive and rhetorical stuff...that's why we have the concept in the first place so the concept 'mind' isn't to be considered *separately* from its uses. It *is* in fact a part of a set of ways of talking, where it's contrasted with other ways of talking...see your footnote 3... so the way to get into the question "what does the word 'mind' mean?" is to look at the settings in which it's *used*.⁹
- MHS: Yes...I think I've assumed that in the next section of analysis...so are you just picking me up on this rather *extreme* statement about indexicality?
- DA: Ye:ah...exactly! Mind talk *is* going to be part of mind-body talk, part of medicine, embedded in a set of contrasts, its meaning worked up and deployed by these folk, here in the [talk]
- HD: *[muttering impatiently]* [in fa]ct...just what they *choose* it to mean, neither more nor less!
- ALICE: *[gleefully]* Ah! But that's *not* to say that the word 'mind' can mean elephant, filing cabinet, door handle, or whatever...!
- MHS: so...let me get this straight...there's a broad set of semiotic affordances that come...kind of pre-packaged with the word 'mind'...but its *precise* meaning is worked up locally...*in situ*...?
(6.0)
[DA glances at his watch and drums his fingers on the table]
- MHS: er...*[coughs]*
(3.0)
I'm still a bit worried about the idea of categories being somewhat ready-made...
- DA: *[sighs]*
- MHS: ...and there's this spectre of 'out-there-ness'...I can imagine somebody reading this and saying "So you're claiming that categories exist 'out-there' and people can draw on them as ready-made resources!"
- DA: Well *I* said that people *deploy* them, not that they *draw* on them! Anyway...why don't you just delete 'out-there' (as if it was *there* to delete in the first place!) and say it's part of people's *competence* that they *know* what these words mean and they can use them?
- MHS: But 'knowing' is 'in-there'...so *that's* cognitivist!
- DA: ah well...*I'm* quite happy with the word 'knowing' *except* that it *can* bring a lot of baggage with it...just using the word 'knowing' might sound as though you're committing yourself to a cognitive theory of talk...but so long as we *know* that the word 'know' can be defined the way Wittgenstein does it...(I

⁹ The Concise Oxford Dictionary (Seventh Edition: p.643) includes the following entries for the term 'mind': 'way of thinking and feeling', 'consciousness', 'thought', 'volition and feeling', 'soul as opposed to body', and 'intellectual powers as opposed to will and emotions'. The latter two examples, even as part of a dictionary definition, conceptualise the 'mind' in terms of its contrast to alternative categories such as 'body', or 'will and emotions'.

mean of course...later Wittgenstein)...in terms of its uses and contrasts...then you can use it...I mean, I don't wanna ban these words from my vocabulary just because psychology uses them in a certain way!

[phone rings]

DA: One angle is...I wanna be like Humpty Dumpty and say "When *I* use a word, I don't mean it with all that theorised psychological baggage...I want it to be re-defined by what *I say in use*".

HD: *[rather smugly]*

Like I *said*... 'the question *is*, which is to be the master - that's all'!

(...)¹⁰

What follows in the next part of the chapter, serves as a point of departure, to display a range of mind-body constructions *and* their rhetorical affordances (thank you DA).

Later, I shall be concerned to show how such categorical resources are constructed, deployed and ongoingly re-formulated in the context of managing some interactionally sensitive business.

The management of agency in constructing categories.

1. The mind as a reflection of the body

This first extract is taken from a discussion at an M E self-help group meeting (which is analysed in greater detail later in the chapter), where FM, a clinical psychologist, is working to introduce the idea that psychology might have something to offer, in the treatment of chronic fatigue syndrome.

(FM/M E group)

the mind comes from the brain (.) the mind isn't separate from the body the mind is just a reflection of what's happening in the brain

Here, FM is working up a definition of what he, a psychologist, understands the 'mind' to be. There are three important points here. First, the brain is given primacy; second, there is no separation of mind and body; and third, the processes of the brain

¹⁰ The bracket at the end of this dialogue indicates that something has been left out, and signifies the potential for the next turn at talk. The unfinalised dialogue, as a textual device, allows me (as author) to display the conversational turns of a controversy or dispute, without necessarily having to resolve it by writing a definitive statement. Since meaning is definable by 'what I say in use', and also in terms of uptake (in the next turn at talk) then the next turn can always challenge, re-define, and ongoingly constitute meaning. In other words, a controversy is not finally resolvable, and a conversation is not finally ended because there is always the potential for the next turn.

are treated as the *reality*, whereas the mind is ‘just’ the *reflection* of real processes that are going on in the brain. This is somewhat analagous to a representational model of language as a representational system, that is employed to describe real events and objects that have an existence prior to and independent of human constructive practices. In the context of FM’s efforts to overcome any resistance to a psychological approach to illness (which I shall analyse later in the chapter) this formulation of the mind as a reflection of brain processes can be heard as working to obviate human agency from the notion of the mind, and to construct psychological illness as a purely neurophysiological phenomenon. In other words, this kind of formulation of the mind works to make the category of psychological processes equivalent to bodily processes, and lends itself conceptually and rhetorically to *avoiding* any suggestion of personal agency, and therefore, *responsibility* for illness.

2. The body as a reflection of the mind

This next extract is taken from a talk given by a general practitioner to a different M E self-help group. The topic of the talk was “A GP’s view of M E”, and Dr Brown is working here to explain the relevance of the mind in the production of physical symptoms.

the other concept I’d like to put across to you is that you can only actually know what’s happening in your mind because of what you can feel in your body (1.0) cause the only reason that I know that I’m anxious is perhaps because I’ll feel myself sweating (1.0) so we rely on our bodies to tell us what’s happening in our minds
(Dr Brown/M E group)

Here, Dr Brown explains the body as a kind of ‘text’ or ‘barometer’ of the processes of the mind. What you “feel in your body”, is construed as the outward signs of something that is *really* going on elsewhere, to which we do not have direct access. In contrast to FM’s formulation, mind processes are being given primacy by Dr Brown; but here the mind processes are construed to be at the level of *unawareness*. Since the machinations of the unconscious mind are outside the realm of our control, and we have no direct way to know about “what’s happening in the mind”, Dr Brown’s formulation does not provide for the relevance of agency. In the context of his talk to the self-help group, this works to place psychology on the agenda as a candidate

explanation for some of the physical symptoms of its members, whilst at the same time managing to avoid the implication that they could be in some way personally accountable for their illness.

3. Mind over matter

The following piece of data is again taken from Dr Brown's talk to the self-help group, where he uses a specific example to construct an image of the mind.

a classic one, if you like, is the couple who go through about ten years of fertility investigations (.) and nothing found (.) and they adopt- this happened to one of our friends er (.) they adopt and within three months the wife's pregnant (.) an- and y'know there's this cruel trick of nature that once you just relax about it and stop having the pressure on you then you conceive (.) and so it really is mind over matter
(Dr Brown/ M E group)

As with his formulation in extract 2, Dr Brown construes the mind and the body as *separate*, with the mind taking *primacy* over the body. Here, the common expression "mind over matter" conjures up images of the material world being mysteriously subdued by force of will-power, as with telekinetic spoon-bending, or levitation. However, here in this context, Dr Brown seems to work up a more *passive* role for the mind, in which being tense or being relaxed could be treated as something that is *not* under conscious control. His use of nominalised event descriptions, where the inability to conceive is put down to "this cruel trick of nature", and you are "actually having the pressure on you" rather than 'putting yourself under pressure', constitutes events as agentless. On the other hand, the expression "once you just relax about it" implies that there might be a space for someone to actively effect such a change. Such descriptions, coupled with the magical phrase, "mind over matter", work ambiguously, to make *both* kinds of implication available. In the context of Dr Brown's talk to an M E group, where the suggestion of mental illness is a sensitive issue, this vagueness works to manage the implications of suggesting to people that the mind can have a powerful influence on bodily processes. In both extracts 2 and 3, Dr Brown trades on an inferential ambiguity in his use of the category 'mind', which is hearable as both equivalent to, and also beyond the realms of personal will-power.

4. 'All in the mind' : a dangerous category?

The following extracts are taken from an interview with a GP on the topic of M E.

a.

y'know it's something that I think doctors are sometimes more comfortable with (.) they can say "well this is a bit like glandular fever (.) it's the aftermath of an infection" (.) and it's a working model if you like (.) which gives some reassurance that it isn't in the mind (.) there is something (.) there's a possible explanation for it
(Dr Walker/MHS)

The category of 'in the mind' is being constructed here, as a contrast to the category in which "there is something", like "the aftermath of an infection". The medical category of an infection is constituted here as a reality that is comforting and reassuring, and this necessarily involves the implication of its opposite, an *absence* of such a reality (see Sacks, 1989). In other words 'it *is* in the mind'; if it isn't real, then it does not exist. By contrast, "it isn't in the mind" means "there is something".

b.

I think what is a difficulty (.) I think it's this (.) I think it's something that (.) certainly (.) see:n by patients (.) and I think to some extent (.) would be seen by doctors as well (.) is this business of whether physical and mental things equate with real and imagined (.) do you know what I mean (.) and I think that's the danger of it
(Dr Walker/MHS)

In a different part of the same interview, Dr Walker problematises the kind of explanation of M E that he offered in extract 4a. That is, he takes up a *metaposition* in commenting on the consequences of the kind of categorisation where physical is made equivalent to real. In 4a this is described as being a position that "doctors are more comfortable with", whereas here in extract 4b Dr Walker is constituting this kind of categorisation as being "a difficulty", and points out "the danger of it". He specifies here the precise nature of the relationship that was implicated in extract 4a; that is, "this business of whether physical and mental things equate with real and imagined". The equation 'mental equals imaginary' constitutes mind as a realm of fantasy, fiction, or dreams. The category of imaginary is here contrasted with the category 'real', and Dr Walker is working to distance himself from the potential implications of categorising the mind and the body in this 'dangerous' manner. For example, he is

orienting to a concern that mental illness might not be given serious attention, or, as pointed out in the previous chapter, giving primacy to physical illness might encourage patients and doctors to collude with each other in the definition (or expression) of illness in purely physical terms.

5. “something nice and physical”

The danger of this kind of categorisation is itself topicalised by both Drs Brown and Walker in the following two extracts (5a, and 5b).

a.

and there's still this in people's minds they link nerves with the fact that somehow the doctor is gonna be dismissing it (.) and that they're being fobbed off er and these sort of things (.) so again something nice and physical like your heart attack or your broken bone (.) you feel that your doctor's going to give you much more (.) you're higher up in his importance scales (Dr Brown/M E group)

Dr Brown works up his explanation for why patients might *prefer* to present their doctor with “something nice and physical”. Nerves are not taken seriously, whereas physical things place you “higher up in his importance scales”. In the context of Dr Brown's talk to the M E group, this description works to mitigate the suggestion he has already made available (in extracts 2 and 3) that M E sufferers might be somatisers.¹¹ His explanation lays out what might be taken as their *reasonable* grounds for preferring to have a physical diagnosis. On the other hand, it is the *patients* who are construed as *projecting* this kind of prejudice onto their doctors; “there is still this in people's minds”. Even the category of “nice and physical” is hearable as Dr Brown's gloss on what he construes, in the first place, as a *patients'* naive category. He is thus able to produce this version of doctors' prejudices about patients' beliefs, whilst at the same time distancing himself both from the category, and the Other's use of it. Nevertheless, his description also does the work of

¹¹ Somatisation is defined (see, for example, Kleinman and Kleinman, 1985) as a process by which people express psychological distress in the form of physical symptoms (which is of course itself a dualistic construction, since the processes of the mind are thereby treated as prior to, and having an effect upon bodily symptoms). The counter rhetorical move is the ‘exposure’ of the medical practice of ‘psychologisation’ (in chapter four, above, referring to a claim that physical illness is sometimes interpreted in terms of psychological distress). This kind of explanation similarly implies a dualistic separation of mind and body.

constructing common knowledge of heart attacks and broken bones as physical phenomena that are easily identifiable as *bona fide* medical concerns.

The following extract, taken from an interview with Dr Walker, further demonstrates how the activity of distinguishing between mind and body is taken up as a topic of concern and treated as problematic.

b.

people are searching desperately to find a physical cause of it (.) an- when- when y'know it may well be that there are physical causes (.) but there may be mental causes as well (.) but people see a mental cause of it as being somehow (.) less adequate (.) as having sort of (.) less currency y'know
(Dr Walker/MHS)

The activity of “searching desperately for a physical cause” is mitigated here again in terms of a differential *value* that people place on mental and physical causes for illness. Mental causes are seen as having “less currency”; which implies that there is less ‘buying power’ in having their distress defined as mental illness. Dr Walker’s gloss on how people generally construe the categories of mental and physical, orients to the idea that attributing *causes* for illness is an activity that takes place in the context of *justification*, where mental causes are somehow thought of as being less justifiable as explanations for illness than physical ones. Dr Walker’s *own* formulation, “it may well be that there are physical causes (.) but there may well be mental causes as well”, *itself* constitutes a separation of mind and body where different causal factors contribute to the illness, and mental causes are construed as additional to physical ones.

6. ‘the devil’s own job’

In the next extract, Dr Brown talks about the relationship between the mind and the body in the context of his talk to an M E group.

there are both physical and emotional mental components (.) and trying to figure out which is which is the devil’s own job at times (.) but I suppose what I would say is “it really doesn’t matter” because er (.) if you actually look I would say that it isn’t really mind versus body it’s mind and body and the two are completely intertwined
(Dr Brown/M E group)

Dr Brown's formulation of the mind and the body is rhetorically positioned against an alternative account in which these categories might be depicted as mutually exclusive, competing explanations. He retains the dualistic construction of factors or "physical and emotional mental components", whilst drawing them so closely together that they might be almost impossible to pick apart. The use of the phrase "the two are completely intertwined" itself constitutes the mind and the body as separate, but they are woven together like the threads of a cloth, and difficult to disentangle. Dr Brown has been working to make available the possibility that there might be a psychological component in M E, but has to manage both the problem of uncertainty, where there is no definitive medical knowledge about the nature of the illness, and also the resistance from his audience to the idea that there might be a psychological explanation for their illnesses. His construction of two separate parts that are "the devil's own job" to disentangle, works to avoid having to make any *precise*, or *contentious* claims about the role of the mind in the illness process, and also justifies the vagueness surrounding the whole area of explaining M E in the first place.

7. Physical things; physical processes.

In this extract of talk, where Dr Turner is discussing one of his patients, there is an interesting distinction being made between physical things, and variable physical processes.

one has a lot of gynaecological problems (.) predominantly hormonal (.) you're not talking about physical things like fibroids or cysts or anything like that (.) predominantly related to irregular periods (.) and things of variable duration and intensity (.) er (.) if they're generally hormonal (.) there's a sort of input from the pituitary gland in the brain (.) so stress can influence that as well
(Dr Turner/MHS)

Physical *things* are construed here as solid objects that one might be able to see and touch, like fibroids, and cysts. These are being distinguished from variable biochemical processes such as hormonal activity, that can be affected by stress via the action of the pituitary gland in the brain. As pointed out earlier, stress related illness can be made an accountable issue via the rhetoric of coping. The realm of "physical things like fibroids or cysts" is constituted as a different category, which has a more solid ontological status than the fluctuating processes that are "of variable duration

and intensity”. In a way, this is reminiscent of Dr Brown’s construction of “something nice and physical”, like heart attacks and broken bones. Although heart disease might be medically considered as a result of various lifestyle related problems, such as stress, diet and smoking; the category of ‘heart attack’ is hearable in this context as an *event* that happens to the physical body in the material world. That is in contrast to physical *processes*, which are construed as being more nebulous, changeable, and being more closely linked with psychosocial influences such as stress.

In the previous section, I have analysed some of the ways that mind and body have been categorised by medical practitioners. These categorisations work in the contexts of illness talk to make people’s illnesses more or less physical and real, and their actions either more or less accountable. I do not mean to imply that the categories of mind and the body have a prior one to one relationship with accountability or the lack of it. Rather, I am arguing that the *precise* meaning of the categories, and their implications for agency are worked up together on and for the occasions of talk. These constructions differ from one another in various significant ways; such as for example, whether it is the mind or the body that is given primacy; whether, the processes of the mind are constructed as under conscious control, or unconscious; and how far the speaker works to construct the mind and the body as separate or integrated. An interesting feature of this talk is the way that the mind itself can be constituted as either having an equivalent ontological status with the physical body, or otherwise. Participants appear to construct a continuum of more or less ontologically solid members of the category ‘real’ (solid physical objects at one end, imaginary processes at the other, and mental processes somewhere in the middle), where physiological processes constitute a rather nebulous realm of transformations, where the one can either affect the other, or even become the other. Such variability constitutes a rich resource for the management of accountability as a practical activity, and my analysis of it here has served as a context to inform the following analysis of an extended piece of dialogue.

Managing the Potential for Confrontation in Mind and Body Talk **(A 'struggle for the authorship of meaning')**

In this following analysis I shall show how the mind and body are constructed in the situated context of a dialogue between the speaker, FM, and his audience, the members of an M E self-help group. In this context, the construction of meaning and its implications for personal responsibility for illness, are constituted in and through, the situated activity of managing the potential for confrontation.

Now prior to this next turn at talk by FM, he has introduced himself as a clinical psychologist.¹² He has provided for the relevance of a possible misalignment with his audience (the M E self-help group) by raising the contentious topic of labels.¹³ He has announced his intention to speak about CFS, and queried the members' understanding of its equivalence with, or its distinction from M E. However, there is a tacit understanding that FM has been invited to talk to the group about the role of psychology, and in particular cognitive behavioural therapy, in the treatment of chronic fatigue syndrome.

Extract 8: 'What / mean by the mind'

Here, my analytic focus is to look at what FM constitutes the category of 'mind' to be, and how he deploys this meaning as a resource to manage some interactionally sensitive business. Specifically this refers to the explanation of disease facts and the accountability of sufferers.

1. FM I mean (.) I get the impression that er (.) not from this group (.) but
2. generally (.) there's unease about the application of the psychological
3. approach to Chronic Fatigue Syndrome (.) I mean (.) I suspect that's for
4. two reasons (.) one is the fact I- I think some people have difficulty with
5. the idea that the mind
6. (0.6)
7. FM they like to see the mind and the body as two separate things (.) we've got a
8. body that's physical (.) and we have a mind that's separate (.) and of course as
9. a psychologist I mean that doesn't make any sense (.) the mind (.) and the

¹² This is an extract of 'naturally occurring' data, in the sense that the tape recording was made as part of the normal activities of the self-help group, and is freely available to members of the group as a library resource, rather than having being set up and recorded especially for the purposes of research.

¹³ See chapter three (above) for an analysis of labels as a participants' concern.

10. body are two halves of the same thing (.) the mind comes from the brain (.)
 11. the mind isn't separate from the body the mind is just a reflection of what's
 12. happening in your brain er if anything happens to your brain like a stroke or an
 13. injury (.) then the mind changes (.) the personality changes (.) your way of
 14. seeing the world changes (.) the mind is the bra:in and the brain is an organ of
 15. the body like any other organ of the body (.) and your brain is linked to every
 16. y'know every other organ in your body
 17. (0.8)
 18.FM by the nervous system (.) and by your hormonal system (.) the brain's got
 19. hormone glands in it- the adrenal gland that releases hormones that control
 20. various aspects of your bodily functioning (.) so I personally don't have any
 21. difficulty in understanding how the mi:nd and the body can affect each
 22. other cause they aren't two separate things (.) the mind's the brain and the
 23. brain's a part of the body so to me
 24. (0.6)
 25.FM y'know I (.) whatever the problem is I can quite easily understand how (.) the
 26. mind and the body affect each other and I suppose you see that in illnesses
 27. like (.) stomach ulcers (.) most people accept that stomach ulcer's (.) a real
 28. physical problem caused often by stress (.)'cause the stress increases the
 29. nervous activity, to the nerves to the stomach, the stomach produces more
 30. acid, the acid burns holes in your stomach (.) and you've got a stomach ulcer
 31. (.) so there's no suggestion that people imagine the pain of stomach ulcers- it's
 32. real pain but it's caused by a psychological problem originally (.) in a lot of
 33. cases- not in every case but in a lot of cases (.) so I mean it's quite easy to see
 34. how the mind affects the body (.) er (.) and there's evidence in other areas as
 35. well for instance heart- research into heart disease (.) that shows that type A
 36. personalities have a much higher risk of heart disease than type B
 37. personalities-type A's aheh y'know high achi:eving (.) people who are under
 38. a lot of time pressure more than most people do- very high standards for what
 39. they want to achieve
 40. (0.6)
 41.FM in your Type A's that are much higher risk it's something to do with (.) no
 42. one really quite knows how that mechanism works whether it's affe:cting (.)
 43. the blood vascular system directly or (.) quite how it wo:rks but it's a well (.)
 44. it's a fairly world widely accepted finding (.) so ah- I personally don't have
 45. any difficulty with the idea that the mind (.) affects the body and the body
 46. affects the mind-how your body is affects how you feel mentally as well (.)
 47. er

In this extract of talk, FM addresses his comments regarding an “unease about the application of the psychological approach to Chronic Fatigue Syndrome”(lines 2-3), toward a non-specific group, distinguishing between that and the present audience (lines 1-2). The unease about psychology is construed as happening in a different place, and not in the present context. This manages the potential for FM's comments

to be heard as directly oppositional to the concerns of this particular group, and works here to minimise the possibility that members might take his comments as being confrontational. This allows FM considerable rhetorical space to present his case for the 'acceptable face of psychology', which is represented by his own definition of the mind and its relevance for their illness.

He does this by starting to formulate his "two reasons" why *some* people should be uneasy about psychology (line 4). In the first place, he suggests that they have a basic misconception of the relationship between mind and body. This is construed as a *preference* whereby "they *like* to see the mind and body as two separate things" (line 7, emphasis added). This conveys the idea that their conceptualisation of the mind and body as separate is a prejudice, based on what they want to see rather than empirical evidence. FM then goes on to offer a 'correct' explanation of the relationship between mind and body, which is *discursively underwritten* by citing his status as a psychologist, who is entitled to speak with authority on this topic; "as a psychologist I mean that doesn't make any sense (.) the mind (.) and the body are two halves of the same thing" (lines 9-10); "the mind is the brain and the brain is an organ of the body like any other organ of the body (.) and your brain is linked to every y'know every other organ in your body (0.8) by the nervous system (.) and by your hormonal system" (lines 14-16).

The relationship between mind and body that FM develops in these remarks is hearable as a materialist formulation, which is premised on the assumption that the mind is not a separate non-material *substance* from the body, but is in fact the same thing as the brain. This is not to claim that FM's formulation of the mind and the brain indicates that he holds a specific philosophical position¹⁴. Rather, the language of neuropsychology and monism provides a resource to dismiss dualistic separations like the one that FM attributes to those who are uneasy about psychology. He is thereby able to offer a mechanism by which the category of psychological can be construed as

¹⁴ Materialism is a philosophy which reduces mental events to physical ones. Identity theory is another form of materialism which claims that consciousness is a brain process.

being synonymous with the category physical, and in *this* case dispose of the ‘dangerous category’, which is the one that makes people feel uneasy. In other words, the mind is conceptualised as a mere *reflection* of bodily processes, of “what’s happening in your brain”, which is constituted here as being one and the same thing. At the same time the use of the term “reflection” lends itself to an ambiguous reading, since there would necessarily have to be an ontological reality to *be* reflected in the first place.

Now, although FM’s equation of the mind with the body might, at first glance, appear to be a conciliatory move that works to make his audience less uneasy, I would like to point out the more subtle implications of such a formulation. When FM makes the claim “the mind is the brain” (at line 14), it is deployed as an indexical marker that ‘defines his terms’ for the rest of his talk. In other words, he is telling the audience, ‘from now on, when I say “mind”; you should hear “brain”!’ *Effectively, therefore*, FM (in the style of Humpty Dumpty) has both defined his own meaning of the word ‘mind’, and also made it more difficult for his audience to use the term without further re-definition. This point will be taken up later, when a member of the self-help group responds to FM’s comments. For now, (as analyst) I shall treat FM’s remarks as being both an indexical marker that works rhetorically as a conciliatory gesture to manage the potential for confrontation between himself and the members of the group.

FM’s use of intransitives¹⁵, such as “happens” and “changes”, works further here to obviate agency, and construct processes of the mind-brain as things that just happen to people (lines 11-14); “what’s happening in your brain or if anything happens to your brain like a stroke or an injury (.) then the mind changes (.) the personality changes (.) your way of seeing the world changes”. In using this kind of grammatical construction, by which agency is obviated, FM’s account works to further avoid imputing personal

¹⁵ Critical linguistics (such as Kress & Hodge, 1979) explicates the role of transitive, intransitive, and passive verbs in action descriptions, such that structures are accounted for with reference to social relations of (assymetrical) power. (In transformational linguistics, this can be contrasted with the Chomskian view of structures that are hardwired into the brain).

responsibility for psychological changes whilst retaining the category as a means to account for illness.

Having set up the rationale for his explanation of illness, he is next able to apply this to the details of a specific case. He chooses the example of stomach ulcers to lay emphasis on the *physical* processes that are a consequence of psychological stress, “cause the stress increases the nervous activity, to the nerves to the stomach (lines 28-9), the stomach produces more acid (lines 29-30), and “the acid burns holes in your stomach” (line 30). FM positions this explanation against the realm of *imaginary* pain, where someone might ‘conjure up’ a symptom or delude themselves that they have an illness. Here (at line 31), FM introduces this as if he were fending off a potential accusation that psychology might be used as a way to define people’s ailments as being imaginary rather than real; “so there’s no suggestion that people imagine the pain of stomach ulcers”. In his use of this implicit (and somewhat gerrymandered) analogy, FM can make his point about the relationship of psychology to M E, whilst avoiding the necessity of being openly committed to a precise explanation that might be applied to anyone’s specific problem.

FM goes on, at lines 34-46, to formulate an argument in which both stress and personality are brought into his explanation of heart disease; “type A’s aheh y’know high achieving (.) people who are under a lot of time pressure more than most people do- very high standards for what they want to achieve” (lines 37-9). Having defined the business of psychology as a concern with *physical* processes, FM now introduces the idea that there are types of personality (type A’s) that are associated with a higher risk for some kinds of illness. The implication of his statement at lines 37-9 is that the source of stress (“time pressure”) might be something self-imposed because they have “very high standards for what they want to achieve”. On the other hand, “time pressure” is something that they are “under”, so this is also hearable as something *imposed* upon them. In either case, the problem of heart disease is formulated as something to which people of a certain type are susceptible, rather than as something that strikes in any kind of arbitrary way.

FM's use of the term 'personality' is nicely ambiguous because it makes available a range of inferences that might be used to construe someone as more or less accountable. It could be heard as a way to introduce the idea that people might have a degree of *control* over the physiological processes of their bodies, via their typical behavioural responses. Although, "no one really quite knows how that mechanism works whether it's affecting (.) the blood vascular system directly or (.) quite how it works" (lines 41-43), it can be construed as a way that personal tendencies, can somehow *mediate* the physiological functioning of the bodily systems. On the other hand, 'personality type' could easily be construed as something that people have *little* control over, after all, being "high achieving" having "high standards" are some of the defining characteristics of 'type A's' in the first place, so maybe personality can be taken as a dispositional tendency that determines how people act. Paradoxically, the use of the concept of personality in this context works ambiguously to *avoid* implicating people in blame for their own state of health, whilst leaving a rhetorical space for FM's later claims about therapeutic interventions (such as CBT) that are designed *specifically* to help patients to gain a sense of self-efficacy and *control* over the contingencies of their lives.

Extract 9: Fending off the Category of Mental Illness

At line 48 in the next section of transcript, JJ, a member of the group, responds to FM's formulation of the mind and its implications for the explanation of illness.

- 48.JJ = I think what has upset some people with M E in the past (.) is that some
 49. doctors say M E is caused by mental problems
 50.FM = ye::s well [that's]
 51.JJ [er...tha-that] has been disproven (.) it annoys people with
 52. M E when they hear this said and it is occasionally it's still said today
 53.FM =well nobody[...I think it is still] said now and I think that is still said
 54.JJ [()]
 55.FM when you're in a condition where nobody knows (.) the real reason.Well in
 56. a way everybody's gonna have their theories and it's very hard to say who's
 57. right and who's wrong (.) because there isn't anything known

JJ responds to *FM*'s construal of the mind/body relationship (in extract 8) by formulating some justifiable grounds for being uneasy about psychological explanations; "I think what has upset some people with M E in the past (.) is that some doctors say

M E is caused by mental problems” (extract 9, lines 48-9). Notice here JJ’s choice of the term ‘mental problems’, rather than for instance, ‘the mind’, which FM had earlier defined as equivalent to the brain. The use of the term ‘mental problems’ differentiates what JJ is talking about in a way that makes it more difficult for FM to dismiss JJ’s complaint on a point of definition.

JJ manages the potential for misalignment with FM by attributing this explanation of ME as “caused by mental problems” to “some doctors” (lines 48-9); the emphasis of which contrasts with FM’s status as a psychologist. When FM replies with an equivocal “ye::s well”, JJ is quick to head off the potential for *disagreement* by refuting the claim, in a manner suggesting that, rather than this being merely a statement of *personal* opinion, there is actually some research evidence to support his claim, “that has been disproven” (line 51). FM’s attempt at mitigation of the doctors’ claims, “when you’re in a condition where nobody knows”(line 55), are a direct contradiction of JJ’s claim that “that has been disproven”. Contrary to what FM is suggesting, JJ works to support the argument that there *is* in fact a justification for taking a position about who is right and who is wrong and what is known.

Extract 10: Taking the Epistemological High-Ground: ‘people know’.

Then follows a section (lines 58-70) where two members of the self-help group jointly claim the ‘epistemological high ground’ by constructing an *experiential* claim about the status of their illness.

58.JJ people who have(.) experience of M E
59. kno:w
60. (0.3)
61.JJ know (.) somehow or other within themselves that it's not true
62.FM = yeah
63.JG = that's right people know (.) they know they've got a physical illness

- 64.JJ = they know
 65.JG = when (they've been passed off by) their doctors as psychosomatic it makes
 66. her very angry and that's why we don't really want anything to do with this
 67. sort of psy- psy- psychiatry
 68.JJ I think that's what I was trying to say (.) this is what's upset some people with
 69. M E the fact that they've been told (.) or they've read (.) that it's purely a
 70. psychological illness (.) and they know very well it isn't

Not only do JJ and JG collaboratively construct an experiential claim, they also do this by reference to the *general* experience of people who have M E rather than just their own *personal* experience. This construction of experience as something that members of the group *share* as common knowledge, is reinforced by repetition and emphasis of the word 'know' by different speakers; "people who have (.) experience of M E know:w (0.3) know (.) somehow or other within themselves that it's not true" (lines 58-61), "that's right people know (.) they know they've got a physical illness" (line 63) "they know" (line 64), and " they know very well it isn't" (line 70). When positioned against FM's earlier remarks about M E being "a condition where nobody knows" (line 55), the combination of an evidential claim (at line 51), an experiential claim, and the joint construction of common experiential knowledge (at lines 58-70), are powerful rhetorical devices that work to dismiss a view of M E as "caused by mental problems", that JJ has first problematised at line 49. JJ and JG's comments at lines 58-70 display that they take FM's comments at lines 55-57 (*extract 9*) to allow for a possible psychologised reading of their illness. So whatever else FM wishes to say next about the category of the mind or psychology in the context of talking about M E, he must work to manage these issues of "mental problems" (line 49), "psychosomatic" (line 65), "psychiatry" (line 67), and "purely a psychological illness" (lines 69-70) that have been constructed by the participants as contentious. In the next section FM addresses these issues by returning to his work on defining meanings in the realm of psychology.

Extract 11: Managing the 'dangerous category'.

- 71.FM = I suppose this is the other area that(.) I think gets very confused- what do you
 72. mean when you say something's psychological? Are you're saying that (.)
 73. people think there's nothing physically wrong with you at all (.) that you're
 74. sort of in a way imagining it ? (.) Is that what they mean? (.) Or do they mean

75. that it's (.) like a stomach ulcer- nobody (.) you could say a stomach ulcer is a
 76. psychologically caused problem but that doesn't mean you imagine the pain
 77. do you? Because (.) if you look in your stomach you can see the hole there (.)
 78. but that is psychosomatic as much as it's caused by the mind affecting the
 79. body (.) so it's very confusing what you mean when something is- is
 80. psychological are you saying that it's all imagined (.) there's nothing
 81. physically wrong with the body it's all in the mind (.) are you saying that the
 82. mind affects the body (.) and therefore things could be partly psychological (.)
 83. y'know an- and that to me when I (>talk about it being psychological<) that's
 84. how I think of it (.) that the mind and the body affect each other
 85. (1.2)
 86. FM I don't- I certainly wouldn't seriously suggest that people (.) ima:agine the
 87. symptoms that they have and they are genuine physical symptoms
 88. (1.2)

At the start of the sequence (extract 1, lines 2-4) FM had referred to his “two reasons” why “there’s unease about the application of the psychological approach to Chronic Fatigue Syndrome”. His first reason was that people “like to see the mind and the body as two separate things” (line 7). At lines 71-2, FM starts to formulate his *second* reason in reponse to the increasing misalignment between himself and the group members in the previous section; “I suppose this is the other area that (.) I think gets very confused-what do you mean when you say something’s psychological?”. The “unease about the application of the psychological approach” is *now* being treated by FM as hearable in the talk of the members of the group, rather than existing vaguely elsewhere.

FM responds to this by addressing the members *personally* and tying his comments into the references he made *generally* at the start of the session, where “people have difficulty”, and “they like to see”, and “there’s unease” (extract 1, lines 2-4). This he delicately manages by interweaving the pronouns ‘you’ and ‘they’, and using phrases like; “what do you mean”, “are you saying that”, and weaving them together with more *general* terms of reference like, “is that what they mean”, “do they mean”. The term “you” (at lines 71-3) is ambiguous, between the audience, and people in general, and the use of “they” (at line 74) moves its meaning to the latter. This discursively works up the idea that there may be a more general level of misunderstanding of psychology, in which the people in the group might *also* be implicated. FM finds a

delicate way to avoid the difficulty of having to suggest to JJ and JG that they *personally* are confused, by offering psychology to them as a category that *generally* “gets very confused” (line 71).

FM works up his own formulation of what that confusion might consist of by making a distinction between two categories; the *imaginary*, and the *psychosomatic*, where the imaginary implies that the illness is not real, “there’s nothing physically wrong with you at all” (line 73), and the psychosomatic is explained in a cause and effect way as “the mind affecting the body” (lines 78-9) and as with the example of a stomach ulcer, there are observable bodily signs, “if you look in your stomach you can see the hole there”. FM aligns himself with the latter explanation, “when I (>talk about it being psychological<) that’s how I think of it (.) the mind and the body affect each other”(lines 83-4) and then works to distance himself from those who might suggest the ‘dangerous category’ of imaginary illness, “I certainly wouldn’t seriously suggest that people (.) imagine the symptoms that they have and they are genuine physical symptoms”. He thus distances himself from the rhetoric of ‘all in the mind’ explanations for M E and in using the term “genuine physical symptoms” he works to re-align himself with the group as ‘the acceptable face of psychology’; he is someone who is prepared to take their problems seriously as physical problems, albeit caused by the mind and the body affecting each other.

Now, at different parts of his talk FM has worked up two different positions on the relationship between the mind and the body. In extract 8 he formulates the mind as equivalent to the brain, whereas in extract 11 he formulates an interactionist model, where the mind and the body affect each other. This latter position is a dualistic formulation where the causal relationship can be effective in either direction. Being able to take two different positions on the relationship of mind and body enables him to accomplish some important and sensitive interactional business. First, it allows him to formulate psychology as non-threatening (mind equals body); second, it allows him to define away people’s potential grievances; and third (mind and body affect each other) allows him to suggest that, in some cases, physical symptoms are caused by

psychological problems. If the direction of causality becomes an issue for the audience, then he can always respecify his previous arguments, calling on the 'mind equals body' construction as a resource to re-theorise the problem away.

JJ responds to this gerrymandering in the next section by reinstating the primacy of the physical over the mental.

Extract 12: Mental problems: Cause or Consequence?

- 89.JJ but so often though people with M E have found that the M E (.) the physical
90. part of the M E has come on before the mental problems the mental
91. problems have followed on (.) as a result of the physical problems (.) not the
92. other way around
93. (1.5)
94.FM well I think there have been (.) chronic fatigue syndrome is principally a
95. physical based syndrome- the main symptoms are the fatigue (.) you might
96. sometimes have other (.) lack of concentration, dizziness, and other
97. symptoms which is a physical (.) actual muscular pains (.) er (.) well not
98. everybody gets muscular pain (.) everybody gets the fatigue and some people
99. get pains as well (.) as fatigue
100.JJ = well I'm convinced that there is a psychological element in M E (.) I'm
101. certain of it (.) but I don't think it's a-I-I think it's a consequence rather than a
102. cause
103.KH = well with any long-term illness (.) you're bound to get psychological
104. effects (.) you're bound to because (.) M E primarily affects active go-ahead
105. people (.) it doesn't affect couch potatoes

At line 89, JJ rhetorically positions his comments against a linear cause and effect explanation of mind and body, where the physical problems of M E are *caused* by mental problems. In doing so he is responding as if FM's explanation either makes such an interpretation available, or at least fails to address it. He replies by challenging the direction of causality, where mental problems and physical problems are being construed as separate components of M E, where the physical part takes place *before* the mental part which 'follows on'. This works against a possible psychosomatic explanation of illness where real physical symptoms are either the *result* of stress (as

with the example of the stomach ulcer), or might be interpreted as the physical manifestation of mental disturbances (such as depression or anxiety).¹⁶

FM responds to JJ at line 94 by conceding that “chronic fatigue syndrome is principally a physical based syndrome”, but then goes on to differentiate between people’s symptoms; “well not everybody gets muscular pain (.) everybody gets the fatigue and some people get pains as well” (lines 97-9). His use of the word *principally* at line 94, his reference to “physical (.) actual muscular pains” at line 97, and his move to distinguish between people with CFS who have different collections of symptoms, allows him to retain a space for at least *some* instances of CFS to be defined as psychosomatic, where the direction of causality is psychological to physical.

‘Talking past each other’

Notice also the switch from JJ’s use of the term M E to FM’s use of the term CFS, where (as pointed out above in chapter three, on labels) the use of the category CFS enables the speaker to claim a more ‘neutral’ stance with respect to what causes the illness, and also allows there to be a differentiation between various categories of illness that might come under the umbrella term CFS. As I argued in chapter three, one way to manage the threat that a ‘reality disjuncture’ (Pollner, 1987) poses to the idea of an objective reality is to claim that people might be labelling different things. In this case, throughout the dialogue, FM’s use of the term CFS, and the group’s use of the term M E allows for them to be talking about different categories that are more or less physical in nature, rather than to be disagreeing about the same category. ‘Talking past each other’ thus avoids the potential for the dialogue to turn into an acrimonious

¹⁶ This section of talk all assumes a *linear* model of causation, versus (say) a synchronistic (or process) explanatory model. (The interesting point for *this* thesis is not to adjudicate between such models, but to show how linear and process models are rhetorically useful for different discursive purposes. Also, as pointed out in chapters two, three, and four, an appeal to a different kind of model can form the basis for making a ‘truth will out’ claim (see Dr Walker, chapter three: extracts 14 & 16); or to claim the theoretical ‘high ground’, a metaposition (see, for example, chapter two: extract 33); or as an appeal to complexity to mitigate uncertainty of knowledge in the current interaction, and in medical science itself (see Dr Brown, this chapter: extract 6). Cause and effect models work to make a definite claim in either, or both directions, whereas complex synchronistic/process models work to *constitute* and *celebrate* uncertainty.

debate between FM and the group members about the nature of their own illnesses and the status of FM's knowledge and opinion.

'Active go-ahead people'

JJ responds to this at line 100 with "well I'm convinced there is a psychological element in M E (.) I'm certain of it (.) but I don't think it's a- I- I think it's a consequence rather than a cause", which claims for M E the status of a primarily *physical* condition with an ontological solidity existing prior to any psychological effects. KH intervenes to elaborate JJ's point, "well with any long-term illness (.) you're bound to get psychological effects" (line 103-4). Here, the psychological effect of long-term illness is worked up as an *ordinary* phenomenon, which is an *inevitable* consequence of chronic illness. Not only is this effect defined as ordinary (Sacks, 1984) the sort of thing that *anyone* would normally be expected to suffer, thereby aligning M E/CFS with medically conventional diseases, but also as something for which any single individual could not be held personally or dispositionally *accountable*.

KH goes on to formulate some reasons why people with M E are likely to suffer in this way. "because (.) M E primarily affects active go-ahead people" (lines 104-5). Not only does this explain the *reason* why people who are disabled by long-term illnesses should suffer psychological effects, as a rational, commonplace response to the restrictive conditions imposed by their illness, but also defines for us a *typical* kind of person who suffers from M E. This positive image of "active go-ahead people" is a valorised account that is being contrasted here with a more perjorative image of the 'couch potato'. KH is here working to dismiss an image that is oriented to here as being another dangerous one for M E sufferers; that of a malingerer, or someone whose illness is purely functional. The image of "active go-ahead people" works here as a kind of 'stake inoculation'¹⁷, constructing the natural disposition of M E sufferers as running counter to the circumstances of their illness. The formulation of "active go-ahead" people who are more likely than most to experience psychological effects from

¹⁷ See my reference to 'stake inoculation' in chapter one, page 15.

enforced inactivity works here to dismiss any suggestion that they are really just couch potatoes who are naturally lazy.

The Spectre of Blame in Talk about Depression

“you’re bound to get psychological effects”

As pointed out earlier, in the analysis of extract 12 above, KH had offered the suggestion that psychological effects are a consequence or an ordinary *experiential reaction* that is inevitable in the circumstances of long-term illness. However, even though KH has formulated such ‘psychological effects’ as normal, there is still a danger here that this category could be construed as pathological rather than normal. There might be grounds for claiming that there are degrees of difference between people, in the strength of such effects, on a scale of normal to pathological. For example, ‘active go-ahead people’ might be rather more susceptible than most to experience the frustrations of enforced inactivity. In any event, even the ordinarily understandable psychological effects of chronic illness could be made an accountable issue by means of the rhetoric of coping.

At lines 107-110, JJ re-specifies the “psychological effects” mentioned by KH at lines 103-4. He does this by elaborating an alternative account of depression as a physical category, which is subsequently taken up as a topic of talk by other participants. In the previous extract (12), and the three that follow (13, 14 and 15), there are a total of five different categories of depression worked up in the dialogue. These categories are ongoingly constituted by appealing to different constructions of the mind, and the relationship between the mind and the body. At stake here, as before, is the issue of different versions of reality about the nature of the illness, and the accountability of sufferers.

Extract 13: “A chemical in the brain isn’t it?”

107. JJ I think it’s a bit deeper than that though with M E (.) I know-I know physical
108. illnesses cause psychological problems but I think with M E there’s a closer
109. link (.) it’s not just the fact that you’ve got M E that makes you feel
110. depressed

111.KH = well there is becau[se there]
112.JJ [there's a]closer link (.) I think it's something affecting
113. the brain itself
114.EC = a chemical in the brain isn't it?
115.KH = it's quite possible but (.) I mean M- MS is the same (.) because they get
116. personality changes and all sorts of things

JJ goes on to *qualify* KH's comments (lines 103-4) about the psychological consequences of illness, arguing that "it's a bit deeper than that" (line 107), "there's a closer link (.) it's not just the fact that you've got M E that makes you feel depressed" (lines 108-10). JJ here distinguishes between two kinds of depression that M E sufferers might experience. The first is an ordinary *reaction* to a chronic physical illness; that is, "you've got M E", and "that makes you feel depressed"(lines 109-10), and the second is "something affecting the brain itself" (lines 112-13), which EC then elaborates as "a chemical in the brain" (line 114). There is quite a subtle difference between these two accounts in terms of defining the nature of depression itself. In the first account, M E is being conceptualised as a separate physical illness that makes people feel miserable, whereas in the latter version, M E has a direct action on the chemistry of the brain. As pointed out above, there is a danger with the first account, that sufferers could be made accountable for feeling miserable about their illness, via the rhetoric of coping. JJ's construction works to counter that possibility by providing an account of a physical mechanism to explain depression.

This work is further corroborated in KH's comparison with multiple sclerosis (lines 115-6), "I mean M- MS is the same (.) because they get personality changes and all sorts of things". The implication in citing MS as an analogous case is that personality changes in MS are said to be a *consequence* of chemical brain states resulting from a physical illness. This therefore works to position M E within the category of physical medical conditions and also offers a way to align KH's earlier remarks about psychological effects with the idea of a physical illness, via brain states. This means that both accounts can be heard as plausible physical explanations that work to dismiss any possible suggestion of a prior mental problem, and relatedly, personal responsibility for illness.

Extract 14: Is M E some type of depression?

117. (0.5)
118.FM you see you get chemical changes in the brain in anxiety and depression
119.HK = is this (.) is this where doctors give M E sufferers anti-depressants?
120.FM = well (.) when people have done research (.) looking at Chronic Fatigue
121. Syndrome or M E sufferers they do find if you give them standard psychiatric
122. interviews (.) they have a much higher level of depression (.) than say another
123. group with a chronic health problem, chronic heart disease, or other problems
124. so that's why (.) it's not by any means all people but it's higher than you'd
125. normally expect there's a higher incidence of depression that is one suggestion
126. is that y'know that (.) is there some type then of depression (.) is it (.) that
127. chronic fatigue (.) the actual symptom of fatigue is a symptom of depression
128. (.) >there are other symptoms as well with depression (.) but that is a
129. symptom of depression (.) and so there has been an interest in giving anti
130. depressants and again it's been one of these things where there's been some
131. positive studies that show benefit in some people and other studies that
132. haven't found much (.) maybe it depends on which group of chronic fatigue
133. syndrome people you happen to get (.) that does seem to be (.) *when people I*
134. think present with a chronic fatigue syndrome problem you are- will be
135. assessed for symptoms of depression- there's other symptoms of depression as
136. well (.) early morning wakening, low mood, bouts of tearfulness, (.) and you
137. are likely to be offered anti-depressants by- whether it's the physician or
138. your GP

In the previous section (extract 13), KH and JJ have worked to establish the idea that M E is purely physical, and any depression is purely a result of the separate illness, M E. FM's response to this, after a significant pause indicating a dispreferred response (Pomerantz, 1984), is to suggest an alternative explanation; that is, there are *other* conditions, *apart* from M E, that are associated with changes in the brain. The implication of this is that maybe anxiety or depression are the *only* explanations that are necessary in the first place. He follows this up (lines 119-125) by formulating some grounds that effectively dismiss KH's earlier account about depression being a normal reaction to chronic physical illness; he points out that M E sufferers have "a much higher level of depression (.) than say another group with a chronic health problem, chronic heart disease". He then goes on to offer an explanation for this higher level of depression "than you'd normally expect" (line 124-5) by suggesting "y'know that (.) is there some type then of depression". Effectively, in this turn at talk,

FM has neatly rearticulated M E as *not* itself being a separate category from depression, and has thereby attempted to remove the concept from his lexicon. This is similar to the move he performed earlier on the meaning of the term ‘mind’.

Next, FM attends to HK’s comment at 119, as a request for information about the prescriptive practices of doctors in treating M E sufferers. First, FM aligns the two categories of M E and CFS as being *one* category for the purposes of his explanation, “research (.) looking at Chronic Fatigue Syndrome or M E sufferers” (lines 120-21). This works to anticipate the possibility that group members might claim that CFS research findings do not apply to *them* as M E sufferers. Second, FM gives an account of the findings of such research, “if you give them standard psychiatric interviews (.) they have a much higher level of depression (.) than say another group with a chronic health problem, chronic heart disease, or other problems” (lines 121-23), which is used as evidence upon which *doctors might base a claim that CFS or M E is “some type then of depression”* (line 126) and might wish to offer anti-depressant treatments to patients. FM again constructs a differentiation *within* the category of CFS in order to manage the *inconclusiveness* of the research results, “maybe it depends on which group of chronic fatigue syndrome people you happen to get” (lines 132-33), where the inconclusiveness itself provides enough rhetorical space for the explanation of depression to be inapplicable in *some* cases of M E or CFS.

This is an elegant piece of discourse, where FM is attending to the mutually implicative consequences of *either* providing for the claim that research is inconclusive, *or* treating CFS and M E as belonging in the same research category, as he had done earlier (lines 120-121). Research that is inconclusive threatens his *grounds* for making any kind of a claim at all about the nature of M E, CFS, or its treatment. For instance, there could also be objections from the group members that antidepressant drugs had not cured *their* illnesses. But having different categories *within* CFS allows for the researchers not to have been comparing like with like. In the context of this interaction, FM’s re-definition of M E as a type of depression can remain implicitly available as “one suggestion”(line 125), without having to spell it

out as his own opinion in so many words; thus avoiding a direct confrontation with his audience.

Extract 15: 'Iatrogenic injury'¹⁸: Shifting the blame

- 139.HK = but I think a lot of the sort of (.) depression side of M E in sufferers comes
140. from the fact that we become depressed trying to convince the doctors, the
141. medical profession that there's something wrong with us
142.All (laughter)
143.SB I told my doctor 'I am not depressed (.) I am bloody fed-up with it (.) I am not
144. depressed' (.) but he still wanted to give me (.) anti-depressants
145. (0.5)
146.FM well I ye:s [y'see]
147.SB [how]do you get round getting through to some of these doctors
148. you get annoyed with the pain

HK responds to FM's gloss, on the doctors' rationale for treating M E as some kind of depression, by re-working the category of depression as the consequence of injury caused in the first place by interaction with the medical profession, "we become depressed trying to convince the doctors, the medical profession that there's something wrong with us" (lines 140-41). This claim is produced by KH as ironic. Iatrogenic injury is of course a serious matter, but also humorous as indicated by the laughter, since medical intervention is supposed to provide healing rather than harm. The rhetorical force of this irony is to account for doctors' diagnoses by turning the tables, such that the doctors' insistence of a diagnosis of depression becomes itself the very cause of depression. This effectively shifts the accountability for the patient's state back to the doctor who 'caused' it in the first place.

In support of this claim, SB gives an account of her consultation with the doctor, "I told my doctor 'I am not depressed (.) I am bloody fed-up with it (.) I am not depressed' (.) but he still wanted to give me (.) anti-depressants". This neatly constructs the injury as being in *this* case a consequence of having one's *experience* of illness denied, or disregarded. "I am bloody fed up with it" works up her *mind* state as being an *ordinary* (and perfectly normal) response of anger or frustration such that

¹⁸ Iatrogenic injury refers to injury sustained by patients as a result of medical or therapeutic interventions.

without actually *feeling* depressed, “you might still feel quite cheerful” (line 156), and it is represented here as “an unusual way of presenting- presentation of depression” (line 160). One implication of the category of masked depression is that by definition, sufferers no longer have *any* grounds to speak about themselves from *experience*, since “you might still feel quite cheerful” even though you are depressed. On the one hand, this category can be used (as it is in this dialogue) as a rhetorical counter to undermine experiential claims (see extract 10), since it is a way of implying that personal experience is likely to be misleading. On the other hand, the lack of self-awareness inherent in the concept of masked depression reduces the potential for this to be heard as a way to blame the victim for their own medical condition.

For doctors (and for FM, in this context) masked depression constitutes a ‘catch-all’ category¹⁹ that completes the all-encompassing circle of types of depression that can explain people’s health problems in terms of psychological processes. Having such a ‘catch-all’ category is a way of being able to sustain a basic explanatory model for all contingencies, even those that are anomalies. In *this* context, whatever symptoms the patient presents can be interpreted as an example, or at least a hidden example of *depression*. As I pointed out earlier, a final twist in the argument is that if M E patients are defined as suffering from masked depression, they are in a sense disenfranchised, since they have no grounds on which to *speak* about their own experience.²⁰ But even further than this, if symptoms, and their experience of them *cannot* be taken at face value patients also risk being implicated in the even more ‘dangerous category’ of *imaginary* illness or delusions. Rhetorically, the category of masked depression is therefore well designed for maintaining medical control over the meaning of the patient’s illness, and in the context of *this* dialogue it works to disenfranchise the other participants thereby allowing FM to have the ‘last word’.

“The question is”, said Humpty Dumpty, “which is to be the master- that’s all!”

¹⁹ This works in a similar way to the categories of ‘stress’, and ‘the rag-bag of funny illnesses’ that featured in chapter 3: extract 16.

²⁰ This is rather like the rationale of psychodynamic explanations, where patients are deemed not to have access to the workings of the unconscious mind.

(...)

To summarise, this chapter sought to analyse how categories of mind and body and the relationship between them is ongoingly constituted in talk about M E and CFS. In the introduction I suggested that the constitution of mind and body as separate categories in previous theoretical and philosophical conceptualisations, might itself signify the discursive *utility* of those categories. I argued that they are in the first place constituted in and through commonsense accounting practices, and are useful as resources to manage sickness as a realm of moral accountability.

The co-implicative construction of categories and the management of agency was explored in the first part of the chapter by looking at some formulations of mind and body that have been worked up by medical practitioners in the context of talk about M E. What is important is the rhetorical context of using the term 'mind'. In other words, it is defined by what those who employ the term say in use. Constructions differed in various significant ways: for example, whether the mind or the body is given primacy; whether the mind is afforded conscious or unconscious control, or an equivalent ontological status with the body; and how far the speaker works to deploy a linear cause and effect model of mind and body, or a process model of mind and body as integrated. Such variability constitutes a rich resource for the construction of different versions of illness, and the management of accountability as a practical activity.

In the second part of the chapter, I looked at the use of mind and body constructions in the context of a participants' dialogue, where participants work to avoid becoming implicated in the 'dangerous' category of 'all in the mind' explanations for illness. The construction of meaning and its implications for personal responsibility for illness are constituted in and through the situated activity of managing the potential for confrontation. Mind and body as categorical resources are constructed, deployed and ongoingly re-formulated in the context of managing some interactionally sensitive business. These categorisations work in the context of talk about illness to construct people's illnesses as being more or less physical and real. The precise meanings of

categories and their relationship to each other, and their implications for agency are worked up together on and for the occasions of talk.

The analysis in this chapter has demonstrated how different models of mind/body are rhetorically useful for different discursive purposes. A linear cause and effect model was useful for the participants in the dialogue of this chapter, to make a definite claim in either or both directions. On the other hand, a complex process model works both to constitute and celebrate uncertainty. Three examples of the latter can be drawn from the analysis of data so far in this thesis. First, in this chapter, Dr Brown (extract 6) deploys such a model to mitigate and account for uncertainty in the current interaction of the interview, and also to claim that in the wider context of medical science, complexity may obscure rather than enlighten; second, David *et al.* (1988) (see footnote 4, this chapter) deploy a process model to claim the theoretical high ground in the M E controversy; and third, in chapter three (above) Dr Walker appeals to a new kind of model as a basis for claiming that ‘the truth will out’ in the end (chapter 3: extracts 14 and 16).

One of the reasoning practices that was also employed by doctors in chapter three (and by some of the contributors to the extracts in chapter two, and also by the attribution theorists in the previous chapter) was the use of a *contingent* repertoire to explain why patients might *want* a physical diagnosis for their illness. The assumption built into this argument is that an interpretation of their ailments in terms of bodily processes makes them *less* accountable for their illness, and therefore the deployment of such explanations is a move to avoid facing up to their ‘real’ problems which are deemed by the doctor to be psychological. Of course, this account fails to acknowledge the reciprocally contingent explanation that doctors might want to interpret their patients’ symptoms as psychological in order to make *themselves* less accountable for understanding and treating the illness. As one M E sufferer put it, “It’s a cop out!”²¹

²¹ This quotation is taken from Angela and Joe’s narrative, which is analysed in detail in the following chapter (six).

The assumption underlying these kinds of commonsense constructions is that there might be a one to one correspondence between psychological explanations and high accountability of patients, and physical explanations and low accountability of patients. In other words, the argument *itself* would lead to the conclusion that physical diseases of the body are associated with things that just happen to people, whereas psychological or psychosomatic illnesses are associated with a sense of a morally accountable agent, who might somehow be subverting the presentation of an actual mental dysfunction, (such as anxiety or depression) as a physical symptom.

The analyses of this chapter have indicated that there is *not* such a perfect fit between the mind as a realm of personal accountability, and the body, as a passive or acted upon object. These two are, in the first place, participants' categories, and although they certainly *can* be used in this way, as indicated in the above examples of doctors' and patients' reasoning practices; a closer look at mind and body talk in different contexts tends to work against such a neat and tidy categorisation.

As the analysis of dialogue in this chapter has demonstrated, the dualism that is built into linear models of illness explanation, the interaction of mind and body in process models, and the monism of FM's approach where the mind is made equivalent to the body, are well designed to manage some rhetorical business. In the dialogue between FM and the members of the group various bids for authorship of the meaning of categories (such as mind and depression) are made in and through various moves and counter moves. At stake in this dialogue is the meaning of the illness and the implications of that for personal accountability, and the potential for misalignment and confrontation with other participants. One way to summarise this would be to argue that the definition of M E is itself a product of the interactional dynamics within which that struggle for authorship takes place.

The next chapter analyses the relationship between attributional discourse, and moral accountability in the context of an illness narrative, where the identity of the sufferer and the nature of M E are co-constituted *in situ*.

CHAPTER SIX

The Narrative Construction of 'Self' and M E.

The aims of this chapter are two-fold: First, to examine the way that M E and identity are co-constituted in and through the management of competing concerns in an illness narrative; second, to show how the theoretical approach of discursive psychology (Edwards and Potter, 1992) differs from other approaches and can make a contribution to the analyses and understanding of illness narratives and the discourse of medical practitioners.

A discursive psychology approach to narrative has been elaborated by Derek Edwards (1997), whose comprehensive critique of cognitivism¹ in psychology includes a chapter on "Narrative: Stories and Rememberings", where narrative analysis is re-worked from the perspective of discursive psychology. He distinguishes between three types of analysis that have been applied to narrative (*ibid*: 271). A type one analysis is common to much of ethnography and oral history, where the aim is to collect stories as a route to finding out about events. Language is treated as a representation of reality, and people's descriptions are taken as being more or less accurate accounts of 'what happened'; they are deemed to be a route to a world of reality beyond the talk, which is discoverable within the limitations of human memory, error or bias. A type two analysis aims to discover people's *perceptions* of, or *understanding* of events; in other words it treats their discourse as revealing something about their internal psychology, their world-views, beliefs, cognitions and attitudes etcetera. Much of narrative psychology, especially as it applies to health and illness, takes this second approach which aims to identify people's personal views of the world, or how they, as individuals, make sense of the events and experience of their illness. The next section briefly outlines the rationale of some of these approaches with reference to a recent review by Murray (1997).

¹ "Cognitivism is a perspective that reduces all of psychological life, including discourse and social interaction, to the workings of cognitive, or even computational, mental processes." [It is] "currently psychology's dominant theoretical and methodological perspective" (Edwards, 1997: 19).

Murray has summarised the main aims of a narrative approach to health psychology as a way to study people's experiences, and a way to gain insights into people's identity and culture. These aims are described as being inherent in a 'humanistic' or 'antipositivist turn' in psychology, which is concerned to develop "an understanding of human experience" and how people make sense of their own and other people's identities and life experiences.

Murray has identified attribution theory as a precursor of narrative psychology, since it has been argued that there is a human tendency to seek causal connections between events (Heider and Simmel, 1944; Heider, 1958). In other words, from this view "Narrative thinking is, therefore a type of *causal* thinking." (Robinson and Hawpe, 1986: 111). Apart from this interest in individual cognition, some analysts have sought to understand storied accounts as a product of the interpersonal context (see for example Baumeister and Newman, 1994), where the central claim is that interpersonal and interpretative motives influence how stories are told. An example that is relevant to the context of illness talk is Riessman's (1990) study of an MS illness narrative in which Goffman's theory of 'self-presentation' (Goffman, 1959) is used to interpret interview talk. The participant's use of a 'narrative genre' is treated as motivated to create a particular image of self; that is, a 'competent self' in the reconstruction of a biography which had been disrupted by multiple sclerosis and divorce. Riessman points out that 'how the story is told' is as important as its content. The 'narrative genre' is rhetorically powerful because it draws the listener into the author's version of the world. The narrator's authorship of himself and his version of events are inextricably related, as he constructs a 'reality' and a 'self' that are "sealed inside the narrative".

Narrative has also been used as a "root metaphor" (Sarbin, 1986) by different schools of psychotherapy. The central claim is that people can *organise* their experience in such a way as to create personal distress, or in ways that emancipate them from psychic suffering; in other words, it is possible "to articulate the subtext that undergirds the plot of the client's life and to help him or her experiment with new plots that open possibilities for fresh chapters" (Neimeyer, 1995b: 22). This can be

contrasted with “cognitive theorists who seek to dismantle distorted automatic thoughts irrational beliefs, and illogical inferences”. Both of these approaches have in common the notion that the story “resides inside the head of the individual and is a personal construction” (Murray, 1997: 14). They also make the assumption that it is possible for the therapist to identify constraining stories or irrational beliefs and distorted thoughts. These are taken to be the source of the client’s troubles, needing to be worked on by therapeutic intervention and replaced with a ‘better story’; a more rational explanation. This argument, necessarily presupposes a bottom line of better stories and more rational explanations against which to make this kind of judgement.

The idea that people begin to make sense of illness by creating a story about it is a common theme in narrative psychology. For example, typical cancer narrative structures (Murray, in press) tell the story of *before the diagnosis and after, where it is claimed that the narrator is attempting to cope by gaining control over the crisis by constructing stories of re-adjustment*. In other words, they are using a ‘progressive narrative’² to enable them to “redefine the crisis as an opportunity for rebirth and growth” (Frank, 1993)

In contrast to these kinds of approaches that have informed narrative work in health psychology (which are all to some extent underpinned by cognitivist assumptions), discursive psychology (the third type of analysis outlined by Derek Edwards, 1997: 271) represents a non-cognitive approach to narrative. It does not seek to discover the nature of events, nor to find out about people’s internal cognitions, but rather treats narrative accounts as discursive actions. Essentially this approach treats *any* kind of

² Gergen and Gergen (1986) proposed three broad narrative structures (progressive, regressive and stability) that they argue govern popular discourse and also scientific discourse. They claim that this classification covers the dominant Western narrative genres of *comedy, tragedy, romance and satire* (Frye, 1957), which have been more recently cited by others, such as the historian, Hayden White (1973) as being dominant narrative types in Western cultures. White’s point was that such narrative structures (used by historians) lend plausibility to accounts of the past, by showing the reader “how the data conform to an *icon* of a comprehensible finished process, a plot structure with which he is familiar as a part of his cultural endowment.” (White, 1978: 86) In other words, in order to be convincing historical reports about “the way things really were” (*ibid*: 122) facts about the past have to acquire a kind of coherence by being embedded in a narrative form that is familiar to the reader. The narrative forms of history (and literature) are treated as a kind of ‘deep structure’ that lie beneath the surface of texts and are characterised as “part of the psychological endowment of members of a culture” (Potter, 1996: 169).

discourse (including narrative) as a *performative* domain of social action. This differs from the other two types of analysis in that it does not assume a bottom line social (or psychological) reality of either events and objects in the external world or internal cognitions that are more or less discoverable via the analysis of people's talk.

However, discursive psychology does not necessarily *debunk* all of the other work on narrative analysis, but rather re-specifies its findings in the analytic context of a 'discursive action model'.³ In discursive psychology the order of the three types of analysis is reversed. Although it seems to be commonsense that *events* in the social world are *prior* to our (distorted) perceptions and understandings of them, and that this is followed by our 'best effort' descriptions of those cognitions, a type three analysis inverts this order by taking discourse as the starting point. That is, the world ('external reality'), and our understanding of it ('internal reality') then become analysable only as *participants'* concerns, in the sense that they appear (or are attended to by participants) as the topic of their talk. In other words, in constructing a version of reality, people's internal psychology (memory, attributions, identities, beliefs and attitudes, etcetera) are *precisely* the issues that are at stake for speakers in the telling of narrative. From this view, therefore, the analytically interesting thing about an illness narrative would be the way that reports of past events (memories) are accomplished with reference to issues of accountability (causal attributions), and how this relates to identity talk. This is managed on two levels; both in the narrative, and in the current interaction of the interview itself (Edwards and Potter, 1992; 1993).

Edwards (1997) has emphasised that the task of discursive psychology is neither to enter the world of the narrative, thus more or less accepting its authority as a 'best effort' representation of a reality beyond the account (as do type one and two analyses), nor to disagree with it, but rather to analyse its workings as a discursive accomplishment. This is not to be confused with treating people's accounts as motivated by dishonesty, insincerity, or 'face-saving'; but rather to argue, as analyst, that issues of factuality, sincerity, and personal identity are the very issues that are

³ This is the model described by Edwards & Potter (1992: 154) that I have outlined in chapter one, above.

oriented to by narrators as discursive concerns, and are therefore part of what needs to be analysed. In this chapter I take the approach of discursive psychology to analyse how an illness narrative is formulated, and how it functions discursively; particularly in the way that narrative descriptions, attributions and identity formulations are linked together in lay accounts of illness.

It has also been noted that discursive practices that are made explicit in courtroom talk, are implicit in everyday conversation (Atkinson and Drew, 1979; Edwards and Potter, 1992). As Edwards and Potter have pointed out:

Courtroom testimony is a special kind of talk, but it is developed from, and draws upon, the resources of mundane talk. It is a routine feature of conversation, and a special feature of courtroom dialogue, that establishing 'what happened' is done with regard to issues of personal responsibility, such that the psychological categories of memory and attribution have to be seen as intimately connected, even as mutually constitutive. Reportings of events carry their attributional implications with them, and are constructed precisely to do that. (*ibid*: 53)

Descriptions are marshalled and facts are produced in so far as they have, or can be seen to have, bearing on specific accounts and narratives. That is so, whether we are dealing with courtroom dialogue or any ordinary conversation. It is a matter of constructing suitable descriptions of events, for the pragmatic business at hand (such as establishing blame). What counts as appropriate descriptions, relevant events and proper criteria for them, including criteria apparently outside the current talk (physical evidence, corroborating testimony and so on), are also issues that participants address in talk. One of the central goals of discursive psychology is to explicate this process. (*ibid*: 51-2)

The analysis that follows takes the form of a case study of Angela and Joe's M E narrative.⁴ A courtroom metaphor seems particularly applicable to the following analysis of Angela and Joe's narrative for several reasons; first, it is the *legitimacy* of Angela's illness as a *real* disease that is being constructed⁵; second, in constructing a theory of M E, they are also building a 'case for the defence' of Angela's illness as real and *physical*, and third, the 'voices' of other people are recruited as 'eye-witness'

⁴ Angela and Joe are a married couple who kindly agreed to tell me the story of Angela's long-term illness. I am indebted to them for their co-operation with my research. My analysis of their story is intended to be an acknowledgement of their struggle (and that of other sufferers and carers) for the recognition and definition of an illness that has blighted so many people's lives.

⁵ Bruner has pointed out how one of the important elements of a narrative is "a sensitivity to what is canonical and what violates canonicity in human interaction" (Bruner, 1990: 77). The term 'canon' can be defined as a "general law, rule or principle" (Concise Oxford Dictionary). From this (and its occasion of use in Bruner's writing), the term canonical can be inferred to mean that which is regarded as authoritative, standard, or accepted. However, as I pointed out in the previous chapter (five), in the Wittgensteinian sense, norms are something that people can appeal to in making explanations and justifications for their actions.

and 'character-witness' accounts and 'expert-testimony', in the *corroboration* and 'defence' of their case.⁶

In the analysis that follows, I shall be concerned to show how an account of past events is constructed in a way that relates a particular set of attributions about the *nature* of Angela's illness, and to her *identity* as sufferer. The 'theory of M E' that is formulated, and the accounting for 'self as sufferer' of (or 'self as believer' in) M E can be seen as functionally inter-related in a narrative that establishes their version of reality against a background of on-going controversy, and possible competing explanations (Billig,1987).

'A Case for the Defence'

An Analysis of Angela and Joe's Story

How it all began.

- 21.MHS mm and how did it (.) can you remember much about how it started?
22.Joe =heh heh
23. ...
24.Angela it started off with
25.Joe = it started with a sore throat
26.Angela = I had a sore throat and I had the very worst headache I've ever had in
27. my life (.) it was one evening
28.Joe = go back to where we believe it was caught at the swimming baths in
29. (town)
30.Angela = yeah
31.Joe = we'd been going down in the evening (.) swimming once a week (.)
32. and er it was after one of our sessions
33.Angela = yeah we thought we'd picked it up
34.Joe = I went swimming one week (.) you didn't feel up to it (.) then the
35. following week
36.Angela = you were alright weren't you?
37.Joe = yeah and this ties in because it's now known that M E is caused by
38. er (.) an enterovirus which is a prime place to pick up an enterovirus is
39. a swimming baths (.) it's also the classic(.) used to be the classic place
40. to catch polio in the old days (.) hot summers (.) and I think with

⁶ I am, of course, not suggesting here that the interview discourse is equivalent to courtroom interaction, only that some discursive practices are common to courtroom and everyday discourse.

41. swimming (.) kids being in the bath all through the day (.) at the end of
42. the day the water wasn't getting through the cleansing plant quick
43. enough (.) I suspect if you'd gone first thing in the morning it would be
44. absolutely spot on clean (.) but er I suppose by the time we got there (.)
45. I suppose the enteroviruses were still there (.) yeah (.) just unfortunate

At the beginning of this sequence of talk, occasioned by the interviewer's question (line 21), Angela has started to tell her story (line 24) with prompting by Joe at line 25. She continues (lines 26-7) until Joe's interruption at line 28 where he directs her to "go back to where we believe it was caught". This joint re-construction of events is indexed by Joe, at line 27, as the rehearsal of a familiar tale, and the repetitive pattern of lines 24-26 accomplishes a display of consensus, which helps to build the factuality of their account (Edwards and Middleton, 1986a; Tannen, 1989).⁷

At the beginning of any narrative there is likely to be a sequence that provides some background 'scene-setting' detail; this is what Labov (1972) has referred to as 'orientation'. Rather than interpreting such a sequence as merely giving information that sets the story in its proper context in order that it makes sense to the reader or listener, discursive psychology analyses 'scene setting' to see what interactive business it may perform.⁸ For example, beginning a story at one point in time rather than another sets the parameters for what is to be made relevant. This has profound consequences for the kind of causal account that the speakers go on later to construct, and in this case provides the grounds for what will follow in the narrative as Joe's contribution to the story. Riessman (1993) has pointed out that where people start a story is rhetorically powerful for the management of causality and accountability, and that competing kinds of narrative are likely to differ in terms of when and where they begin; "Where one chooses to begin and end a narrative can profoundly alter its shape and meaning." (*ibid*: 18). For example, Angela's problems are here being dated very specifically to a point in historical time, and grounded in the activity of a visit to the swimming baths. Joe constitutes this as part of their normal routine by categorising it

⁷ Edwards & Middleton (1986a) Joint remembering: Constructing an account of shared experience through conversational discourse *Discourse processes*, 9, 423-459. Also, Deborah Tannen (1989) *Talking Voices: Repetition, Dialogue and Imagery in Conversational Discourse*. Cambridge University Press.

⁸ See, for example, my own use of chapter two as a 'scene setting' device, which sets up the grounds for what follows in the rest of the thesis.

as “one of our sessions” (line 32). Life events that pre-date this point are not, in this case, being made relevant to the process of becoming sick. This account could be contrasted with the kind of description that might draw on a psychosocial repertoire to make relevant the effects of traumatic life events and personal psychology as predisposing factors in the origin of her illness.

The device of starting and ending stories in a particular place, and ordering events in ways that makes links between them, can be seen as one way that people construct one version of events and their causes rather than another. This is more than just the representation of some kind of internal cognitive ‘sense-making’, where people’s illness narratives are treated as their best effort at explaining their ‘world-view’, health beliefs or illness attributions. Rather, the narrative ordering of events, and the causal links that are made between them can be seen as accomplishing rhetorical business in constructing a particular *version* of social reality. From this view, descriptions of events and causal attributions are inextricably linked together, since the giving of a particular description of events *necessarily implicates* the construction of particular kinds of causal links and accountabilities.

A ‘theory of M E’ as a medically recognisable organic disease caused by an enterovirus (formulated by Joe at lines 37-45), and the sequence of events that link Angela’s illness with the ordinary everyday event of going to the swimming baths, are being constructed here as uncontroversial in the first instance. This is accomplished by means of Joe’s scientific explanation (lines 41-5) for why enteroviruses might be in the water at the baths, which resonates with his earlier assertion about the baths being the *classic* place to catch polio. His theory is being worked up here as not a *new* or *untested* idea; his claims are warranted by the authoritative voice of established science, which is represented at lines 37-40 as the ‘classic’ script⁹ of a polio story. Joe is here blending the detail of Angela’s *personal* narrative with a *classic* narrative of how people used to catch polio in the old days. This accomplishes alignment between

⁹ The term script is being used here in the same way that Derek Edwards uses it in chapter 6, ‘Discourse and Cognition’, and in contrast to ‘script theory’ in cognitive psychology: “Events are described as scripted, as instances of some general pattern, or as anomalies or exceptions. At stake in such descriptions are the normative basis of such actions, and the accountability of the actors.”

the two accounts, and makes her personal story more easily recognisable as an instance of an organic disease phenomenon.

Why she never recovered: 'Catch-22'

This next part of the narrative builds an account to explain why Angela has been ill for such a long while (over twenty years).

- 76.Joe one of the problems which caused (.) we suspect which pushed the
77. M E (1.0) was (coughs) she had a friend in the village (.) the same
78. friend who's now got a grand-daughter with a funny name (.) and she
79. came round to see Angela (.) I think your mother had gone back (.) or
80. your mother had gone back because she'd begun to become very
81. slightly better but she was still ill when she arrived (.) but Janet came
82. round and said 'oh you wanna get out you wanna fight it y'know'
83.Angela = 'push yourself (.)[you push yours]elf you'll be alri[ght']
84.Joe ['push yourself'] [and] she did
85.Angela = and I did (.) and I got worse and worse and worse after that
86.Joe = and I'll always remember the time I came home from work (.) the
87. kids were out (.) the house (.) when I opened the back door the house
88. was dead silent y'know (.) and I knew she was back in bed again and
89. that really was the thing that pushed her [into]
90.Angela [push]ed it over the top
91.Joe = my Mum came back again (.) she thought Angela was ill (.) she
92. came back for three weeks initially I-I-initially was off work for two
93. weeks anyway (.) that was special leave to look after her (.) so there
94. was two weeks and then another three (.) both parents (.) that brings it
95. to nine weeks =
96.Angela = well this can't[go on forever can it? (.) so in] the end everybody had
97.Joe [and then she pushed herself]
98.Angela gone back (.) Joe was at work (.) cause I've got two children there's
99. alot of washing isn't there? I used to crawl round the floor and hang
100. over the sink and the washing machine trying to do a bit of washing (.)
101. and of course now we know this is the last thing you must ever do is to
102. push yourself when you first go down with M E (.) and I was doing all
103. the wrong things (.) and I think that's why I've never ever recovered

This is an attributional story that begins at line 76 ("one of the problems which caused (.) we suspect which pushed the M E") and is resolved at line 103 ("and I think that's why I've never recovered"). Having earlier established an external, but invasive organic cause for her illness (rather than, say, an internal psychological one) the question of possible *blame* and *personal accountability* is oriented to at this point as a participants' concern.

The severity and chronicity of her illness is explained here as being the result of following bad advice from a friend. Joe uses the *voice* of the friend, “oh you wanna get out (.) you wanna fight it y’know” (lines 81-82), and Angela also uses the *voice* of the friend (line 83) to emphasise Joe’s point, “push yourself (.) you push yourself you’ll be alright”. This sequence of joint construction (lines 83-4, and 89-90) functions again to build consensus and corroboration into the account of events. Joe’s story about coming home from work (lines 86-89) is the dramatic consequence of the story, “the house was dead silent y’know (.) and I knew she was back in bed again”.

At lines 95-102 Angela goes on to fill in the narrative details of her struggle to fulfill the obligations of her normal role “I used to crawl around the floor and hang over the sink and the washing machine trying to do a bit of washing” (lines 99-100), and in so doing she elaborates the severity of her worsening condition. From a realist perspective the problem would be to establish how far Angela’s description of events is an accurate representation of reality. The question of accuracy and authenticity in people’s narrative accounts, such as this one, is often construed as a major issue which threatens to undermine the validity of ‘type one’ analyses. As Robinson (1990) points out;

Personal accounts of illness are often viewed with considerable ambivalence as a research resource. On the one hand they provide a density of texture, a depth of personal meaning, and an insight into the experience of illness not readily available through other means. On the other hand these very qualities seem to make any systematic, valid and reliable attempts to create generalisable propositions difficult, if not impossible. (*ibid*: 1173)

However, factuality and authenticity is only considered relevant to a discursive analysis as either a discursive accomplishment, or a participant’s topic. This is *not* to agree with Robinson’s concern that systematic analysis might be impossible. My detailed analysis of Angela and Joe’s narrative is itself a display of the many discursive devices that (have been identified by discourse and conversation analysts) and are commonly used by participants in mundane, everyday talk to accomplish authenticity.

For example, one such device is the construction of fact through the inclusion of contextual detail. This has been well documented in ethnographic literature on ‘I-

witnessing' (Geertz, 1988)¹⁰, and also on the textual construction of eye-witnessed reports in studies of courtroom cross examination of witnesses testimony (Atkinson and Drew, 1979; Drew, 1990; Edwards and Potter, 1992; Molotch and Bogen, 1985). This work is relevant to my analysis here to the extent that, Angela's account of struggling to manage her household chores (lines 98-103), Joe's provision of details about the day he came home from work to find Angela in bed (lines 86-88), and his account of the care arrangements (lines 91-95) provide vivid detail which *constitute* the factual and authentic nature of their descriptions. The provision of such detail works to give some assurance that the account is not inaccurate or fictional.

Their account also constitutes a paradox which attends to the 'double-jeopardy'¹¹ of illness management talk. In citing the friend's 'bad advice' Joe has made relevant a particular notion of 'illness management'; that people should try not to 'give way' to illness. But Angela also deploys *the notion of shared knowledge as a discursive* resource "of course now we know that this is the last thing you must ever do is to push yourself when you go down with M E." Although the use of the term "we" is not specific, it does convey the sense of an authoritative consensus about the management of M E. In this case the speakers are making available the explanation that fighting the illness has itself created the conditions for going down with M E and that Angela's case is a recognisable instance of a typical M E story. In a similar way to Joe's account at lines 37-40, the blending of personal narrative with the classic script is co-constitutive, and each serves to reinforce the other. Stories of illness can be seen as being constructed in such a way that the single instance (the details of the case) conform to a 'typical illness script', where both the details of the individual case, *and* the normative order of the script are constructed alongside each other in a co-implicative way. The case fits the theory, and the theory is further evidenced by the case.¹²

¹⁰ See also my reference to 'I-witnessing' in chapter two, above, where contributors to the correspondence in medical journal deployed detailed 'eye-witness' accounts of the 'Royal Free' phenomenon.

¹¹ See Radley and Billig (1996) for a further explication of 'double-jeopardy' in illness talk.

¹² This example of 'scripting' is also an example of the 'documentary method' as outlined by Garfinkel (1967). For further explication, see chapter one, above.

In accounting for herself as an M E sufferer, Angela would ideally need to strike a balance between ‘giving in’ to illness, which could implicate her in discrediting definitions of malingering; or ‘fighting’ the illness, by which she risks being blamed for a self-inflicted worsening of symptoms. And of course, one of the things that makes her case recognisable as M E in the first place, is the worsening of symptoms following a period of ‘soldiering on’. This is constructed here as a ‘Catch-22’ dilemma in which she admits “I was doing all the wrong things” (lines 102-3). Of course, ‘doing all the wrong things’ is by definition a morally accountable issue, and her statement is therefore rather a dangerous admission. But the virtue of not ‘giving in’ to illness has also been made relevant by Angela’s reference to the advice of her friend. Therefore, the account functions interactionally, both as a direct refutation of any possible suggestion that this could be a self-serving illness, and also as a way to account for her worsening condition without having to directly apportion blame.

In the following section of talk, Joe supplies further evidence to support the theory of M E they are building, by citing another case which corroborates their own experience.

- 106.Joe we know of somebody who lived or lives in (name) who was a nurse
 107. who’s got it (.) and she’s worse than Angela (.) the reason being that
 108. she was mistreated at hospital
 109.Angela = at the hospital
 110.Joe = they put her on physiotherapy (.) she’s in a wheelchair most of the
 111. time now after that (.) so sure you’ve gotta rest

This is a *moral tale* of someone who got worse because of being given the *wrong* medical treatment; “she’s worse than Angela the reason being she was mistreated at hospital”(107-8). Angela echoes part of this line, “at the hospital”, which works to raise the question of medical competency for the first time in the narrative. This ironising of medical authority is made available in her emphasis of the word ‘hospital’. Joe continues with the consequence of the story at lines 110-1, “they put her on physiotherapy (.) she’s in a wheelchair most of the time now after that (.) so sure you’ve gotta rest”. This was both a cautionary tale, *and* a display of evidence to back up the theory of M E that they are building. In other words, the consequence of the hospital treatment, that the patient is now in a wheelchair, backs up their own

experiential claim which in this narrative cautions Angela, and other M E sufferers to rest and ‘give in’ to the illness.

Corroborating Evidence for the Theory

Jonathan Potter (1996: 158-9) has pointed out that the production of reliable independent witnesses who provide consensus reports, is one way to transform a description of events into a more solid factual account. One way that people can display the voices of such witnesses in the construction of narrative is to use quotations. The point is not whether they actually *are* quotes, but rather, that they are designed to be *heard* as such in the context of the narrative. Quotations or “active-voicing”, as Robin Wooffitt (1992) terms this device, can provide corroborative witness accounts that work to support the speaker’s narrative version of events. The following sections of transcript and their analyses illustrate the processes by which Angela and Joe have assembled an array of corroborating evidence to support the case they are building.

The Naive Eye-Witness as Stake Inoculation

51. Angela Jane was ten (.) nine (.) Steven was [six]
52. Joe [Jan]e(.) Jane would have been
53. about ten and Steven would be about six
54. Angela = no (.) she'd be nine (.) he'd be six (.) er yeah because Steven didn't
55. seem as he'd been at school very long and he was always a good little
56. boy (.) and I'll always remember he'd started acting up at school and
57. the teacher asked him 'why are you being so naughty Steven (.) you're
58. such a good little boy?' (.) and er she wanted to get to the bottom of it
59. (.) and he says 'I think my Mum's dying' (.) I was so ill he thought I
60. was dying (.) nobody had said much to him about it I suppose
61. Joe =(clears throat)
62. (.)
63. Angela and I was like that for a very long while

In this extract (line 51) Angela resumes her account of the illness narrative that she began at the start of the interview. She tells the story of how six year old Steven's teacher discovered the reason for his uncharacteristically bad behaviour at school. In this account the quotation, "I think my Mum's dying" is the *voice* of an *eye-witness* to corroborate the severity of her physical symptoms. For several reasons, the child's *voice* is a more powerful rhetorical device than if Angela were to give a simple

account of how severely ill she had been. First, it works against the possible inference that her account is exaggerated; second, Steven's 'voice' is here appropriated as a response to his teacher's (rather than Angela's) question "why are you being so naughty Steven"(line 57); and third, the child's naivete is precisely what underwrites his credibility as a witness in this case. With consensus accounts (such as the one that is jointly constructed by Angela and Joe at the beginning of the narrative) there is always the potential for it to be heard as collusion. On the other hand, in the context of this narrative where "nobody had said much to him" about his mother's illness (line 60), Steven is an untutored, innocent witness with no stake in what he says. Further, Steven's behaviour at school is formulated in his teacher's voice as untypical of him; "you're usually such a good little boy". The implication of this is made available by standard attributional reasoning; that his behaviour is explainable by his *circumstances* (his mother's illness) rather than by his character.

In the next section, Joe continues the narrative by calling on the testimony of an 'expert witness' to back up his account.

135. suspect he's got over that critical period where he would have
136. regressed if he did go in

In his choice of Betty Dowsett¹³, Joe introduces the evidence of a notable authority within the field of medical research into M E. This effectively reinstates the credibility of medical science and again formulates a 'typical M E script' in comparison to their own case. The testimony constructs women in general as more vulnerable to illness because of their role in the family. Angela's case is constructed here as being just a typical example of a more general pattern that has been recognised by an expert. This scripting functions to exonerate Angela from any suggestion of individual weakness or personal responsibility, especially as this might relate to the question of why *she* and not Joe, should have been susceptible to the illness. This also supports the 'theory of M E' that is being built in the narrative, in which rest at the early stages is seen as crucial to better recovery. Angela has already given vivid details of her struggle to fulfill her role as mother, which they argue has been a contributory factor in her illness. Joe then uses the notion of a *critical period* to explain the difference in men's and women's experience of illness: "by the time a man goes back to work he's got over that critical period when he would have regressed if he did go in" (line 135). Susceptibility to illness is thus being linked with the different demands placed on men and women, rather than being an inherent female or personal weakness.

In his deployment of hearsay evidence (the friend who was mistreated by the hospital) and corroborative expert testimony (the microbiologist who is an M E expert), Joe has also made available the suggestion of a *divide* between two different medical points of view. The hospital is cited as treating an M E patient with *physiotherapy*, and the microbiologist is cited here by Joe as advocating *complete rest* from the outset of the illness. In this context, the hospital has been construed as incompetent and the microbiologist as expert. Thus, the seeds of confusion are made apparent in the tension between these two 'medical voices' each "demanding that we acknowledge it (.) with it's authority already fused to it" (Holquist 1981: 342). But here in the narrative, this division of the medical world into two contrary camps (which in this

¹³ Dr Betty Dowsett is both a microbiologist/researcher into the organic causes of M E (e.g. Dowsett *et al.* 1990), and a President of the M E Association.

case correspond to science and practice) works rhetorically to undermine the solidity of medical opinion. It cannot be considered an *ipso facto* guarantee of what is real or advisable and can therefore no longer provide a credible counter case to the one that Angela and Joe are constructing.

Introducing the psychosomatic version

In the next part of the narrative, Angela and Joe give an account of a crisis when Angela was first acutely ill.

- 163.Joe the doctor sent for the specialist (.) the actual consultant physician
 164. from (town) hospital came to the house (.) which was a bit unusual
 165. 'cause he usually sees people (.) and they did all sorts of tests (.) took
 166. blood tests and all sorts of examinations (.) they went in the bathroom
 167. and went sort of quiet (.) it was obvious they were testing for all sorts
 168. of (.) all the classic things like tumour on the brain (.) MS and various
 169. other things (.) weren't they? (.) which would have been (.) brought
 170. this on because her legs were definitely been very very weak and
 171. immobile (.) and then really it was a case of 'well that's really it
 172. y'know' (.) she used to go and see the doctor (.) as time went on his
 173. sympathy dropped away and it was a case of 'well [you should be
 174.Angela ['why aren't you
 175.Joe getting better by now']
 176.Angela getting better?' y'know]
 177.Joe = and that's when this attitude of ['oh (.) psychosomatic!']
 178.Angela [so 'oh I wonder if it's] all in the
 179. [mind?']
 180.Joe [yeah he] [said]
 181.MHS [did he] actually say that to you?
 182.Joe =he didn't say that to Angela (.) but he said it to me (.) [he was] going to
 183.MHS [did he?]
 184.Joe examine her and he asked her to go and get undressed (.) and while she
 185. was doing that he said to me (.) 'the m::ind's a funny thing you know!'
 186. I said 'it's nothing to do with the mind (.) it's physical' (.) but I mean
 187. he didn't see it

This extract does the same kind of rhetorical work as the deployment of Steven's 'eye-witness' testimony. However, in this case, the consultant's testimony is that of '*expert eye-witness*', drawing attention to the severity of the illness she suffered: "the actual consultant physician from (town) hospital came to the house (.) which was a bit unusual"(lines 163-4). This is given as evidence that the GP *must* have acknowledged the severity of Angela's illness at the outset, since consultants do not normally pay housecalls. Thus, it was not just Angela and Joe's opinion that she was seriously ill.

The narrative continues from lines 165-169, to describe how tests were done for various serious diseases, and at line 170, “well that’s really it” implies that the tests did not identify any clinical signs that might indicate an organic disease, and there was nothing more to be done. So the outcome after a while was that “the doctor (.) his sympathy dropped away and it was a case of ‘well you should be getting better by now’ (.) and that’s when this attitude of ‘oh (.) psychosomatic!’...” (lines 172-3). This part of the narrative works to introduce the controversial aspects of the status of her illness. Their parody of the GP’s ‘voice’, “this attitude of ‘oh (.) psychosomatic!’ ” sets up his response as stereotypical of the medical profession, and in order to distance themselves from it, they introduce a mocking tone. Joe recalls how the GP said to *him* “the m::ind’s a funny thing you know”.

There is considerable ambiguity in their use of this story. First, it backs up their claim that Angela was seriously ill but second, it introduces a competing psychosomatic explanation for the first time. To offset the challenge that this type of explanation represents for the case they are building, they are working to achieve two things by parodying the GP’s ‘voice’. First, they are exposing his lack of knowledge, since he cannot explain why she does not get better: “well that’s really it y’know”(lines 171-2). Second, they are ironising and thereby dismissing his use of ‘crude’ psychological explanations. The implication of line 177: “and that’s when this attitude of ‘oh (.) psychosomatic!’..” is that such explanations are *typically* used by doctors who fail to find any clinical evidence. At a later point in the narrative (in the next extract, below), the issue of disagreement between members of the medical profession is *again* raised, but unlike the earlier story of hospital incompetence, the hospital consultant is being given higher status for being open-minded or not voicing an ‘unwarranted’ and ‘discrediting’ psychiatric explanation: “to his credit (.) the consultant never did voice that thought” (line 198).

A very important aspect of this story is that the *whole* of the narrative *pivots* on a ‘breach of the implicit canonical script’ - which in this case is oriented to as the scientific biomedical explanation of illness. As pointed out earlier (in footnote 5) one

element of a well formed narrative is “a sensitivity to what is canonical and what violates canonicity in human interaction” (Bruner, 1990; 1991: White, 1980). In the Wittgensteinian sense, however, norms are something that people can appeal to as a resource to explain and justify (or legitimate) their actions and those of others. This means that in the context of an illness narrative such as Angela and Joe’s, the participants can *constitute* the sense of their own actions, and those of medical professionals, by reference to a set of rules or principles about the scientific status of medical knowledge and practice.

A breach of canonicity is therefore constituted here by Angela’s claim that, despite the tests being negative, she has been suffering from the effects of an organic disease. However, the ‘*voices*’ of the medical profession are also being deployed as inconsistent, confused and contradictory, and of course, the rhetorical force of the work that Angela and Joe do in the whole of this narrative rests on the implicit assumption that although there is much confusion between practitioners and experts, medicine *could* (at least theoretically) account for M E as an organic disease. It is therefore not only Angela and Joe’s persistent claim, but also the failure of medical practitioners that is being made relevant here as an accountable matter. In the case that Angela and Joe are building, there are two competing versions that have been made available in and through their account. In their preferred version, the breach of canonicity is constituted by the failure of medical practitioners to diagnose and treat her illness in the light of available knowledge about M E. This is positioned against the dispreferred version, which is that their own persistent claims about the organic nature of Angela’s illness constitute a breach because they are inconsistent with what is medically known about her case - the lack of positive clinical evidence to identify a medically recognisable disease.

The Character-Witness.

At this point in the narrative, the introduction of the suggestion that Angela might be suffering from a psychosomatic illness, has made available an alternative interpretation of events that could undermine the case that Angela and Joe are

building. In the next section of talk, Angela works to re-establish her credibility to the listener, since her very identity is at stake.

189. Angela I think my mother was around at one of these times when that was
190. mentioned too (.) my mother said 'I know my daughter' (.) I can always
191. remember my mother saying that (.) 'I know my daughter' (.) because I
192. was always so active heh heh hyperactive in some respects
193. actually (.) because my Mum used to say to me 'for goodness sake
194. Angela sit down' (.) this was before I went down with M E (.) I never
195. wanted to sit down (.) I wanted to be on the go all the while (.) I was
196. happy that way (.) but er (.) things change (.) you're forced to sit
197. down
198. Joe = to his credit (.) the consultant never did ever voice that thought
199. Angela = no (.) he didn't believe that

Here Angela tells a story using her mother's 'voice' to construct herself as being the kind of person who is unlikely to have a mental illness, or to be a malingerer: (189-190) "my mother was around at one of those times when that was mentioned too (.) my mother said 'I know my daughter'. She continues to qualify this by supplying the details of what her mother knows, so that her mother's 'voice' is heard to sound within her own.¹⁴ But there is also a rhetorical danger in the use of her mother as a character-witness. Although she knows her daughter well, she can also be dismissed as biased. Furthermore, the mother's statement (lines 190-191) is quoted as a retort to a damaging accusation made by the doctor, and this context threatens to weaken the status of her claims as an independent witness. These tensions are managed at lines 193-4, by also quoting what the mother used to say *prior* to the illness, before there was a need for her to defend her daughter. The way that the pre- M E story is formulated as a direct speech quotation, which constructs the *opposite* of her current M E state rather than just its *absence*, neatly performs that function.

In this section of talk, the links between scripts, attributions and dispositions are made clear. Script formulations (that were applied earlier in the narrative to the construction of Angela's illness as conforming to a typical M E script) can also be used to construct one's own, or other people's identities in particular ways. People's actions can be scripted as being *in* or *out* of character as the kind of actions they are likely or unlikely

¹⁴ The discursive function of 'stylisation' is discussed in Morson & Emerson (1990:149) with reference to the work of Mikhail Bakhtin. "The styliser adopts the discourse of an earlier speaker or writer whose way of speaking is regarded as essentially correct and in accord with the task to be accomplished."

to perform (for example, the scripting of Steven's bad behaviour as out of character). In the context of narrative accounts, this scripting accomplishes rhetorical business that attends to issues of blame and accountability. This can be further illustrated with reference to the following extract from the illness narrative of a person who suffers from multiple sclerosis:

I used to enjoy dancing, gardening and general 'busyness'. I now sit down all day either in a chair, wheelchair or motor car and I am fed up with having to ask people to do things for me and pass things to me... (Robinson, 1990: 1183)

This example resonates with the account that Angela has provided, above (using her mother as witness) and earlier (lines 98-103) where Angela gives an account of her struggle to do her household chores. Even Joe's earlier remarks about "one of our sessions" at the swimming baths (line 32), feed into the normative image of Angela as a naturally active person.

In narratives of biographical disruption (such as Angela's, and the example from Robinson's study) what is at stake for the person telling the story is what Charmaz has referred to as a "fundamental loss of self". She expresses this idea as follows:

Over time many debilitated chronically ill persons become dependent and immobilised. As they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and their futures, affected individuals commonly lose not only self-esteem, but even self-identity. Hence suffering such losses results in a diminished self. (Charmaz, 1983: 168-195)

However, rather than making *inferences* from such narratives in the way that Charmaz's account suggests, my analysis has looked at the way that people draw on the notion of identity interactively as a *resource* to manage their own accountability for telling tales of an increasingly restricted and dependent existence. In the context of a narrative of biographical disruption, such as an M E narrative or an MS narrative, the personal narrative is hearable as a way that the narrator can *script* herself as being a particular kind of person- one who would not *normally* choose to live a restricted existence: "I *used* to enjoy dancing [...] I *now* sit down all day..." (Robinson, 1990: 1183). This is similarly represented in Angela's account: "I never wanted to sit down (.) I wanted to be on the go all the while" (lines 194-5). Thus, the 'sitting down all day' is constructed here as *deviating* from the normal routine of life before M S (or M E). This effectively manages the dilemmatics where "illness talk carries with it the

threat that one might be seen as a potential malingerer or even a habitual complainer” (Radley and Billig, 1994).¹⁵

Challenging the Canonical Script.

- 199.Joe as time went on he saw her (.) he basically gave (.) he couldn't give
 200. an answer (.) you begin then to sort of search around for other
 201. things (.) we went to a herbalist in (city) (.) we went (.) eventually after
 202. three years we went to the Royal Homeopathic Hospital (.) but before
 203. that (.) it was after about eighteen months (.) two years having been to
 204. the herbalist (.) I'd picked up and read it (.) and there was a disease
 205. called 'myasthenia gravis' which sounded very very much like this
 206. (.) I was trying to get a name (.) find out what it was (.) and we went to
 207. see the consultant again after about two years (.) and er well again (.)
 208. she was getting undressed and this is the (.) this is the expert (.) he said
 209. 'what do you think she's had?' (.) what did I ! (.) so obviously he must
 210. have thought 'well (.) he must have thought about it and read about it'
 211. (.) so I said 'I think she's either had polio and got over it because she's
 212. had the polio jabs (.) innocations (.) 'no (.) it wasn't polio' he said
 213. 'it wasn't polio' (.) I think he was a bit out on that because it's since
 214. been discovered that the M E virus is very similar to polio (.) so
 215.MHS = did they test for polio?
 216. (.)
 217.Joe well presumably all the tests they did (.) presumably that's what they
 218. were (.) yeah

After Angela has dismissed any suggestion of malingering and re-established her credibility using a character-witness, Joe then continues with her defence by dismissing the consultant as being unable to supply an answer, and describing how they turned to alternative medicine for help. The temporal sequencing of events is important here because it implicates a cause and effect story which justifies their actions in eventually consulting alternative medicine. A damaging counter argument to their case might be that Angela and Joe are the kind of people who have no respect for conventional medicine and readily resort to fringe alternatives. However, their challenge to the 'canonical script' is formulated here as a justifiable consequence of the consultant's failure to supply an answer after *three* years had passed.

¹⁵ See also chapter five, above, for an analysis of how participants formulate the category of "active go-ahead people" as a valourised account that works to counter any possible suggestion that they are malingerers or 'couch potatoes'. This constructs their dispositional tendencies as being counter to the conditions of their illness.

Joe gives an account of events that took place when they returned from the Royal Homeopathic Hospital to see the local hospital consultant. He deploys a biomedical repertoire ambiguously to construe the consultant as lacking in expertise and to display himself as someone knowledgeable who has read widely in an attempt to understand his wife's illness. At lines 208-9, Joe uses parody to ironise the consultant's lack of expertise, "this is the expert (.) he said 'what do you think she's had?' (.) what did I !"

The doctor's 'voice', requesting Joe's opinion, functions to undermine the consultant who has no answers and also *warrants* the giving of Joe's opinion, thereby placing Joe on a par with the consultant in this context, thus lending greater status to Joe's opinion as a truth claim. This piece of reconstructed dialogue again raises the question of what constitutes a breach of canonicity. In this context the consultant's entitlement to expert knowledge is being challenged, but as Joe's ironisation would indicate, not to the extent that this undermines the *whole* of medical expertise.

Given that Angela and Joe's case is that Angela suffers from an organic medical condition, for the point of the narrative to be successful medical knowledge and expertise *must* be finally reinstated and made available to legitimate their case.

The important narrative function of this account of their consultations with the Royal Homeopathic Hospital is that the retrospective (if tentative) diagnosis of viral encephalitis fits in with and legitimates the ‘theory of M E’ that they are now building. It is formulated as a kind of contradiction (reality disjuncture) that is resolved within the narrative. This is reconstructed at line 246-7, “we used to say ‘someone in this country must know what you’ve got’”, and provides further justification for going over their doctor’s head. More importantly it functions, in the trajectory of the narrative, to resolve the tension inherent in the simultaneous deployment of two versions of reality (represented by empiricist and contingent repertoires), both of which are central to the rhetorical success of the narrative.

They have drawn on a scientific biomedical account to explicate a ‘theory of M E’ as an organic disease. But part of *doing* that, within the narrative, has been to manage the threat to their account occasioned by the failure of scientific tests to identify any observable clinical signs that would explain Angela’s illness in organic terms. So whilst Angela and Joe have been able to provide a causal *story* within the narrative for a physical illness, there are no scientifically *solid* grounds for Angela’s illness being *clinically* defined as organic.

They have dealt with this ambiguity ongoingly by challenging the authority of medical knowledge and expertise, in the shape of their local GP and hospital consultant; but this in turn to some extent threatens to undermine the status of any claims they might make about Angela’s illness having been *medically* legitimated. How *can* the medical profession legitimate her illness if they have been constructed as lacking in appropriate knowledge and expertise? Thus, the ‘canonical script’ of scientific biomedical expertise, which has previously been undermined by the use of a contingent repertoire, is also *essential* to the medical legitimation of Angela’s illness *and* the case they are building.

At this point in the narrative, this contradiction is *partially* resolved by something that resembles a ‘Truth Will Out’ device¹⁶: “someone in this country must know what you’ve got”, and also by the suggestion of the two doctors at the Royal Homeopathic Hospital that she might have had viral encephalitis. An important aspect of how the contradiction gets managed is the suggestion that there must be *someone* in the medical profession, who possesses sufficient knowledge to diagnose Angela’s condition. So the knowledge or truth about M E is itself assumed as *given*, whilst the different members of the medical profession are constructed as being *variable* in expertise and knowledge. In other words ‘truth will out’ if we can only find *someone* who has sufficient expertise.¹⁷

The *tentative* nature of the diagnosis is further bolstered by Joe’s account of Angela’s illness experience, which meshes with the doctor’s assertion at line 236 that: “you’re lucky to be alive”. So at lines 236-8 Angela’s case can be identified as an example of that: “and looking back (.) it is like (...) you felt you were going to die”. The interweaving of the doctor’s and Joe’s references to the respective severity of viral encephalitis and Angela’s illness, followed by the linking of this with “this new thing called M E (.) myalgic encephalomyelitis” (line 242), constructs some solid grounds for the legitimacy of Angela’s illness as a real, physical disease, which was even potentially life threatening. The remarks that construct Angela’s illness as life threatening, (lines 236-238) also work to confirm the validity of medical diagnostics. As Joe points out - they were right “you felt you were going to die”(line 238). This manages the extent to which medical expertise has been challenged, such that it can still be held accountable for a ‘proper’ diagnosis. It is within the *interactional* context of the management of this contradiction that the participants’ talk about M E is itself constituted.¹⁸

¹⁶ The ‘Truth Will Out’ device (Gilbert & Mulkay, 1984) has been explicated earlier in chapter one, above.

¹⁷ As a device, this is rather similar to the way that medical scientists have appealed to a more sophisticated explanatory model to resolve the reality disjuncture constituted in and through the ‘M E controversy’, referred to in chapter two, above.

¹⁸ This mirrors a claim I made in chapter five, above, where I argued that the definition of M E is itself a product of the interactional dynamics within which the struggle for authorship takes place. In chapter five, the context was a dialogue, where participants managed the potential for misalignment and confrontation in the activity of defining the meaning of their illness and the implications of different versions for personal accountability.

‘Labels and Things’ revisited.

This point in the trajectory of the narrative (lines 240-2), is indexed as the point at which Angela and Joe “began to think that ‘well there’s some sort of a name to this peculiar disease’”. This is emphasised by Angela’s repetition of what Joe has said: “someone was putting a name to it at last”(lines 244-5). Implicit in their formulation is the notion that something does not properly exist unless it has a *name*, or that by giving it a name one recognises it as being a medical disease entity and that confers a more objective reality.¹⁹ But also they are implicitly suggesting that scientific biomedical techniques had previously simply *failed* to identify the disease, which was *there* all along, waiting to be discovered.

The controversial issue of the *name* now occasions an account of how Angela and Joe suffered *before* they had a name for the illness. Accounting for ‘self’ to others is bound up with one’s right to be sick, in terms of what is acceptable as a *genuine* or *false* claim to illness. In this case, the right to be sick is being related to the existence of M E as a ‘real’ disease entity: (248-9) “but in the meantime before that we got so much disbelief (.) I mean you lose friends”. This is oriented to later on in the narrative:

258. Angela and I think one or two
259. (2.0)
260. Angela probably thought ‘it’s all in my mind (.) it’s all in my mind’ (.) they
261. become almost frightened of it..

This theme recurs frequently in M E narratives, and again relates to the ‘pivotal theme’ of legitimacy and a ‘breach of the canonical script’. In this context, Angela is orienting to the biomedical explanation as if it had a greater power to define what counts as a legitimate claim to illness, and also to a narrative concern with having to persuade others (including the interviewer) that her illness is ‘real’, and has a name and a biomedical, scientific explanation.

¹⁹ See chapter three, above, for a further analysis of participant’s discourse about labels.

Gergen and Gergen (1986) have pointed out that narrative construction is never a private matter. The narrator needs to persuade the listener of the veracity of the narrative, and the maintenance of a given narrative depends on the teller's ability to negotiate with others about the meaning of events. Active negotiation, or challenges, are especially likely in circumstances where the narrator's actions depart from common frames of understanding (or at least those that are constituted as such within the narrative). However, the narrator typically avoids having to negotiate such 'breaches', by taking prior account of potential criticisms (such as illness that is not socially or medically sanctioned) or competing explanations (Billig, 1987) such as for example, 'all in the mind' accounts of illness.

Getting it on her Records/ Legitimizing the Illness.

303.Joe one day she (just gave) up (.) her legs just wouldn't take her
 304. round there (.) and that was sort of in eighty nine I suppose (.) and I
 305. don't think her mother really [understood]
 306.Angela [it caught up] with me in the end (.) it
 307. was the [lack of]
 308.Joe [she had] a regression (.) that was when we realised that you
 309. could actually get this
 310.Angela = it was the first time I had a relapse actually (.) and I didn't even
 311. know that you could relapse (.) that's why I thought 'oh it's alright as
 312. long as I'm [sat' and]
 313.Joe [but at that] point we joined the M E Association and got
 314. alot of information about it and found that yes you can relapse (.) it
 315. was at that point we decided (.) having got different doctors (.) at least
 316. two who she felt were sympathetic (.) we thought it was about time we
 317. laid this on the line and got this thing out into the open and got it on
 318. her records (.) so when we went to see Doctor Wilson who was a
 319. man (.) the other one Doctor Hill was a lady but she's very
 320. sympathetic (.) we saw Wilson and went in and basically said to him
 321. 'look (.) do you recognise and accept the condition known as myalgic
 322. encephalomyelitis (.) and does the practice?' (.) to which he replied 'I
 323. can't speak for the practice but I do' (.) and then he made a confession
 324. which I thought was appalling for a doctor to say 'but what I know
 325. about M E is only what I've read in women's magazines'
 326. (2.0)
 327.Joe he got out her records which were about this thick by then (.) and went
 328. through and eventually found a letter from this hospital consultant
 329. dated ten years previously in which he talked about all the visits
 330. we (.) Angela had had with him (.) he went through it and he
 331. talked about (.) encephalitis cropped up again (.) not myalgic (.)

332. because I don't think even he knew (.) in the end (.) Doctor Wilson
 333. (.) having gone through all the things and talked to us both about the
 334. symptoms and said 'yeah (.) you've got the classic symptoms' he said
 335. 'definitely M E you've got because it started with a virus (.) most
 336. people who come just say "don't feel well (.) tired" but you've had it
 337. all these years' (.) so it's on her records she's got M E and that's great
 338. that it's recognised by the doctor

Angela's relapse is represented here in the narrative as a crisis which prompted them to get an 'official' diagnosis from orthodox medicine. Past events are here again being reconstructed and interpreted in terms of current knowledge: (313-18) "at that point we joined the M E Association and got alot of information about it and found out yes you can relapse (.) it was at that point we decided (.) we thought it was about time we laid this on the line and got this thing out in the open and on her records". The implication here is that the medical profession had so far avoided making an official diagnosis, and that Angela and Joe now wanted Angela's illness *named* as M E by her own GP who could confer legitimate status by recording it on her notes. Getting it 'on her records' is different from just giving it a name and recognising its existence. It makes it part of her medical biography, that can be referred back to in the future as an official written history. This can be contrasted with a tentative opinion or deniable diagnosis, such as the one provided by the Royal Homeopathic Hospital earlier in the narrative.

At lines 321-322, Joe describes how he confronted the doctor, "we went in and basically said to him 'do you recognise and accept the condition known as myalgic encephalomyelitis..and does the practice?'"'. In posing this question Joe makes relevant the suggestion that there are controversial aspects of M E and also displays an awareness of medical scepticism.

A Witness for the Defence?

The previous story of how the GP came to diagnose M E sixteen years after the onset of Angela's illness has elements of a confrontation: (lines 316-7) " we thought it was about time we laid it on the line". But it also functions to set up the GP as a 'witness for the defence' who confirms the diagnosis of M E: "yeah, you've got the classic symptoms (.) definitely M E you've got (.) so it's on her records she's got M E and

that's great it's recognised by a doctor". However, it is paradoxical that Angela's M E has been recognised by a doctor who has already shocked them by his ignorance: "he made a confession which I thought was appalling for a doctor (.) 'but what I know about M E is only what I've read in women's magazines' ". Thus, the doctor's testimony functions ambiguously both to support their 'case for the defence', and also again to discredit the medical profession on the grounds of ignorance. The problem with this is that the epistemological warrant of medical practioners is again at stake in Angela and Joe's account. This is reminiscent of the earlier part of Joe's account (line 207) where the hospital consultant was construed as being unable to make a diagnosis: "this is the expert (.) he said 'what do you think she's had ?'"

'The M E Bandwagon.'

The next short observation by Angela functions both to bolster the reality of her illness, and also to soften the criticism of the medical profession that Joe delivered earlier.

336.Angela I can understand the dilemma the doctors are in at the moment though
 337. because I think there's alot of people jumping on the M E
 338. bandwagon (.) they get a bit of fatigue and tiredness
 339.MHS = yeah
 340.Angela = they've got M E (.) y'know it's so ridiculous (.) I can understand
 341. the doctors being a bit edgy over it

First, Angela concedes the problems that doctors have in making a definite diagnosis of M E, and second, she goes on to make a category distinction between people who make false claims, and thus implicitly, people like herself who are really sick. She is here arguing that an inherently problematic diagnosis is *further* complicated by people who make trivial claims to illness by jumping on "the M E bandwagon" if "they get a bit of fatigue and tiredness" (lines 337-8). The term 'bandwagon' is suggestive of a more *general* level of misunderstanding of M E by the public who might think that ME is just "a bit of fatigue". Angela's comment here works to inform us that genuine cases of M E are *more* than that, but that in view of this ambiguity it is perfectly understandable why doctors should need to separate the 'sheep from the goats'. This neatly functions to limit the scope of medical scepticism so as not to extend to cases such as her own.

A 'Before and After' Story.

- 480.Joe mm (.) it has had (.) 'cause it's altered my way of life really (.) I feel at
 481. times frustrated y'know (.) after all this time (.) frustrated (.) I suppose
 482. you could say 'yes we could go out and have a walk' but er (.) you feel
 483. there's things to be done perhaps (.) but you get out of the habit of
 484. doing that [anyway]
 485.Angela [because]we did it together you see (.) 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 in to 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 (.) so it affects the other
 495. one as well
 496.MHS = quite disruptive then really
 497.Angela = and of course I'll tell you how it does affect you very badly (.) er
 498. with me with having it (.) it's the grandchildren (.) now it's repeating
 499. itself because I can't play with them and my arms at the moment are so
 500. weak I can't even lift the baby d'you know?
 501.Joe = well we (.) the [only]
 502.Angela [which] is awful

At lines 480-84, Joe begins an account of how Angela's illness has affected *him* as her husband and carer, and how it has restricted his lifestyle. At line 485 Angela intervenes to provide corroborative details of the vigorous outdoor leisure activities they used to enjoy. This is made relevant as a contrast to the sedentary lifestyle they are now forced to accept because of Angela's M E.²⁰

This 'before and after' story, corroborated earlier (page 187) by Angela's account of her mother's character-witness testimony, works rhetorically in the narrative to manage the 'double-jeopardy' of illness talk.²¹ In any kind of talk about illness one risks being construed as the type of person who is looking for secondary gain. This kind of construal is a particular threat to an illness narrative in which the legitimacy of

²⁰ This account resonates with other narratives that people have told, both in *this* study and also in others (see for example, Robinson, 1990: 1183), about active/hectic lifestyles prior to the onset of their illness, as a contrast to the restricted lives they are forced to live when they have M E. For a more comprehensive analysis of this kind of data, see chapter seven, below.

²¹ The notion of the 'double-jeopardy' of illness talk is explicated in Billig & Radley (1996).

the illness is itself 'at stake'. The account orients to, and works against, alternative explanations that it is a 'self-serving' illness, or that Angela is malingering or making some kind of trivial claim to illness (like the people she earlier described who jump on 'the M E bandwagon'). Her account counters such motive explanations by working up as *prior* to the illness, an active 'self' who was not the type to enjoy or wish for a sedentary lifestyle (lines 485-95). She formulates the *consequence* of her illness as being now *deprived* of the things that are most enjoyable to her: their physical sports and leisure activities as a couple, and (at lines 497-502), her relationship with her grandchildren. Her account constructs the implicit rhetorical question: What *possible* motive could she have to give up all the things that would make her life more enjoyable?

Summing up.

In my case study of Angela and Joe's illness narrative, I have used a courtroom metaphor as a framework to organise my analysis. This was not merely to impose an analyst's gloss, but rather to recognise a set of discursive phenomena that are demonstrably participant's concerns in the data. Examples of these are the joint construction of consensus, the use of corroborating 'witness' accounts, and the undermining of 'hostile' witnesses, that are common to both courtroom and ordinary talk. These, and such devices as script formulations, work to construct the factuality of the account and to establish their 'theory of M E' and the identity of the sufferer.

In chapter three (above), names were argued to be not *merely* descriptive but also implicative of causal attributions. So also in Angela and Joe's account, narrative descriptions and attributions of cause, or blame and responsibility, are inextricably linked together. In other words, the narrators' authorship of identity and the events and meaning of the illness are linked together in this co-implicative, action performative way. Angela and Joe's story, like all other illness narratives, cannot be taken as a *mere* description of their experiences (as with 'type 1' analysis), or even as a route to finding out something about their internal psychology, (as with 'type 2' analysis). Instead the account that they have constructed has been analysed as an occasioned production, which performs interactional business in the telling, thereby attending to dilemmas of stake in building the factuality of their case. Angela and Joe's narrative can be seen as functioning rhetorically in a way that constructs M E as

a physical disease entity, and Angela as it's victim. The legitimacy of Angela's claim to physical illness has been 'defended' by 'building up a case' in which a particular 'theory of M E.' has been jointly constructed, and supported by credible witnesses. This 'testimony' has been constructed in a way that dismisses alternative explanations that Angela's illness might be psychosomatic or merely functional. These are the very issues that are 'at stake' for Angela and Joe. The charges of ignorance and lack of consensus against the medical profession function here in the narrative to reduce the discursive force of medical scepticism about Angela's illness. However, the legitimacy of medical science *itself* is one of the *central* issues that is 'at stake' in Angela and Joe's narrative, functioning both to undermine and support their case. One of the most sensitive things about the construction of the narrative, is their management of the simultaneous breach and reinforcement of 'the canonical script' of medical science. Within the narrative, Angela and Joe (like Gilbert & Mulkay's biochemists) are deploying two kinds of repertoire in their story of her illness, their encounters with the medical profession, and the diagnosis of M E. First, they deploy an empiricist repertoire to establish her illness as physical and real- a position that is underwritten by 'expert' medical research. This account is positioned rhetorically in the narrative against a competing psychosomatic explanation for her illness. But the doctors who make such claims are formulated here, in terms of a contingent repertoire, as ignorant, lacking in expertise, yet to learn the medical truth, or understandably misled by patients who make false claims. Their criticism of the medical profession has carried with it the rhetorical risk that the credibility of medical opinion might be so far undermined, to the extent that they could no longer use it as a resource to legitimate Angela's illness. In their use of empiricist and contingent repertoires, and the management of such contradiction, it is ultimately not medical science *itself* that is undermined, but only *some* of its practitioners. The next chapter goes on to analyse doctors' case narratives about their patients, and compares these with patients' stories about their illnesses. Rather than making contrasts between lay and professional accounts, I shall demonstrate how doctors' case narratives can be analysed in the same way as patients' illness narratives, especially in constructing claims about the nature of illness and the identity of sufferers.

CHAPTER SEVEN

Doctors' Cases: Patients' Stories.

The psychosocial repertoire as a flexible resource.

In the previous chapter I took a discursive psychology approach to the analysis of an illness narrative¹. My concern was to explore how people construct narratives that give rhetorical support to the legitimacy of their claim to illness². Angela and Joe's story was shown to be constructed in ways that 'built up a case' to defend the legitimacy of Angela's illness as both 'real' and organic, and was positioned rhetorically against possible alternative (psychosomatic) attributions.

In this chapter I shall analyse the way that doctors' talk about individual patients similarly functions as discursive action. Earlier (in chapter four) I described two different models of medicine, the biomedical, and the biopsychosocial, which I reformulated as culturally available interpretative repertoires that can be deployed as a discursive resource, rather than being cognitive/schematic models that guide doctors' reasoning and diagnostic practices. I argued that these repertoires can be deployed by both professional and lay people alike in constructing claims about the nature of illness, the identity of its sufferers, and the skills of medical practitioners to diagnose, treat, heal, and advise.

My analysis of Angela and Joe's story (in chapter six) showed how psychosocial information and a biomedical 'theory of M E' had been woven together in a co-implicative way to produce a particular version of the events of the illness and the identity of the sufferer. The psychosocial repertoire functioned rhetorically in *their* account to *warrant* the construction of a biomedical explanation for Angela's illness and their *dismissal* of a psychogenic one. I shall continue along the lines that doctors' case narratives about their diagnostic practices can be analysed in the same way as patients' stories about their illnesses.

¹ A "discursive action model" is outlined in Edwards & Potter (1992: 154).

² This specifically relates to an illness narrative in the context of an interview on the topic of M E, which is a controversial category. However the principles of such analysis could be applied to *any* kind of account or description.

Doctors' talk in medical contexts has previously been analysed by writers and theorists such as Montgomery Hunter (1991), and Atkinson (1995). Hunter claims that in the everyday practice of medicine, a "diagnostic circle" (*ibid*: 9) operates which resembles the 'hermeneutic circle' described by Dilthey (1972) as the process of reasoning from part to whole to part again. This is said to be characteristic of the way that texts are interpreted by readers. Hunter claims that medicine's way of determining the 'facts' of a case and making sense of them is similar to Glaser and Strauss' (1967) method of 'the discovery of grounded theory', in which theory is drawn from the data as it is collected, and the emerging hypothesis directs the further collection of data.³

From Hunter's view, the goal of medical investigation is to find a *narrative* explanation for the patient's problems. She describes how physicians who are presenting papers at medical seminars typically begin with a narrative of a single case that first inspired their interest, "there was this one guy" (*ibid*: xii). She claims that medicine is *fundamentally* narrative. Patients' stories are 'pared-down' autobiographical accounts of the events of their illness and commonsense aetiology that are taken by physicians and reformulated into medical information before returning them to their patients as diagnoses⁴. Patients are likened to 'texts' to be examined and 'read' by physicians, such that the 'plot' of the illness is located by the physician in a taxonomy of similar narrative cases. The patient's formulation of his/her story is construed as the preliminary 'reading' of the illness, and the physician, like a literary critic, is said to arrive at the 'text' laden with theory, assumptions, and hypotheses. To take the literary metaphor a step further, the 'patient as text' can be 'read' in terms of the author's past, life events, lifestyle, diet, personal disposition and

³ One objection to this formulation of the diagnostic process in terms of grounded theory, would be that the analytic categories are, in this instance, prefigured by medicine's catalogue of diseases and treatments, rather than each individual doctor developing his/her own categories inductively from the data.

⁴ Hunter points out (*ibid*: 13) that the doctor's reformulation of the patient's story might be unrecognisable to the patient as a version of their own story. In the context of a contestable illness such as M E, the doctor and patient can draw on various kinds of explanatory repertoires to construct different and possibly competing interpretations of the illness. This is manifest as a 'reality disjuncture' of the type described by Laing (1967) and Pollner (1987) and I referred to in chapter three on 'Labels'. Hunter construes such possible tensions between doctors and patients in terms of a *struggle* for the interpretation of life events - a "silent tug of war" (*ibid*: 13) over the authorship of the story of the illness. (For further analysis of this 'struggle for authorship', see also chapters five and six.)

habits etcetera, and the story can also be compared with ‘earlier works by the same author’ to look for common themes. Medical interpretation then creates a ‘metastory’ of the illness, which is authored by the doctor from a reformulation of the events of the patient’s narrative, observation of clinical or physical signs, and the history and events of the illness.

The point of Hunter’s metaphor is to make the claim that although the notion of scientific rationality has become central to our ideas about medical knowledge, medicine has an essentially *narrative* structure and can be thought of as a fundamentally *interpretative* activity⁵. Atkinson makes a similar point in reference to case presentations in the context of weekly ward conferences in a hospital setting.

Narrative is not confined to the interpretative methods of lay people in their construction of illness experience...Disease is accomplished through narrative as well. Most importantly, it is precisely the narrative that establishes the story *as a case*. For a story to count as a case, it is not merely a listing of signs, symptoms and test results. The narrative provides a framework within which that story takes shape; it furnishes sequence and consequence for the recounted phenomena, it constricts the case as a topic of medical discourse, and establishes the parameters of what is noteworthy. (Atkinson. 1995: 108-9)

From the analytic viewpoint of discursive psychology (with its roots in ethnomethodology), medical reasoning, or accounting can be seen primarily as a *constructive* activity in the same way as the illness narrative I analysed in chapter six. In terms of ethnomethodology, Hunter’s notion of a “diagnostic circle” (and also Dilthey’s notion of a ‘hermeneutic circle’, and Glaser and Strauss’ method of ‘the discovery of grounded theory’⁶) can be reformulated as examples of the ‘documentary method’⁷ in which: “Not only is the underlying pattern derived from its individual documentary evidences, but the individual documentary evidences, in their turn, are

⁵ See Bruner’s distinction between two types of thought/language; narrative and paradigmatic, where paradigmatic thought/language refers to scientific or philosophical discourse which is abstract, generalised and logical, and the narrative mode is described in terms of literary fiction and ideal types. Bruner draws a dichotomy between “two modes of cognitive functioning, two modes of thought, each providing distinct ways of ordering experience” (Bruner, 1986: 11).

⁶ Dilthey’s (1972) ‘hermeneutic circle’ can be reinterpreted as an example of the way that theorists have taken member’s mundane reasoning practices, and worked them up into a type of social scientific methodological construct like ‘the discovery of grounded theory’ (Glaser & Strauss, 1967).

⁷ Garfinkel (1967) derived the term from Mannheim who proposed that the documentary method involves the search for “an identical homologous pattern underlying a vast variety of totally different realisations of meaning” (Mannheim cited in Garfinkel, 1967c:78). Garfinkel elaborated this as “the method consists of treating an actual appearance as the ‘document of’, as ‘pointing to’, as ‘standing on behalf of’ a presupposed underlying pattern” (*ibid*).

interpreted on the basis of ‘what is known’ about the underlying pattern. Each is used to elaborate the other”(Garfinkel, 1967c: 78). As this rationale applies to medical reasoning, the details of the single case fit the diagnostic theory, and the theory is further evidenced by the phenomena of the case, for example, clinical signs, medical history, events, personal disposition etcetera.

The processes of the ‘documentary method’ were explicated in my analysis of Angela and Joe’s narrative, where the blending of the narrative details of Angela’s illness with the ‘classic illness script’ is co-constitutive- each serving to bolster the solidity of the other. On page 177 (chapter six) Angela’s illness is constructed as being a typical example of a more general pattern that has been recognised as a physical condition by an expert research microbiologist. ‘Documentary evidences’ of the details of Angela’s illness are constructed as instances that point to an underlying pattern of a recognisable medical condition, and instructions are provided in the text that lead the reader to a particular conclusion about the evidence provided. However, within the narrative, Angela and Joe reflexively attend to the possibility that if the same ‘documentary evidences’ were given a different emphasis and significance, they could combine to form a different underlying pattern. They do this, for example, on pages 184-5 (chapter six) where they give an account of how the ‘psychosomatic version’ was introduced by the medical profession as an alternative explanation for Angela’s illness. This is the alternative against which their whole account is rhetorically positioned.⁸

Smith (1978) has shown how versions and their documentary evidences are worked up in her analysis of how a young student came to be defined by her friends as mentally ill. In the narrator’s account, the co-constitutive processes of the ‘documentary

⁸ Without the analytic stance of discursive psychology, which attends to the “rhetorico-responsive” nature of discourse, the documentary method is typically interpreted by analysts as ‘perceptual sense-making’. In other words, the (level two) analyst is likely to take the narrative as being evidence of how the participants *actually* make (cognitive) sense of their illness experience in the context of their social world. This type of analysis leads to claims being made about people’s health beliefs and illness attributions, which ignores the interesting complex, rhetorical, constructive work that goes into the telling of narrative, and can also be the basis for certain kinds of ‘therapeutic’ interventions which seek to encourage people to change their ‘inappropriate’ cognitions and ‘re-invent’ themselves by telling a ‘better’ story.

method' work to construct the factuality of the claim that 'K is mentally ill'. Smith points out how initially the narrator's account could be read for the 'mental illness effect' in such a way that any possible alternative account was hardly discernible to the reader. But like the 'figure-ground' effect of visual illusions⁹, she was later able to impute a different interpretation and significance to the cited instances of K's 'mentally ill type behaviour', and reformulate them as part of a "communal freezing-out process"¹⁰ in which K's behaviour was being formulated as anomalous¹¹ when contrasted with the norms of a social reality that is being defined *in situ* by the narrator of events.

Smith's analysis of the constructive processes involved in building the account of 'K as mentally ill', works to emphasise the notion that social reality itself is a discursive accomplishment. A feature of *any* description of events is that it 'could have been otherwise' (Edwards & Potter, 1992; Edwards, 1997) and that in any description there is constructive work going on that functions to accomplish some kind of business. There are two senses in which alternative versions of social reality might be relevant. The first is where the analyst might be able to *imagine* how an account could have been different. The second (and more empirically tractable) is where the participants themselves *attend* to those alternatives and the possibility of denial, in the way that they talk.

What follows in the rest of this chapter attends to the latter as a participants' concern, and also analyses how the co-constitutive processes of the documentary method work in a similar way in both doctors' case narratives and patients' stories. I am particularly interested in the use of the psychosocial repertoire and how this functions as a flexible resource in doctors' and patients' mundane reasoning practices, in the context of talk about M E. More specifically I am interested in the way that 'documentary evidence' of a psychosocial nature, and the underlying pattern that it points to, are aligned

⁹ A frequently quoted figure/ground visual illusion is Rubin's vase (Rubin, 1915; Fig. 9.9.) which can be seen as either a vase or two profiles, depending on what is taken as the figure and what is backgrounded.

¹⁰ This process was described by Lemert (1962) in an article entitled, "Paranoia and the Dynamics of Exclusion".

¹¹ Anomalous behaviour is described by Smith (1978) as behaviour for which no rule or set of instructions can be found.

together in a co-implicative way that functions to make a particular interpretation of the patient's illness available whilst dismissing other possible kinds of explanation.

My analysis focuses on three kinds of participants' concerns that are common in the case narratives of doctors and in the illness narratives of patients. These are: 'before and after stories', a concern with 'where the story starts', and the process of categorising people as mentally or physically ill.

'Before and After Stories'

The first part of my analysis focuses on doctors' and patients' use of 'before and after stories', in which a contrast is worked up between the patient's lifestyle and activities before and after the onset of illness. The first three extracts are here compared with one another to see how Dr Evans, Dr Brown and Dr Butler formulate their grounds for categorising the patient's illness as physical or psychological.

Extract 1. (MHS/Dr.Evans/ 24-46)

1. MHS yeah (.) can you describe a particular case that you had ?
2. (.)
3. Dr Evans ri:ght er (.) that's why I was going to get these notes out (.) probably
4. the (.) I mean one that I see quite a bit of is (.) a girl of about (.) or girl
5. as she first was (.) she was probably late teens (.) nineteen twenty when
6. she first started with it and she's now about twenty four twenty
7. five (.) I'm sure she's been coming to see me as long as I've been in
8. the practice (.) er (.) and hers did- she was a (.) fit (.) sort of active
9. young lady when she- before she had it (.) working in a shop in town
10. as a dress sales woman (.) that sort of thing (.) er (.) well dressed and
11. sort of always going out and about
- 12.MHS = how old would she be?
- 13.Dr Evans = she'd be late teens (.) very early twenties I think (.) when she first
14. started with it (.) very outgoing and everything (.) she had a definite
15. (.) recognisable viral illness (.) er I think she actually had positive
16. monospot¹² at the time (.) for glandular fe:ver (.) or at least she had
17. some- a blood picture that suggested viral illness (.) at the time (.)
18. and then really also at that time (.) she had a lot of (.) pain in the upper
19. right hand side of her abdomen (.) which (.) everyone was thinking was
20. either gallstones or some liver problem (.) or (.) in the end turned out to
21. be inflammation of the rib cartilages I think and she had them injected
22. and all this sort of thing (.) but around about that time when she got the

¹² A 'monospot' is a blood test for infectious mononucleosis which indicates the presence of the glandular fever virus.

23. initial painful illness (.) she also had a viral picture which er (.) seemed
24. to go along with that (.) and then ever since then she ha:s (.) been a
25. different person really

First, at lines 4-7, Dr Evans gives a description of his patient in which she is identified as a familiar case: “one that I see quite a bit of”, which displays his entitlement to speak with some authority about the patient. His description of the patient at lines 4-11 formulates a detailed identity ascription which makes available some information about her, the length of time she has been ill, and what kind of a person she was *before* her illness. This constructs a scenario in which a fit, active, outgoing, teenage girl who is smart and hard working is suddenly laid low by a viral illness.

The inclusion of such ‘scene setting’ detail has a crucial bearing on the kinds of actions that the narrative performs (Edwards, 1997: 264). The account functions as *more* than just a neutral display of information giving or ‘scene setting’ - it is a reformulation of the patient’s ‘before and after’ story. In this case the ‘before and after’ story is the patient’s adequate grounds for claiming that she is sick and is reconstructed here by the doctor as part of *his* adequate grounds for making a diagnosis of a physical illness.

Alongside this identity ascription, at lines 14-24, Dr Evans also constructs his formulation of the clinical events of her illness using the biomedical repertoire. She had “a definite recognisable viral illness”; “a positive monospot”; “a viral picture”; “pain in the upper right side of her abdomen”; and “inflammation of the rib cartilages”. Her illness is in this way constituted as a recognisable medical condition, with objective clinical signs (a positive monospot), which indicates a recognisable viral illness - glandular fever. The physical ‘reality’ and cause of her illness is thus constructed rhetorically, both in the way that she is ascribed a particular kind of identity, *and* in the formulation of a biomedical narrative. The doctor’s endorsement of her illness and his construction of it as a recognisable medical category with an identifiable cause are linked together. If the doctor endorses the patient’s illness as fitting into a physical diagnostic category, then ideally he needs to warrant this in medical terms. But, in the case of a long term chronic fatigue state, the biomedical

explanation alone is an insufficient and inconclusive one¹³, so he also needs to provide additional grounds for making such a claim. The formulation of her identity that he offers - 'fit, active, well dressed, outgoing' - works in this case to constitute her as someone to whom he can credibly attribute a physical diagnosis. The account is descriptively produced in a way that works to counter any possible alternative explanation for the patient's illness - for example, that she might have a psychological illness or that she is a malingerer who is looking for time off work.

The next extract can be analysed in a similar way to extract 1 in the sense that in both cases, an account of identity is interwoven with a biomedical narrative.

Extract 2. (MHS/Dr Brown/23-39)

1. MHS can you remember a particular case
2. Dr. Brown = m[m]
3. MHS [can you describe a particular case to me of somebody that (.) came
4. to you like that?
5. Dr. Brown = mm WELL YEAH like this chap (.) he::'s I suppose (.) early forties
6. who came in and actually he had-his job had been tough for a couple
7. of years (.) but he'd sort of coped with that and he was (.) he went on
8. holiday (.) and he got this urine infection (.) it burned and scalded (.)
9. so it was fairly (.) quite definite (.) and then shortly after that he sort of
10. came back and sort of said "Hey I'm not quite sure what's happened
11. but I don't seem to have got o:ver that (.) it's left me completely
12. exhausted (.) a::nd er if I try and do anything I'm just worn o::ut (.) and
13. my muscles ache" (.) y'know (.) previously I think he'd taken part in
14. fun-runs (.) and he said there was just no way that he (.) even if he just
15. walked up and down the stairs a couple of times (.) all his muscles
16. would sort of ache (.) a::nd he was finding that he would have to go to
17. bed at eight or nine o'clock at night (.) couldn't keep awake in
18. meetings
19. (0.5)
20. Dr Brown and this was (.) quite a change for-for him

Dr Brown also begins his narrative by 'setting the scene': "this chap (.) he::'s I suppose (.) early forties" (lines 4-6). As with the last extract, some information is given about the patient's age, occupation and identity. Similarly to Dr Evans' account, Dr Brown is formulating a 'before and after' story which functions as more than neutral 'information giving' about psychosocial aspects of his patient's case. At lines

¹³ This is because chronic fatigue can be a symptom of many conditions - both organic and psychological.

8-9 Dr Brown's account of an infection that led to symptoms of fatigue and muscle aches, is worked up as a biomedically recognisable post-viral illness. The grounds for an organic causal story are built up by the doctor in a narrative sequencing of events: "He went on holiday (.) and he got this urine infection (.) it burned and it scalded (...) then shortly after that he sort of came back and said 'it's left me completely exhausted (...) I'm just worn out (.) and my muscles ache'"

Sharp contrasts are formulated between the patient's physical activity before and after the infection: "previously I think he'd taken part in fun runs", and afterwards, "even if he just walked up and down the stairs a couple of times (.) all his muscles would sort of ache"(lines 13-20). The formulation of 'before and after' around the pivotal event of the infection works to establish adequate grounds for the patient to claim that something is wrong, and also for the doctor to warrant the diagnosis of a genuine physical illness. The psychosocial repertoire is used here as a resource by Dr Brown, (in the same way as in extract 1 by Dr Evans) to provide additional grounds for making a physical attribution for his patient's illness.

The previous 'before and after' formulations are now compared with how Dr Butler talks about her patient in this next extract.

Extract 3. (MHS/Dr Butler/353-387)

1. Dr Butler I can remember one particular lady (.) who
2. (2.0)
3. Dr Butler I felt she probably had got M E (.) and referred her on (.) and I don't
4. know how that lady's getting on actually because she's moved on of
5. the area
6. (2.0)
7. Dr Butler and her symptoms came on when she was about three months post-
8. natal
9. (1.5)
10. Dr Butler and again (.) I find it difficult to pull out how much could have been an
11. element of post-natal depression with her
12. MHS = right (.) did you suggest that to her as a possible?
13. Dr Butler = oh yes I mean y'know (.) we discussed that-I mean she wasn't overtly
14. depressed (.) as some of them seem
15. (1.5)
16. Dr Butler but er (.) and y'know she'd got more symptoms of just the lethargy (.)
17. the myalgia bit and (.) which is why I went sort of more down the M E
18. line with her
19. MHS = what sort of things (.) er y'know in addition to the lethargy (.) what

20. other things indicated to you that it might be M E (.) rather than just
 21. post-natal?
 22.Dr Butler = I think with her it had again followed (.) y'know a distinct systemic
 23. illness as well (.) er
 24. (1.5)
 25.MHS like a viral illness?
 26.Dr Butler = yeah (.) she'd had like a sort of (.) y'know a grotty fluey bug
 27.MHS = right
 28. (2.6)
 29.Dr Butler the other thing that made me (.) wonder more about the depression side
 30. was her ba:by had got ear deformities and was going to need surgery
 31. and things like that (.) I wondered y'know whether [*interruption*]
 32. y'know (.) I wondered how much (.) was this y'know (.) whether she
 33. was possibly expressing
 34. (1.2)
 35.Dr Butler almost like a grief reaction

In this account Dr Butler is formulating the identity of the patient alongside her two candidate explanations for the illness; one being that she had M E following a viral illness, and the other that it was post-natal depressive illness brought on by a grief reaction.

The case narrative begins, like the previous two extracts, with a 'scene setting' device at lines 7-8: "her symptoms came on when she was about three months post-natal". As before, this functions in the narrative as more than just a bit of background information. Dr Butler is situating the beginning of the patient's illness story in the context of an earlier event, the birth of her baby. This effectively makes relevant the patient's identity as the mother of a new baby, which turns out to have problems: "her ba:by had got ear deformaties" (line 30). The description "three months post-natal" at line 7, (rather than say 'three months after the birth') does the work of setting up the diagnostic category of "post-natal depression". Rather than merely setting the patient's problems into a time frame of when the illness began, the formulation of "three months post-natal" tells us something about the condition of the patient herself - suggesting the strong possibility that she was vulnerable. In other words, this psychosocial 'information giving' provides reasonable grounds for the doctor's candidate explanation that "it could have been a bit of post-natal depression"(lines 10-

11), and that, “she was possibly expressing (1.2) almost like a grief reaction” (lines 32-35).

On the other hand, at lines 13-14, Dr Butler formulates a disjuncture between *this* case and *typical* cases of post-natal depression: “she wasn’t overtly depressed (.) as some of them seem”, and also: “she’d got more symptoms than just the lethargy (.) the myalgia bit”(lines 16-17). In other words, she is not scripting the patient’s illness as a simple, clear cut, classic instance, such that it neatly fits the category of post-natal depression. Therefore, this lack of matching fails to *entirely* warrant the giving of a psychiatric explanation for her patient’s illness. Here the working up of complexity is part of a *retrospective* accounting for her statement at lines 1-3: “I felt she probably had got M E”, and provides grounds for both her *diagnosis* and its *tentativeness*, which is further bolstered by an appeal to a higher authority, “and referred her on”(line 3). When asked to account for the diagnosis (lines 19-21), she offers an alternative candidate explanation where the patient’s illness may have been triggered by a “distinct systemic illness” (lines 22-23), and more specifically a “grotty fluey bug” (line 26).

When Dr Butler’s account is compared with those of Dr Evans and Dr Brown, we can see that all of the narratives supply the same kind of biomedical information about a possible or likely organic explanation for the patient’s illness. Dr Evans refers to a “positive monospot (...) for glandular fever (...) a blood picture” (extract 1, lines 14-15). Dr Brown claims that his patient “got this urine infection” (extract 2, line 7). And Dr Butler refers to a “distinct systemic illness (...) a grotty fluey bug” (extract 3, lines 22-23, 26). However, the accounts *differ* in the way that this biomedical information is interpreted in terms of the patient’s identity and life events. In other words, the psychosocial repertoire is drawn on as a *flexible* resource (in the context of the interview) to interpret similar biomedical events in different ways. Dr Evans and Dr Brown construe *their* patients in a way that makes available psychosocial ‘evidence’ that warrants the giving of an organic medical diagnosis, whereas Dr Butler makes available psychosocial ‘evidence’ that might also back up a claim that her patient’s illness is psychiatric.

‘Where the story starts’.

The format of Dr Butler’s account can be distinguished from the kind of *contrast structures* used by Dr Evans and Dr Brown. These ‘before and after’ structures function in the doctor’s narratives to build up their grounds for making a diagnosis of physical illness, and to dismiss alternative psychological or ‘motive’ interpretations for the patient’s condition. Dr Butler’s case is not worked up using exactly the same structure as the other two. Instead of positioning a formulation of her patient’s *disposition* and activities *before* her illness against her behaviour *after* the onset of the illness, Dr Butler makes available the details of *life events* that happened before the patient became ill.

Where the story *starts* is an important part of how *causes* can be attributed to illnesses.¹⁴ As pointed out in the previous chapter, Angela and Joe’s narrative begins with a specific life event. Their account dates Angela’s health problems specifically to a particular time, place, and origin - that of ‘picking up’ a virus during a visit to the local swimming pool. By starting the story at this point, they do not make available any life events that may have happened three months prior as Dr Butler does here in the case of her patient who was “three months post-natal”. In either case, ‘where the story starts’ is a powerful rhetorical device that functions to accomplish the business of grounding an attribution about the cause of the illness by ‘establishing the parameters for what is to be taken as noteworthy’ (Atkinson, 1995:109). Angela and Joe’s story starts in a place that allows them to make narrative sense of a physical attribution, whereas Dr Butler’s story is rhetorically organised to make available the alternative suggestion that her patient might have been vulnerable to post-natal depression.

¹⁴ Reissman (1993: 18) points out that where people start a story is rhetorically powerful for the management of causality and accountability, and that competing kinds of narrative would differ in terms of when and where they begin. See also Edwards (1997: 277) “Where to start a story is a major, and rhetorically potent way of managing causality and accountability. it is an issue not only for personal narratives, but for accounts of all kinds, including histories of nation states” Where a story starts is also an issue for scientists in the construction of ‘discovery accounts’ (see chapter two, this thesis, “A Plausible History of M E”, where competing causal explanations for outbreaks of a mystery illness, variously described as “a new clinical entity”, and “epidemic hysteria”, are managed by this narrative device).

A comparison can now be drawn between the ‘before and after stories’ of M E sufferers in the following extracts (4,5, and 6) and the accounts of doctors about their patients in extracts 1 and 2.¹⁵

Extract 4 (MHS/A&J/189-199)

189. Angela I think my mother was around at one of these times when that was
190. mentioned too (.) my mother said ‘I know my daughter’ (.) I can always
191. remember my mother saying that (.) ‘I know my daughter’ (.) because I
192. was always so active heh heh hyperactive in some respects
193. actually (.) because my Mum used to say to me ‘for goodness sake
194. Angela sit down’ (.) this was before I went down with M E (.) I never
195. wanted to sit down (.) I wanted to be on the go all the while (.) I was
196. happy that way (.) but er (.) things change (.) you’re forced to sit
197. down
198. Joe = to his credit (.) the consultant never did ever voice that thought
199. Angela = no (.) he didn’t believe that

In extract 4, Angela’s comment at line 189 follows on from Joe’s earlier account of how the GP made suggestions that her illness might be “in the mind”.¹⁶ I have argued (in chapter six) that Angela is working here to re-establish her credibility as a particular kind of person - one who is not given to psychosomatic illness or malingering. Her personal disposition is built by scripted formulations such as “my Mum used to say to me ‘for goodness sake Angela sit down’” (lines 193-4), and “I never wanted to sit down” (lines 195-6). Her pre-M E activity (or hyperactivity) is built up as an abiding dispositional trait, something she *always* did, which allows her current state of inactivity to be easily read as ‘out of character’ and the following attribution of a *situational* cause to be made, “things change (.) you’re forced to sit down” (lines 196-7).

The next extract is taken from a television debate - “The Esther Rantzen Report” entitled “*M.E: A modern plague, or a malingerer’s charter?*” (An invited audience

¹⁵ This is a general comparison between the discourse of doctors and patients, rather than a matching of patients to doctors, which would have compromised the doctors’ ethical stance on patient confidentiality.

¹⁶ Extract 4 is more fully analysed elsewhere - in chapter six, page 188, where it is set in the context of Angela and Joe’s illness narrative.

consisted of members of M E self-help groups, general practitioners, consultants, researchers, and a medical journalist.)

Extract 5 (The Esther Rantzen Report / August 5 1996, BBC1)

1. ER¹⁷ = so you think its a kind of depre:ssion?((*hostile audience response*))
2. (.)
3. TS¹⁸ I think it may well be a kind of depression
4. (.)
5. ER RIght (.) right (.) finish what you're say↑ing
6. TS [[I
7. ER [[you think it may well [be?]
8. TS [eh-]er (.) m-may we:ll be >a form of
9. depression< because patients will not realise (.) that depressed
10. (.) patients become ill (.) and therefore they resent being described as
11. (.) >having depression< (.) [listen to them (.) li::sten to them you see]
- 12.ER [well clearly (.) clearly some people do] do
13. you resent it?(.) being described [as depression]
- 14.P1 [well its not th]at I resent it but I mean
15. I don't really look very depressed do I ? (.) I mean I was a head
16. teacher (.) and I loved my job (.) and I played squash (.) and I produced
17. concerts with the children (.) and overni:ght I was like a vegetable (.)
18. suddenly (.) in the most terrible pains [...] I couldn't think properly and
19. I couldn't speak properly and I lost so much power in my muscles (.)
20. the only way I could comb my hair (.) was to rest my elbow on
21. something like this and this was what it was like for me
- [...]
- 146.ER now sir your wife (.) Ellie
- 147.P4 = yes
- 148.ER = had this illness (.) did she not?
149. (.)
- 150.P4 she had it for six years in total
151. (.)
- 152.ER now we have a picture of Ellie as we can see she was a nurse (.) it does
153. seem to strike a lot of nurses doesn't it?
- 154.P4 = it does (.) medical profession and dental profession as well
155. (.)
- 156.ER what kind of person was she? was she depressed at all before [she]
- 157.P4 [not] at
158. all (.) not at all and she just loved life (.) she lived for the family and
159. she lived for her nursing (.) she wasn't what you would call a high
160. flyer (.) she was a hard worker (.) you have to be if you're going to be a
161. mother and a-and a nurse at the same time
- 162.ER = now she died tragically young did she not?
- 163.P4 = she died at fifty two

¹⁷ Esther Rantzen chaired this television debate.

¹⁸ Dr Thomas Stuttford is a medical correspondent for 'The Times' newspaper.

164. (.)
 165.ER and (.) do you feel the death was connected with the M E?
 166.P4 = yes it was (.) it was-obviously you don't die of M E (.) you die as a
 167. result of M E (.) and she died from a deep leg thrombosis (.) for the
 168. simple reason that she was bedridden (.) for the last- well (.) she was
 169. bedridden for four years (.) the last three of those years she was
 170. unable- she was so ill that she was unable to see (.) um our youngest
 171. daughter (.) e::r

The following extract is taken from an interview with an M E sufferer.

Extract 6 (Bev/MHS/1293-1304)

1. MHS I suppose you would have found it difficult to understand it
 2. Bev = sure (.) I most certainly should (.) I mean people used to say to me
 3. 'don't you ever walk anywhere (.) do you always run?' (.) y'know
 4. because I was always going up and downstairs and the boss used to say
 5. to me 'good gracious Bev you're up and down again' heh y'know this
 6. sort of thing (.) well I was that sort of person (.) I'd get up in the
 7. morning and clean and tidy all up before I went to work (.) come back
 8. and then meals (.) the ironing (.) whatever (.) I'd be working 'til late at
 9. night (.) it's always been me (.) I used to dig the garden (.) mow the
 10. lawns y'know and (.) that was just me (.) and so nobody in their right
 11. mi:nd would want to give up all that

A comparison of the data in extracts 4, 5, and 6 supports the claim I made earlier that 'before and after' stories are rhetorically positioned *against* a particular kind of interpretation of the illness. For example, in extract 5 lines 8-11, TS offers a psychological explanation of M E as a "form of depression". At line 14, a member of the audience, P1 (in response to a direct question by ER) makes a denial that she (as an M E sufferer) resents the attribution of depression that has been worked up by TS. She continues (at line 15) by appealing to the audience to judge for themselves: "I don't really look very depressed do I?" The basis for her rejection of depression is thereby rhetorically based on what anyone can see for themselves, rather than being due to resentment, and her denial of this works to contradict the implication of a prior motive to prefer a physical explanation for her illness, and to reject a psychological one. P1 goes on (at lines 15-21) to construct her 'before and after' story, which is rhetorically constructed to dismiss *precisely* the suggestion that has been built up from lines 1-13, that M E might be a "form of depression" (lines 8-9). Similarly, P4 (line 157) works to dismiss this kind of interpretation being placed on his wife's illness. In

the same way that P1 describes her pre- M E self as an active head-teacher and sportswoman, who loved her job, P4 describes his wife, Ellie as a hard-worker who loved life and lived for her family and her nursing.

In both cases, psychosocial ‘evidence’ functions to build up the grounds for making a claim of physical illness. Descriptions of active lifestyles and dispositional traits, such as hard-working and cheerful (someone who “loved life”) are blended together by P4 to dismiss the suggestion that his wife Ellie might have been suffering from a depressive illness. In both cases, this kind of psychosocial ‘evidence’ is contrasted with the post-

M E state of being “like a vegetable (.) suddenly” (lines 31-2), or being “bedridden for four years” (line 165). For P1 the dramatic overnight change is from an independent active head-teacher, to a ‘vegetable’ who can’t think or speak, or look after herself properly. Similarly, for P4’s wife Ellie, the change is formulated as being from hard-working nurse and mother, who lives for her family, to being bedridden and unable even to see her daughter.

Similarly in extract 6, Bev’s account accomplishes the same kind of business. She scripts herself as a person of a particular type of disposition: “I was that sort of person” (line 6) “I’d get up in the morning and clean and tidy all up before I went to work” (lines 6-7) “I’d be working ‘til late at night (.) it’s always been me (.) I used to dig the garden (.) mow the lawns y’know and (.) that was just me”. The upshot of her script formulations (at lines 10-11) works against any possible suggestion that her current inactivity (documented in a different part of the interview) might be symptomatic of any dispositional trait that might predispose her to a self-serving psychosomatic illness or malingering. At lines 10-11 she dismisses such a ‘motive’ explanation for her condition by making an appeal to the consensual nature of commonsense; “nobody in their right mi:nd would want to give up all that”, where “all that” has been worked up in terms of ‘extreme formulations’ (lines 3-6) which describe her as not just a willing worker, but an outstandingly enthusiastic one who would choose to run rather than walk, and do the garden and the housework as well as going to work.

Tales of frenetic lifestyles prior to M E (and I would argue all other kinds of disabling illnesses and conditions) are common themes in literature where researchers have collected illness narratives (eg. Kleinman, 1988; Robinson, 1990; Ware, 1992). One of the discursive functions performed by such accounts is to do the contrastive accounting business that allows a situational rather than internal causal attribution to be made as we have seen in the above extracts. Another function of these kinds of account is to 'script up' the individual case as a recognisable instance of a more general pattern - in this case, a 'typical M E story', where the pre- M E activity stands in stark contrast to highlight the disabling effects of the illness. Of course such 'M E scripts' are *fact-constructive* as well as normalising devices, and *being* typical is what *constructs* it as ME in the first place.

In previous research, when illness narratives have been taken at face value (as with a type 1 analysis¹⁹) these participants' tales of hyperactive people and frenetic lifestyles have provided the 'evidence' for an analysts' gloss which has been offered as a theoretical interpretation of the causes or social meaning of the illness. For example, Norma Ware (1992) uses tales of frenetic lifestyles in M E narratives as evidence to explain the profound fatigue of M E and CFS as a symptom that is meaningful in the context of a highly stressful existence in the twentieth century. The illness, she claims, allows sufferers to 'opt-out' of their previous frenetic lifestyle to adopt a less stressful one characterised by a slower pace and lower activity levels. In treating accounts as a face-value representation of reality, this kind of explanation ignores the complex rhetorical work accomplished in such narratives by the work to dismiss *precisely* such a 'motive' account of their illness. In working to dismiss such an interpretation, sufferers paradoxically implicate themselves in a further range of damaging interpretations about the nature and cause of their illness.²⁰ Simon Wessely makes a

¹⁹ See chapter six, where I outline three types of analysis cited in Edwards (1997).

²⁰ Kevin McKenzie (1997: 2) makes a similar point with respect to the analysis of British and American expatriates' interview talk recorded during the aftermath of the Persian Gulf Conflict of 1990-91. He points out how (in talking about the Gulf conflict) speakers attend to a range of competing demands, such as their "accountability to be neither prejudiced nor unaware of cultural difference". A display of awareness to cultural difference could easily be hearable as evidence for racial prejudice. Paradoxically, if a speaker works to avoid being heard as prejudiced, this could be heard as evidence for

similar point in a transcribed discussion following Ware's paper at the CIBA symposium (Wessely, 1993) suggesting that such face value interpretations by theorists have reinforced the unhelpful media stereotype of "yuppie 'flu" as a self-inflicted illness of the young, upwardly mobile.²¹

In view of such culturally available media stereotypes, accounting for oneself (or one's relative or patient) as a sufferer of M E, is likely to implicate the narrator in something of a dilemma. What is 'at stake' in the illness narrative (or in the doctor's case narrative) is that in order to dismiss the possible interpretation of malingering or dispositional weakness, it is necessary to script oneself (or one's relative or patient) as a previously active, busy person who is thoroughly involved in every aspect of social and working life, and not given to a sedentary lifestyle. In fact these scripts are often worked up as *extreme* and *exceptional*, rather than just normal. (Pomerantz, 1986) The scripting up of this particular kind of identity (as Wessely has observed) clearly risks implicating an equally discrediting interpretation - for example, that the illness is self-inflicted through overwork, ambition, and 'living in the fast lane'. This dilemma can be heard as a participants' issue (rather than an analysts' gloss²²) for P4 in extract 5, where he gives his account of his wife's pre-M E activities, "she wasn't what you'd call a high flyer (.) she was a hard worker" (lines 159-160), where "hard worker" can be heard as commendable, as against "high flyer" which suggests motive, ambition and stress. His statement therefore works against a possible interpretation of Ellie as

cultural insensitivity. McKenzie's analysis explores speakers' efforts to manage this dilemmatic tension in the context of interview talk.

²¹ Simon Wessely goes on to give his own cognitivist 'motive' account of how and why people try to persuade others that their illness is not a psychological one in order to avoid the stigma associated with that kind of explanation. "I wonder if in fact these people were overemphasizing these aspects of their lives to prove to you how physically and psychologically robust they were before they became ill, in order to remove any suggestion of a psychological aetiology to their illness. They are emphasizing a point rather than giving a true description." (p.77: CIBA Symposium 137, 1993) His explanation also draws on realist notions of a 'true description' of achievement, ambition and personality, by way of a contrast to these 'exaggerated' accounts of CFS patients. This notion of a 'true description' corresponds to a 'type 1' analysis of narrative, where accounts are more or less accurate descriptions of events and actions.

²² Taking the dilemma as a participants' concern (one that is oriented to by them in their talk), avoids having to make a realist claim (prior to analysis) that there is a stigma associated with psychological explanations (or that this notion is part of people's world view), and this is what participants are *actually* motivated to avoid. The point is that both the 'stigma' and their 'avoidance' of it are constituted by participants in the talk itself, and the way that their formulations are constructed accomplishes precisely that kind of rhetorical business.

being a case of “yuppie ‘flu’”. P4’s account does the work of formulating Ellie as hard working but *ordinary*, (Sacks, 1984) rather than someone who was pushing herself so hard that she made herself susceptible to a physical or mental breakdown.

The main point of this section is that the stories in extracts 4 and 5 have the same kind of ‘before and after’ contrast structure as those of Dr Evans and Dr Brown in extracts 1 and 2. They also perform the same rhetorical business that Bev’s account (in extract 6) accomplishes when set in the context of her narrative as a whole. In each of the accounts there are clear links between the way that psychosocial ‘evidence’ is used as a warranting device for the formulation of a particular kind of explanation. As with the previous analysis of Angela and Joe’s story, the scripting up of the patient’s identity or internal disposition can be seen as inextricably linked to a particular ‘theory of illness’ or causal attribution that the narrative is rhetorically designed to build. In other words, the identity of the patient and the causal attribution for their illness are co-constituted in these accounts by means of the ‘documentary method’.

The following analysis examines one doctor’s narrative construction of different categories of patient. I shall focus on the way that the different patients are compared and how psychosocial ‘evidence’ is deployed in order to categorise them in terms of *either* mental *or* physical illness. This can be seen as *distinct* from the kind of attributional reasoning that is claimed to be informed by complex process models of disease, such as the biopsychosocial model (Engel, 1977; 1980).

‘Separating the Sheep from the Goats’

Extract 7.(MHS/Dr Mason/ 1-19)

1. MHS I understand you have some experience with M E patients
2. (3.3)
3. Dr Mason Apart from James and his wife we’ve had (.) one two three
4. (2.8)
5. Dr Mason three others who’ve
6. (1.9)
7. Dr Mason achieved consultant diagnosis (.) and one other who
8. (1.0)
9. Dr Mason who may have done
10. (3.5)

- 11.Dr Mason and that was with er (.) the chap who was dubious was seen
 12. by (.) ourselves and eventually (.) a haematologist in [city] with some
 13. interest (.) er but he's so polysymptomatic (.) a:nd (.) the psychiatrist's
 14. also seen him (.) and reached other diagnoses (.) he's the one in doubt
 15. whereas I've had another chap who's (.) an overwhelming
 16. Glandular fever (.) in his mid-twenties (.) came down with the true
 17. viral fatigue syndrome
 18. (1.0)
 19.Dr Mason we're in the eighth year (.) a-and he is getting better
 20. (1.9)
 21.Dr Mason but it taken a long time (.) it's actually- he's tried very hard and he's
 22. done
 23. (1.0)
 24.Dr Mason done an MA while he's been off work (.) he's coped with the ups and
 25. downs
 26. (2.2)
 27.Dr Mason his symptoms seem very
 28. (2.0)
 29.Dr Mason very physical (.) although latterly
 30. (4.0)
 31.Dr Mason to help him cope with the idea of
 32. (1.5)
 33.Dr Mason the frustrations what have you (.) he's actually been assessed with a
 34. view to going to- into therapy
 35. (3.7)
 36.Dr Mason I mean any chronic illness
 37. (1.5)
 38.Dr Mason is going to cause problems (.) to deal with it (.) depressive
 39. side of breast cancer and stuff like that so

In extract 7, MHS's question at line 1 provides the occasion for Dr Mason to categorise his patients. He gives a list (at lines 3-9) which he breaks down into several people who have "achieved consultant diagnosis" (line 7), and one "who may have done" (line 9). His listing of "one two three (2.8) three others" at lines 3-5 displays that this is careful, accurate recollection, and that he has some specific knowledge of these cases on which to base his categorisations. The listing also allows him to do some boundary work in which he sets up the latter case as a "dubious" category (line 11) when compared with the others. His category of people who have "achieved consultant diagnosis" accomplishes some important discursive business by setting up the diagnosis of M E as being one that has been made by consultants rather than by himself. The term 'achieved' is suggestive of a motivated accomplishment on the part of the patients, rather than a result of his own diagnostic practices. M E itself is being

constructed here as a diagnosis that is pursued by patients who have to be referred through the hospital system to achieve it, rather than it being a conclusion that he, as a general practitioner, would make as a matter of routine, as perhaps with diseases such as measles. This works to tell us that diagnosing M E is the business of consultants rather than general practitioners, and allows him to bolster his account by medical consensus, and also to distance himself somewhat from the *fait-accompli* of the consultant's diagnosis without having to risk being heard as a doctor who is *generally* dismissive or unsympathetic to patients who claim to have M E. Having a list of patients who are *bona fide*, consultant-diagnosed cases of M E works to accomplish a *contrast* to his category of "dubious" without having to say that he *himself* has a set of criteria for identifying "dubious" cases.

This contrastive talk works in a similar way to the "cutting out" procedure²³ described by Smith (1978) in "K is mentally ill". Dr Mason's initial categorisation list draws boundaries around which cases are to be read as 'genuine' and which case is to be problematised and excluded from the set of 'genuine' cases. Two consequences of this discursive boundary work are that the "dubious" case "may not be treated as a source of normative definition" (*ibid*: 34), and therefore the patient's version of this case (or at least the one that the doctor's version is rhetorically positioned against) can be more easily discounted from the outset.

Dr Mason's grounds for separating out this dubious case are explicitly set out at lines 11-14. First, "the chap who was dubious was seen by (.) ourselves", second he was seen by a "haematologist in [city] with some interest"(lines 12-13), and third "the psychiatrist's also seen him (.) and reached other diagnoses" (lines 13-14) which gives retrospective support to earlier misgivings about the patient. The dubiousness of this case is partly bolstered by plurality - that is, "ourselves" (line 12) and the psychiatrist who "reached other diagnoses" are aligned in Dr Mason's account. However, the suggestion of *disagreement* between doctors is also built into the phrase

²³ Smith (1978) describes a "cutting-out" procedure in which the narrator of events draws boundaries around those who recognise and share a version of social reality, to exclude someone who they formulate as being unable to recognise that social reality. "The cutting out operation thus involves showing how K's behaviour is not properly instructed by the definitions of the rules or situations which are provided." (*ibid*: 39)

“reached other diagnoses”, and *that* poses a possible threat to the legitimacy of medical opinion.

This tension is managed in the narrative by Dr Mason, who attributes the accountability for doubt onto the patient himself, “he’s so polysymptomatic”(line 13). This effectively construes him as someone who is difficult to categorise one way or the other, given that his symptoms fail to conform to a discrete and recognisable disease category. The use of the term ‘polysymptomatic’ implies that the patient’s symptoms are many but haphazard. In other words they *defy* categorisation in terms of any medically recognisable disease or syndrome. Describing the patient as ‘polysymptomatic’ is therefore a way to *define* the features of this case as an example of *anomalous* illness behaviour.²⁴

Dr Mason’s separation of ‘sheep from goats’ is further warranted by associating ‘genuine’ cases with the “achievement” of consultant diagnosis, and the ‘dubious’ case with a diagnosis from a haematologist “with some interest” (lines 12-13). The implication is that only when a patient has “achieved” a consultant diagnosis, will their illness be medically recognisable as a *bona fide* case. The haematologist, on the other hand, is construed as a dubious ‘witness’ who may have a stake or interest in a diagnosis of M E, and is positioned in the narrative against a psychiatrist who has “reached other diagnoses” (line 14).

The formulation of one of the patients as a ‘dubious’ category is positioned rhetorically in the narrative as a contrast case against Dr Mason’s example of “the true viral fatigue syndrome” at lines 16-17. As previously seen in Dr Evans’ and Dr Brown’s ‘before and after’ stories, the description of this ‘genuine’ case is interwoven with a formulation of the patient’s personal identity. He is described as one who has “tried very hard” (line 21), “done an MA while he’s been off work” (line 24), and has “coped with the ups and downs” (lines 24-25). Primarily this account functions to offer an organic explanation for the patient’s illness, which is warranted in terms of psychosocial ‘evidence’ about the patient’s personal disposition and his illness

²⁴ See footnote 11.

behaviour. He is being construed as the sort of person who does not easily give way to illness, and has a positive coping style. As with the accounts given by Dr Evans and Dr Brown, this formulation of psychosocial 'evidence' serves both to bolster the factuality of the physical diagnosis, and rhetorically counters any possible alternative explanation for the patient's illness, thus managing the doctor's accountability in endorsing it as 'genuine'.

At this point, it is possible to identify two kinds of 'M E narrative' that are used by the doctors (and are also common in patients' narratives). The first is a 'before and after' story, where 'after' is formulated as extremely debilitated and inactive as a contrast to an active (or hyperactive) lifestyle 'before' the illness (e.g. extracts 1 and 2). The second type of narrative is exemplified by Dr Mason's example of the patient who has "the true viral syndrome" (extract 7, line 16-17), where the patient makes strenuous efforts and achievements despite currently suffering from the illness. Both types of narrative work against a 'dispositional' account of illness by formulating the illness as unwanted or resisted, and out of character with the victim's personal disposition. Paradoxically, if the two types of narrative were to appear in the same context, the second type would undermine the contrast that is being worked up in a 'before and after' account. The important point to notice about this is that the different types of narrative are used by participants in a different rhetorical context - even though they accomplish the same kind of business.

Later on during the same interview Dr Mason further explicates his warrant for treating "the chap who started with glandular fever" (line 1) as a 'genuine' case.

Extract 8.(MHS/Dr Mason/34-40)

1. MHS this chap who started with glandular fever (.) would you see that as
2. being er typical of er what you've seen with patients with M E or?
3. Dr Mason = no (.) so:me
4. (2.6)
5. Dr Mason er that's the one that you (.) you expect from the literature
6. (1.0)
7. Dr Mason true post-viral chronic fatigue (.) er
8. (4.6)
9. Dr Mason two of them are cases I know well
10. (2.1)

11. Dr Mason and there's another lady (.) in her mid fifties now and
12. (2.0)
13. Dr Mason she's had years of susceptibility to common depression
14. (1.2)
15. Dr Mason er
16. (3.0)
17. Dr Mason she seems depressed and comes across depressed...

In extract 8 (lines 3-9) Dr Mason categorises the glandular fever patient as being atypical of M E patients, but typical of “true post-viral chronic fatigue”. He marks this at line 5 as “the one you (.) you expect from the literature”, which scripts this case as a *bona fide* instance of a medically recognised and legitimated condition. He further bolsters his account of this case by a reference to his own clinical experience: “two of them are cases I know well”(line 9). So his entitlement to distinguish this ‘genuine’ case is not based on academic knowledge *alone* but also on its medical application in at least two cases that he has treated. In giving his grounds for distinguishing between these cases, he is displaying his ability to separate ‘sheep and goats’ in accordance with his experience of “cases I know well”, and his familiarity with scientific literature that informs his clinical judgement.

This ‘genuine’ case is contrasted with another case which he categorises at line 13 as “common depression”. Dr Mason seems here to be making a distinction between patients who have post-viral syndrome and M E, only the *former* being acknowledged as ‘genuine’ and recognisable as a separate medical category. The second case that he describes indexes his inclusion of people with “common depression” in the interviewer’s category, “patients with M E” (line 2). At lines 13-17 he builds up his warrant for his explanation of this patient’s problems by dividing the claim into a three-part list²⁵ : “she’s had years of susceptibility to common depression (1.2) er (3.0) she seems depressed and comes across depressed”, but otherwise he provides no further clinical evidence for his claim. Her depression is worked up here as an abiding dispositional trait, and in the style of classic attributional reasoning (Heider 1958) his use of psychosocial ‘evidence’ leads to the conclusion that it’s safe enough to attribute her symptoms to “common depression”.

²⁵ The rhetorical force of a ‘three part list’ (Jefferson, 1990) in this context is that it is suggestive of a more general set of reasons and grounds on which observations are being made in the current context.

It is notable that in the case of the “chap who’s (.) an overwhelming Glandular fever” (Extract 7, lines 15-16) the issue of depression was raised as being a ‘reactive’ type of depression (lines 36-38) “I mean any chronic illness (1.5) is going to cause problems”. The depression is formulated in situational terms as a *consequence* of having a ‘true’ post-viral illness, and the direction of causality is thus defined as illness→depression, rather than the depression *being* the illness itself, as in his formulation of the contrast case which he seems to cite here as a more *typical* instance of M E as distinct from post-viral syndrome. The interesting thing in this account is the way that for the patient with glandular fever, the illness itself *becomes* citable as psychosocial ‘evidence’ to warrant a secondary diagnosis of reactive depression, whereas for the patient with “common depression” the argument is reversed, and the psychosocial ‘evidence’ is worked up as a dispositional state.

The next extract appears further on in the same interview with Dr Mason, and allows us to analyse, in more detail, how he formulates the case he earlier referred to in extract 7, line 11 as “the chap who was dubious”.

Extract 9. (MHS Dr Mason/ 97-126)

1. Dr Mason well the one chappy (.) in his mid-forties
2. (3.4)
3. Dr Mason who
4. (3.8)
5. Dr Mason changed his practice because
6. (1.4)
7. Dr Mason this practice in [town] that didn’t want to know (.) and he was fed up
8. with being fobbed off (.) he used to do the advertising in one of the
9. papers and (.) just couldn’t cope with it (.) and
10. (5.6)
11. Dr Mason I listened and was sympathetic
12. (4.8)
13. Dr Mason he started coming up with gastro-intestinal problems (.) we got-he had
14. lots of (.) physical (.) type problems (.) y’know (.) we picked them off
15. one by one (.) but eventually you start getting frustrated letters back
16. from the specialists saying ‘we’ve <scoped this we’ve scoped that>
17. y’know we’ve done this reading (.) we’ve looked at the bowels (.)
18. we’re just getting nowhere’ (.) and er it’s what he makes of it and er
19. (6.7)
20. Dr Mason when people are very polysymptomatic (.) y’know heh y’know it’s

21. quite-it's quite difficult to deal with (.) a:nd
 22. (4.8)
 23.Dr Mason this will sound very unprofessional really (.) it tweaks a sort of a sixth
 24. sense that says heh er
 25. (2.1)
 26.Dr Mason I always (.) when I'm dealing with people lay out an agenda that's both
 27. the physical and psychological (.) and say 'these are the areas it can be
 28. in (.) in both' (.) er
 29.MHS = do you say that to the[m] ?
 30.Dr Mason [oh] and I do it also-it's not just M E patients
 31. (2.3)
 32.Dr Mason and the people who immediately
 33. (1.5)
 34.Dr Mason go 'no way Jose' on the psychological front
 35. (2.3)
 36.Dr Mason it's usually more suspicious heh (.) er
 37.MHS = because there is this conviction that the symptoms do have a physical
 38. origin?
 39. (.)
 40.Dr Mason yeah
 41.MHS = this is quite a topic
 42.Dr Mason = well yes that's er
 43. (3.5)
 44.Dr Mason that's right (.) although
 45. (5.0)
 46.Dr Mason just to stick to this particular advertising chap I mean he er
 47. (1.7)
 48.Dr Mason he has been the most resistant (.) he's fought against this assessment
 49. (.) he's fought against psychiatrists (.) and yet (.) in the letters (.) there
 50. are clear (.) psychodynamic issues in the family (.) powerful ones too
 51. (.) but there's just no going up that road

First, Dr Mason's introduction to his description of his patient is interesting and possibly ambiguous. At line 1 the patient is referred to as "the one chappy", where Dr Mason's use of the term 'chappy' might be heard as informal and friendly, or perhaps even indulgent or patronising. He then goes on to take the moral high ground in contrasting himself "I listened and was sympathetic"(line 11) with doctors in another practice who "didn't want to know" (line 7). This works to manage his accountability as an attentive doctor, and counters any possible suggestion that he might be unsympathetic or cynical, particularly on the topic of patients who claim to have M E. His account works in the opposite direction to this, since he formulates himself as open-minded, sympathetic and indulgent *even* when there is prior 'evidence' (line 5)

that the patient may be troublesome²⁶. This works rhetorically both to build the factuality of the interpretation that he offers in his narrative, and simultaneously to set up his patient's version as more easily dismissable.

Second, Dr Mason builds up the identity of his patient as someone who can't *cope* with his job: "he used to do the advertising for one of the newspapers (.) and just couldn't cope with it" (lines 8-9). Again this is *more* than just a bit of 'scene-setting' for the story he is telling. It is displaying his adequate *grounds* for interpreting the patient's "physical (.) type problems" (line 14) in psychological terms. This interpretation is then *further* bolstered and warranted by his account of how the processes of medical investigation drew a blank. At lines 14-15, "we picked them off one by one" is an expression that gives a *retrospective* account of *prior* scepticism about the patient's "physical (.) type problems", and is suggestive of a row of targets that were 'shot down' one by one.

This kind of 'we knew all along' claim lets the doctor have his cake and eat it. On the one hand he has displayed his willingness to take the patient's "physical (.) type problems" seriously by carrying out a battery of medical tests, but on the other hand he is able to indicate that he was never really taken in by the patient's claims right from the start. Dr Mason's talk about this patient is full of externalising devices and objectifying formulations that are achieved by grammatical choices. For example, the use of the pronoun "we" (lines 13, 14) works to construct the notion of consensus between members of the medical profession. Specifically, it indicates that it was the *practice* in general who were sceptical, rather than just Dr Mason, and thereby allows him to retain his status as an open-minded, sympathetic doctor, whilst also displaying his ability and expertise (and that of other doctors) to discriminate 'genuine' physical illness from "dubious" cases. Avoiding agentive formulations in this case works to dismiss the possibility of being heard as personally prejudiced prior to 'evidence'. The exception to this would be his normative accounts of a good doctor at lines 11 and 26, where that entails being openminded and reasonable.

²⁶ See Stimson (1976) "Trouble and Types of Patient" in which he details various types of patients that doctors have categorised as troublesome.

An interesting comparison can be made here with Dr Mason's earlier account in extract 7, lines 16-17, where he describes a patient who "came down with the true viral fatigue syndrome". This account formulates the patient as a 'coper' whose symptoms are interpreted as primarily physical, although there is no clinical evidence brought to bear in the narrative to explain why the illness has lasted eight years. "he's coped with the ups and downs (2.2) his symptoms seem very (2.0) very physical" (lines 24-29). Any psychological problem is formulated as attributable to a *post* illness consequence rather than a stable pre-disposition that is scripted up in extract 9 for the 'dubious' case.

Dr Mason's psychological interpretation of this 'dubious' case in extract 9 is further warranted by reference to his clinical experience and judgement, which is introduced here at lines 23-24 as a "sort of a sixth sense". At line 23 "*this will sound very unprofessional really*" he distinguishes his "sixth sense" from another more professional, medical and scientifically rational mode of reasoning, thereby foreclosing any possible accusation of 'quackery'. However, Dr Mason can still make legitimate use of his "sixth sense" to warrant his diagnosis, since it is not just an ordinary or even paranormal intuitive category, but rather it is based on years of clinical experience with similar cases. A 'sixth sense' is here constructed as a kind of connoisseur-ship - an expertise that is grounded in empirical experience and provides a *bona fide* basis for clinical judgement. Dr Mason's use of it here functions to display himself as a sensitive healer and attentive doctor who is able to notice and interpret subtle cues about his patients. This non-agentive formulation of his own cognitions at lines 23-24 ("it tweaks a sort of sixth-sense") works against the possible accusation that he has prior convictions or prejudices. The "sixth-sense" is not being formulated as a *prejudice*, but rather as an *expertise* that needs to be "tweaked" by an external stimulus, such as cues about his patients. Later at lines 49-50, his "sixth sense" is supported by the letters from the psychiatrist who has identified "clear psychodynamic issues in the family". Therefore in the narrative that he is building, Dr Mason's intuition turns out to be well-founded, and his construction of the patient's illness as a psychiatric category is thereby supported.

Furthermore, within the narrative, the theoretical framework of the psychodynamic explanation *itself* neatly militates against a possible refutation, since the more the patient's version *resists* this psychiatric definition of his problems, the greater the warrant for such a diagnosis becomes. He is constructed, at line 34, as a "no way Jose" *type*, who irrationally *denies* a psychological interpretation of his problems. And of course, from a psychodynamic perspective, someone who is in 'denial' (by definition) does not have a grip on reality, so their version of events can be legitimately discounted.

At lines 30-36 Dr Mason formulates the "no way Jose" type as a general category that is applicable more widely than just to M E patients. The expression "no way Jose" is an way to claim that a person's basis for refusing something is irrational, dispositional, and prejudiced. Resistance to the psychological agenda by some patients (lines 30-36) is being *scripted* here as a recognisable part of Dr Mason's everyday practice, and it is being contrasted here with the doctor's own 'openmindedness' in 'laying out' the physical and psychological agenda as a matter of routine (lines 26-27). The "no way Jose" type is formulated here as a *general* phenomenon and *this* case as an easily recognisable instance of it. The scripting up of this patient as a recognisable 'type' works here to dismiss an alternative explanation which would offend against the canons of empirical science - that Dr Mason might have prior convictions about his patients before there is any solid evidence on which to base his judgement. And paradoxically, that is *precisely* the nature of his claim about the "no way Jose" type.

This claim is packaged at lines 48-50 as a two-part structure:

- (i) a feature of the patient's attitudes and behaviour is his prior conviction, and active refusal to accept a psychological explanation (lines 48-49).
- (ii) and yet everyone else (the medical practitioners) can see clearly (from the evidence) that a psychological explanation is appropriate (lines 49-50).

The structure of this claim is such that (ii) supplies the defining context for (i) to be interpreted as yet more evidence of the patient's psychological problems.

Smith (1978) has shown how the attribution of mental illness behaves like the attribution of colour blindness. It is the state of not being able to recognise the social reality which is there for anyone else. In this case, social and medical reality is being defined by the medical profession, and as pointed out earlier this 'polysymptomatic' patient defies categorisation in terms of a recognisable disease, or at least in terms of a syndrome where there are symptoms that typically go together. "Polysymptomatic" suggests that the patient's symptoms are haphazard, with no cohesiveness or relationship to each other. It is therefore being construed here as anomalous illness behaviour - symptoms that he "started coming up with" (line 13), and that he interprets inappropriately as physical: "it's what he makes of it" (line 18).

The two-part claim outlined above (lines 48-51) perhaps more accurately describes a 'reality disjuncture', in which the patient's physical illness attributions sharply contrast with the doctor's definitions of his symptoms as psychological. However, what is at *stake* for the doctor in this account is the very *status* of the medical reality that he uses as a defining context. He has concluded here that the patient's "physical type problems" are psychological on the grounds that diagnostic testing proved negative, but a possible alternative account - that the doctors might have missed something - is not even considered. The "no way Jose" *type* is thus formulated as someone who is in 'denial'. He *will* keep coming up with physical type problems, and keep *making* something of it, *even* when he has been reassured by the doctors that there is no evidence of physical disease. A lack of 'objective' clinical evidence implies a *medical* reality of the absence of organic disease, so the patient's persistent illness attributions are hearable in the doctor's account as inappropriate and a breach of the implicit 'canonical script' that defines 'normal' illness behaviour.

An alternative version is that the medical profession might possibly have missed something, or that the patient is suffering from something that medical science does not yet understand. But that kind of explanation would have the potential to undermine the legitimacy of the scientific medical reality that the doctor here defines as a context for formulating his patient's problems as psychological. The doctor's account is rhetorically designed to exclude *precisely* that kind of alternative explanation in a

similar way that Angela and Joe's account is constructed to dismiss a psychological interpretation of Angela's illness. Some theorists (e.g. Yardley, 1996: 495) have argued that psychosomatic explanations have been commonly used as a moralistic device to 'shift the blame' for medicine's 'failure' to diagnose and treat illness in the context of uncertainty. In Dr Mason's account (above), the patient's persistent behaviour, changing doctors, coming up with "physical type" symptoms, being polysymptomatic, making something of it, refusing to go up that (psychological) road, and not accepting the doctor's definition of his problems, are presented as documentary 'evidence' that combines to form an underlying pattern, that he is a "no way Jose" type whose problems are in reality psychosomatic. The construal of the patient as a "no way Jose" type provides an account to explain why the medical profession can make a 'correct' diagnosis, but fail to achieve a successful treatment, because "there's just no going up that road" (line 51). Doubt, contradiction, and confusion are externalised to the object (the "polysymptomatic" patient), rather than being a threatening feature of medicine itself, where diagnoses, rather than symptoms, might be construed as haphazard or even contradictory. This is the kind of externalising rhetoric that sustains medical science, and *this* particular doctor's clinical judgement against criticism or error (Latour, 1987; Woolgar, 1988b).

The conclusion of Dr Mason's story further bolsters the implications that could have been heard from the beginning of his account, where the patient had changed from another doctor's practice that "didn't want to know" (line 7). The indexing of 'trouble' at the start of the story is retrospectively vindicated by the turn that the narrative takes and by its conclusion. This functions discursively to provide the doctor with additional grounds to warrant the construction of a damaging statement about his patient as a self-deluding and unco-operative character, who deserves to be categorised as a 'dubious' case (extract 7, line 11).

The claims made by Guggenbuhl-Craig and Micklem (1988) suggest that psychosomatic explanations for illness are associated with *low* accountability for doctors. The issues at stake were argued to be the legitimacy of medicine, and the doctor's responsibility to diagnose and treat illness according to scientific, medical

knowledge and clinical experience. In the context of uncertainty and lack of clear medical knowledge, doctors become more acutely accountable to provide a warrant for their clinical judgement in medical terms. One way to manage this tension is to construct a narrative which is associated with *low* accountability for doctors, and *high* accountability for patients - that is, a psychological explanation. In other words, the patient's illness is attributed to the psychological weakness of the patient rather than being due to an organic disease process that is not currently well understood by medicine. Scripting up patients as recognisable 'types' to whom doctors can credibly attribute a psychological diagnosis can be seen as part of the way that doctors are able to accomplish this 'shifting the blame' in their discursive categorisation of patients.

Summary

In this chapter, I have focused on the analysis of doctors' case narratives using a discursive psychology rationale. Comparisons have been made between the accounts of doctors about their patients, and the accounts of patients about their illnesses. Two outcomes have been that:

- When analysed as discursive action, the accounts of doctors and patients are similar to one another in certain important respects.
- Specifically, both doctors and patients employ psychosocial 'evidence' to warrant their claims about the nature of illness.

In patients' accounts, the psychosocial repertoire functions rhetorically to warrant the construction of a biomedical explanation for their illnesses. In doctors' case stories, the psychosocial repertoire functions rhetorically to warrant a diagnosis of *either* a physical *or* a mental illness. As I argued in the introduction to this chapter, such reasoning can be counted as an example of the 'documentary method' of reasoning (Garfinkel, 1967), where the details of psychological and social factors are worked up alongside *either* a physical *or* a psychological diagnostic version of the illness. This demonstrably *retains* a dualistic formulation of mind and body as a way to reason about the causes of illness.

An important outcome of the analyses of this chapter relates to the way that doctors *use* psychosocial information in their reasoning about patients' illnesses. In chapter four (above) I traced the origins of two models of medicine - the biomedical model and the biopsychosocial model. The biopsychosocial model was proposed by Engel (1977; 1980) as a way to conceptualise disease as a *process* rather than an entity - the idea being to re-work the whole approach to the diagnosis and treatment of disease. The biopsychosocial model derived its rationale from systems theory in biology, and promised to take into account the complex interplay between the biological, psychological, and social environments in the explanation of disorders. The rationale of such a model therefore leads to the assumption that *all* disease is potentially explainable (and treatable) in complex multifactoral terms. However, the analyses of this chapter indicate that, in the context of interviews, doctors employ quite different ways of reasoning about cases. The psychosocial repertoire is deployed as a *flexible* resource to warrant the giving of *either* a psychological *or* physical diagnosis.

There are two ways that the 'psychosocial repertoire' can be used to construct M E as a physical illness.

- **'before and after' stories** use 'extreme formulations' to do contrastive work about the patient's lifestyle and activity before and after the onset of the illness (e.g. Bev's account of her hardworking lifestyle in extract 6). If taken at face value, these 'extreme formulations' could be interpreted as a cause of the illness (e.g. 'opt-out' (Ware, 1992) or 'burn-out' (Wessely, 1993). Patients, carers and doctors orient to this dilemma of 'double-jeopardy' in the way that they manage the conflict between accounts of 'frenetic lifestyles' and 'ordinariness' - in other words one way to solve the dilemma is to construct the patient as hardworking but ordinary (e.g. Ellie's story, in extract 5).
- **stories about 'fighting', coping, or resisting illness** are told by both doctors and patients, for example, Angela's struggle to carry on despite her illness (chapter six, page 177), the patient who did the MA, and coped despite the 'ups and downs' (extract 7, this chapter).

Two contradictory repertoires?

Although both kinds of story construct the patient's disposition in a way that works to dismiss psychological or 'motive' explanations of illness, the 'fighter' story threatens to undermine the 'after' part of a 'before and after' story. The debilitated 'after' formulation only works in the rhetorical context of its contrast with the 'before' formulation. Like the empiricist and contingent repertoires, which are contradictory and therefore problematic if used together, these two kinds of contradictory 'M E stories' can be managed when they appear within a single narrative. For example, in Angela and Joe's account (chapter six) a 'vicious cycle' of effort and relapse leads to a relapsing cycle of 'before and after' stories. A cycle of 'effort and relapse' is one of the central features that constitutes an illness narrative as a typical 'M E script'. They appear frequently in patients' narratives and also in the M E literature.

These two kinds of M E stories can be contrasted with the way that doctors use the 'psychosocial repertoire' to warrant the giving of a psychological explanation for illness. In this kind of story (e.g. Dr Mason's patient in extract 9) the personal disposition of the patient is worked up such that he has psychological problems that are denied. He is constructed as a 'type' who uses physical symptoms and illness attributions to avoid personal responsibility. This kind of explanation is worked up alongside an account of fruitless medical investigation. It functions to dismiss an alternative explanation - that medical science, or this particular doctor, might have failed to identify an organic disease, or that they do not yet understand the physical nature of the illness.

Managing Accountability in doctors' and patients' accounts.

For doctors psychological accounts of illness can sustain medical science in the face of doubt and inconsistency. This is especially relevant where the relationship between medical science, practice, and clinical judgement needs to be delicately handled as an accountability issue such that the legitimacy of medicine is what is 'at stake' for doctors, and for the profession. An external attribution (a psychological one) does the work of 'shifting the accountability' onto the patient in the context of controversy

within the profession about the illness M E. It is patients who are dubious and polysymptomatic, rather than their diagnoses that are doubtful, etcetera. This is not some new entity that is not well understood, but 'old wine in new bottles' (Wessely, 1990). In other words, some psychological phenomenon that the medical profession has been seeing for years and understands very well. As Dr Mason puts it - doctors see such patients frequently. They are a 'type' that signal trouble.

For patients a physical illness attribution manages personal accountability and works against a psychological account. The illness has an external rather than an internal cause. Patients explain doctors' psychological attributions as a 'motive' account. They argue that doctors are motivated to use those explanations because medical science doesn't understand the illness. In Angela and Joe's account the doctor's diagnosis 'oh psychosomatic!' (chapter six, page 184) is construed as 'a cop out' - a way for doctors to avoid medical accountability for doubt, error and uncertainty. This mirrors the claims of some authors (e.g. Kirmayer, 1988; Yardley, 1996) who have argued that psychosomatic medicine has been marginalised into a category of the 'not quite legitimate' in which accountability is shifted back to the patient. This has been argued to 'protect the legitimacy of medicine' by 'siphoning off cases of uncertainty' when medicine fails to find a biomedical explanation for illness. Reciprocally, doctors talk about patients' physical illness attributions as a 'motive' account - physical attribution is a way for patients to avoid personal responsibility for their illness.

CHAPTER EIGHT

An Analyst's Gloss.

This thesis is an analysis of the discursive construction of a controversial medical condition (M E) and a discussion of some of the issues that have been made available in and through the discourse of medical scientists, general practitioners, and M E sufferers. The controversial topic of this thesis has provided an ideal forum for examining both lay and professional reasoning practices about illness in general, in a context where the 'objective world of medical facts' threatens to disintegrate into merely subjective points of view. At stake in this dialogue has been the meaning of the illness, and the implications of that for personal accountability and the status of both experiential and expert medical knowledge.

Scientific truth and medical knowledge can be seen as socially constructed and continually changing. At any given point in time there are likely to be disputes and controversies that co-exist alongside a category of 'blackboxed' explanations that are treated as factual and correct (at least for now). Controversies and disputes exist at the cutting edge of the dialogical production of scientific 'truths' and medical knowledge, and yet (at the same time) they are somewhat marginalised from the rhetoric of mainstream medical applications. It is therefore at the controversial boundaries of medicine - the area of 'medicine in the making' that we are more easily able to discern how its categories are constituted and deployed.

From the analytic perspective taken in this thesis, the constructive practices of scientists are not treated as distinct from the situated production of factual accounts in lay people's narratives, self-help group discussions, and diagnostic reconstructions. Explanations about the status of M E and its causes are embedded in accounts of the identity of sufferers, the nature and status of medical explanation, and the competencies of medical scientists and practitioners. One way to look at this would be to say that the definition of M E is itself a product of the interactional dynamics within which a struggle for authorship of the illness takes place.

I have analysed various kinds of texts and talk, using the rationale of discursive psychology to show that the meaning of M E is a product of participants' constructive and dialogic practices. My own writing of a thesis on "The discursive construction of M E" has been treated as a part of this reality construction process, which is celebrated through a variety of textual forms that display the dialogical construction of meaning in the thesis.

The main body of the thesis has been organised around three main themes that are glossed here as follows:

- A 'plausible history of M E' that serves both to constitute the controversy and also to provide a background for later analyses.
- An analysis of the discursive categories that are both constituted and deployed by participants in the controversy; for example, diagnostic labels; different models of medicine; and mind and body explanations for illness.
- A 'struggle for authorship of the illness' as displayed in the illness narratives of ME sufferers and in the narrative re-constructions of doctors in talking about their patients.

Although these themes have been organised in the text of the thesis as a linear structure, in practice they overlap and are present in all areas of the thesis and in the participants' discourse.

This concluding chapter gives an overview of the main contributions of the thesis, showing how the issues and findings can generalise beyond the topic of M E to the wider contexts of the production of medical knowledge, the situated use of medical models, and the social scientific study of health and illness. These contributions have both a theoretical significance, and also practical implications for further dialogue in medical training and health and illness research in the social sciences.

A 'Plausible History of M E' revisited.

The textual dialogue of chapter two displayed the context of ongoing controversy and provided an ideal forum to examine the way that medical practitioners and research scientists have set about the process of defining and challenging the existence of a 'new disease entity'. The dialogical processes were displayed, in this chapter, in and through scientific argumentation in research literature and related correspondence. An important feature of scientific controversy is the threat that competing versions and interpretations have posed to the 'canonical script' of an objective, scientific, and discoverable 'truth'. This possible breach or 'reality disjuncture' (Pollner, 1974) has been managed by participants in the debate as a practical discursive accomplishment. My analysis showed how an empiricist repertoire was used by scientists to establish the existence of a new disease entity, and also later, by others, to counter that claim. A contingent repertoire was also used to undermine the arguments of the 'disease entity' lobby as motivated, and in a counter move, to discredit such arguments as lacking in scientific rigour. A further move in this debate has been to challenge the utility of dualistic reasoning in medical explanation by using a 'Truth Will Out' device which suggested that a more complex process model would eventually be able to provide a more sophisticated explanation for the mystery illness.

Discursive categories as resources

1.Diagnostic labels

Chapter three focused on the controversial issue of diagnostic labels. In particular, my analysis showed how authors and speakers have attempted to define and problematise their terms of reference. The chapter looked at labels and their meanings as the topic of discourse as well as being deployed as part of that discourse. Three different kinds of assumption about the relationship between language and reality were identified as part of participants' resources in talk about labels.

- A representational model of language assumed that diagnostic labels are descriptive of disease entities that exist prior to scientists' constructive practices.

- The labeling perspective used the device of ‘selective relativism’ to argue that the same phenomenon has always existed, but has been labeled differently in different socio-historic contexts
- A relativist treatment of language (the approach taken in this thesis) argued that in naming things we actively construct their essence. Thus, reality is constructed in and through our descriptive activities.

In chapter three I have demonstrated how medical authors and speakers have appropriated these assumptions about language in making different analytic moves that work to preserve the notion of an objective medical reality. For example, speakers argue that they are labeling different things, or that different labels have been used to describe the same thing, or that some labels are simply inappropriate as a description of reality. The chapter also showed how speakers use empiricist and contingent repertoires to argue that one label (CFS) is more appropriate than others, and that certain kinds of people are motivated to use particular labels (such as M E) that are claimed to be inaccurate.

Finally, the chapter looked at labels, categorisation, and the kind of medical ‘boundary-work’ that can be accomplished, particularly with reference to the division of mental and physical categories. Physical diagnostic categories are equated in doctors’ talk with clear cut medical business, and everything else as being marginal to that: “a sort of rag-bag of funny illnesses that you can’t explain” (extract, 16, chapter 3) that are probably stress related. The fuzziness of this ‘dustbin’ category when contrasted with the unambiguous business of diagnostic categories is well designed to manage the tension between medical science, knowledge and everyday practice.

Different kinds of medical model are again deployed as an explanatory device in the GPs talk. The construct of unexplained illness is explainable as a *product* of the biomedical model which categorises illness and is exclusive of things that don’t fit into its categories. From this view, mystery illness is explicable only in terms of a new model of disease that will eventually allow medical science to provide complex

biopsychosocial explanations for all illnesses. This is again reminiscent of the ‘truth will out device’ which was suggested (in chapter two) as a way to overcome the “fruitless dichotomy” of dualistic explanations (Jenkins, 1991).

2. Models of medicine

In chapter four, a participants’ concern with the relationship between mind and body was brought forward from chapters two and three where it had emerged as a central issue in the debate about the existence and naming of a mystery illness. My concern, as analyst, has been to look at how the rhetoric of mind and body is constructed in and through professional and lay explanations of illness, and also to analyse the way that some authors have drawn attention to the potential for different models to be used to accomplish certain kinds of business.

Two kinds of model were outlined in this chapter. The first was biomedical and rooted in reductionist and dualistic philosophies; the second was biopsychosocial, and derives its rationale from systems theory in biology, promising to take into account the complex interplay between biological, psychological, and social processes in the explanation of disease. This new model has recently (over the last 20 years) been taken up in primary care practice as the so called “triple diagnosis” (e.g. Cohen-Cole, 1991) and its psychosocial aspects have been addressed by social science research into topics such as illness behaviour; people’s internal psychological states (such as personality, and cognitive states such as health beliefs, and illness attributions, etcetera); and socio-environmental factors. The first two categories are clearly individual. In other words they are things for which patients can be held accountable. The third can be drawn on as a resource to explain internal states such as stress, for which the individual can be held accountable via the rhetoric of coping, or lifestyle change.

Three models of psychosomatic illness (biological psychiatry, psychodynamics, and behavioural medicine) were also outlined in chapter four. Rather than all diseases

being conceptualised as psychosomatic (in the sense that all disease can be treated as a product of complex biopsychosocial processes), only certain disorders have attracted this kind of explanation, thus marginalising them into a separate category of ‘not quite legitimate’. Some authors have claimed that this protects the legitimacy of biomedicine by “siphoning off cases with which it is unsuccessful” (Lock and Gordon, 1988:11). Others have further argued that psychosomatics simply reproduces the dualistic relationship between mind and body that is central to biomedical explanations of illness (Kirmayer, 1988; Yardley, 1996).

The theoretical constructs of somatisation and psychologisation have also been discussed in this chapter, as being two sides of the same coin and related to dualistic conceptualisations of illness. Somatisation is defined by authors as the presentation of psychological problems as physical ailments (e.g. Katon, Reis and Kleinman, 1984: 208). The concept is well designed for the medical explanation of idiopathic symptoms, and has also been deployed as a counter move to dismiss such explanations as motivated by physicians who are unable to explain the patient’s symptoms using the rationale of biomedicine (e.g. Kirmayer, 1988; Goudsmitt and Gadd, 1991).

The main thrust of the argument in chapter four has been that the relationship between mind and body is a central concern in medical discourse. Different explanatory models are re-conceptualised here as repertoires that can provide the resources with which to categorise illness as either mental or physical. The psychosocial aspects of such models have the potential to be made relevant as a realm of moral accountability in explaining and treating illness.

3. Mind and Body

In chapter five, I do not address the distinction between mind and body as an analyst’s concern, to be taken up and potentially resolved in the context of theorising about the causes of illness. Instead I have analysed how the categories of mind and body and the relationship between them is ongoingly constituted in and through the activity of talking about M E and CFS.

I have suggested that the constitution of mind and body as separate categories in previous theoretical and philosophical conceptualisations (such as those described in chapter four), *itself* signifies their discursive utility. I argued that such categories are in the first place constituted in and through commonsense reasoning practices where they are useful as resources to explain illness as a realm of moral accountability. In the first part of the chapter I looked at different ways that medical practitioners have constructed the categories of mind and body on specific occasions of use. For example, either the mind or the body can be given primacy; the mind can be afforded conscious or unconscious control; the mind can be afforded an equivalent or distinct ontological status with the body; and finally, speakers can deploy different models of the relationship between mind and body - a linear cause and effect model (in either or both directions) or a process model of mind and body as fully integrated. These examples have indicated the variability that *can* be constituted in talk, and how this provides a rich resource for the construction of different versions of the nature of illness, and the management of accountability in the context of discussion about illness.

In the second part of the chapter, I looked at the use of mind and body constructions in a dialogue between a clinical psychologist and members of an M E self-help group. Mind and body as categorical resources are constructed, deployed, and ongoingly re-formulated through the interactional activity of managing some sensitive business. For example, categorisations of mind and body work to construct people's illnesses as being more or less physical and real. Notably, the guest speaker, and members of the M E self-help group work to avoid becoming implicated in the 'dangerous category' of 'all in the mind' explanations for illness.

The analysis in this chapter has demonstrated how different models of mind and body are rhetorically useful for different discursive purposes. The precise meanings of categories, their relationship to each other, and their implications for personal agency are co-constituted on and for the occasions of talk. A linear cause and effect model

was useful for making a definite claim in either or both directions. On the other hand, a complex process model works both to constitute and celebrate uncertainty. Three examples of the latter can be drawn from the analysis of data in this and previous chapters of this thesis.

First, in this chapter, Dr Brown (extract 6) used a complex process model to mitigate and account for not being able to give a definitive explanation in the current interaction of the interview, and also to indicate that a more sophisticated understanding of complexity is likely to obscure rather than enlighten medical explanations for illness. Second, in chapter two, David et al (extract 33) deployed a process model to claim a metaposition in the M E controversy. Third, in chapter three, Dr Walker appeals to a new kind of model as a basis for claiming that ‘the truth will out’ and medicine will be able to explain idiopathic symptoms when they use the correct model.

The conclusion of this chapter was that the dualism built into linear models of explanation, the interaction of mind and body assumed in process models, and the monism of approaches that constitute the mind as equivalent to the brain, are all well designed for the management of rhetorical business. It was found that, in practice, there is not a perfect fit between the mind as a realm of personal accountability, and the body as a passive or acted upon object, even though this kind of reasoning has been used by doctors explaining why patients might prefer a physical diagnosis for their illness. A closer look at mind and body talk in the context of a discussion shows how members of the group made various bids for authorship of the meaning of categories (such as mind and depression). It is argued here that the authorship of M E was itself a product of the interactional dynamics that take place within the group.

A reflexive feature of this chapter is the ‘fictional’ dialogue that appeared on pages 136-138). One of the main arguments has been that the meaning of categories is definable by how they are used, and in terms of uptake in the next turn at talk. The unfinalised dialogue explores and highlights the theoretical implications of making

any kind of claim to authorship of meaning. As a textual device, the unfinalised dialogue allows me (as author) to display the conversational turns of a theoretical controversy without necessarily having to resolve it (as I did in chapter two). The topic of the dialogue (the constitution of meaning) can also be heard as a reflexion of the co-constitution of meaning by participants *in* the dialogue that is also represented later in the chapter. As such the 'fictional' dialogue is a reflexive comment on the authorship of meaning in the thesis itself.

A Struggle For the Authorship of the Illness

The final section of the thesis has looked at the narrative construction of illness in patient's stories and doctor's cases.

The Narrative Construction of 'self' and M E.

Having previously (in chapters 3, 4 and 5) discussed and analysed the categorical and discursive resources that can be used in talk about illness, chapter six demonstrated how the approach of discursive psychology can make a theoretical and methodological contribution to the analysis of illness narratives. Specifically, this chapter has problematised narrative analyses that are based on cognitivism and a representational model of language, and instead examines an M E illness narrative as discursive action.

Current approaches to narrative analysis in health psychology have been summarised as a way to study people's personal experience and a way to gain insights into people's identities and culture. The descriptions of events in such narratives has primarily been analysed as a way to discover the details of events that happened, or to find out about the sick person's personal experience, health beliefs, and illness attributions. From a discursive psychology view such approaches to analysis reiterate the participant's explanations rather than analyses them as discursive action.

The rationale for the discursive psychology approach to narrative has been outlined as a prelude to my analysis of Angela and Joe's story, where the aim was to treat their

account as a discursive activity which itself constitutes the meaning of the illness and the sufferer's identity. I have used a courtroom metaphor as a textual device to organise my analysis of the illness narrative. This was not simply an attempt to impose analyst's gloss, but rather to recognise a set of discursive phenomena that are made available in the data, for example, the joint construction of consensus; the use of corroborating witness accounts and the undermining of 'hostile witnesses'. These are features that are common to both courtroom and also to ordinary everyday talk (Atkinson and Drew, 1979; Edwards and Potter, 1992). In the illness narrative, descriptions and attributions of cause or blame were found to be linked together in a co-implicative way to construct the factuality of the account, and to establish a particular 'theory of M E' and the identity of the sufferer.

The legitimacy of Angela's claim to physical illness was defended by '*building up a case*' in which Angela and Joe's 'theory of M E' was supported within the account by credible witnesses. Within the narrative, Angela and Joe (like Gilbert and Mulkay's biochemists, 1984) deploy two kinds of repertoire in their story of Angela's illness and medical encounters. An empiricist repertoire was deployed to establish a biomedical explanation for her illness as physical, real, and acknowledged by medical expertise. This account was positioned rhetorically in the narrative against a competing psychosomatic explanation for Angela's illness. Using a contingent repertoire, this was attributed to medical practitioners who were formulated as ignorant, lacking in expertise, and yet to learn the medical truth, or understandably misled by patients who make false claims. It is therefore not medical science itself that has been discredited in their account, but only *some* of its practitioners. The management of competing concerns to both undermine and uphold the expertise of medical practitioners is pivotal to the success of what is at stake in their narrative, that is, its power to persuade the listener of the medical legitimisation of Angela's illness.

The Narrative Construction of a Diagnosis

In chapter seven, I have continued along the lines that doctors' case narratives can be analysed in the same way as patients' stories about their illnesses. I have emphasised

the similarities between doctors' and patients' accounts and the discursive practices employed, rather than focus on the differences between lay and professional accounts of illness. More specifically, I have shown how 'documentary evidence' of a psychosocial nature and the underlying pattern that it points to are co-constituted in the narrative in a way that makes a particular interpretation of the patient's illness available, whilst dismissing other possible kinds of explanation. This is similar to the way that the psychosocial repertoire functioned in Angela and Joe's account to warrant a biomedical explanation for Angela's illness and to dismiss a psychogenic one.

Three kinds of concern were found to be common to both the case narratives of doctors, and the illness narratives of patients.

- Before and after stories.
- A concern with 'where the story starts'.
- Categorising people as mentally or physically ill.

The first of these concerns can be related to certain theoretical claims that have been made by some researchers about the causes of ME and CFS (e.g. Ware, 1992), and can also be related to media stereotypes of 'yuppie flu'. Tales of frenetic lifestyles prior to the onset of illness have previously been taken at face value and interpreted by researchers as evidence for either a self-inflicted vulnerability to the illness, or to explain the meaning of the symptoms of fatigue as symbolic of life in the fast lane. From this view, illness has been interpreted as a way to 'opt out' of the 'cult of business' (*ibid*).

The assumption underlying either of these interpretations is that 'before and after stories' in illness narratives should simply be taken as a representation of reality. However, I have pointed out in chapters six and seven that there are likely to be some important issues at stake in both doctors' diagnostic narratives and also in illness narratives. For example, these might be the doctor's concern to justify the giving of a particular kind of diagnosis in the context of uncertainty, or the patient's concern to dismiss the dangerous categories of malingerer, or prior psychological weakness.

When analysed as discursive action, 'before and after stories' can be interpreted as attending to such concerns in the way that they build up a contrast between the prior condition of an 'active go ahead' individual who has been completely changed by a debilitating illness. My argument is that assumptions about the nature and cause of ME or CFS that are based on 'before and after stories' fail to take account of the actions that discourse performs. I have noted elsewhere (see chapter seven, page 216) that 'before and after stories' are also a common feature in illness narratives of all kinds (Kleinman, 1988; Robinson, 1990; Ware, 1992) I have argued that this is because of the 'double-jeopardy' of illness talk in the world of the healthy (Radley and Billig, 1996). These observations have important implications for research in the sociology and social psychology of health and illness, especially those studies that are in the business of investigating people's illness experiences with a view to influencing policy-making and treatment.

A concern with 'where the story starts' was also common to the accounts of both doctors and patients in talking about M E. As I pointed out earlier, this relates to a concern with what kind of information is being made relevant in the story. Typically, stories that make available the detail of prior life events, such as stress or bereavement, build up the speaker's grounds for making a psychological interpretation of illness. On the other hand, stories that start with the sudden onset of illness in an otherwise untroubled and active life are well designed to sustain a physical interpretation of illness.

This brings me to the third issue that was at stake in the narrative accounts of both doctors and patients, which was the categorisation of people as either mentally or physically ill. As with Angela and Joe's illness narrative, I found that doctors used psychosocial evidence as a warranting device to make *either* mental or physical diagnoses. This was rather different from the suggested use of a complex process model to explain all disease in biopsychosocial terms (Engel, 1977; 1980), and seemed to maintain and perpetuate dualistic explanations of illness. This finding might have further implications for the practical instantiation of the 'triple diagnosis' so that an

interesting question for further research would be: How is the biopsychosocial model constituted and deployed in the diagnostic practices of doctors in primary care?

The main contributions of this thesis can be glossed as follows:

- The topic of M E has been used as a forum to display the dialogical construction of the meaning of illness as a practical accomplishment in text and talk.
- This has provided the opportunity to explore the rhetoric of mind and body categories in the context of illness talk.
- I have provided an in-depth example of how a discursive psychology approach can contribute to the analysis and understanding of illness narratives, and how that constitutes a challenge to other types of analysis and has implications for theorisation about the nature and meaning of illness.
- My analysis of doctors' narratives also poses questions relating to the practical instantiation of the biopsychosocial model in constructing primary care diagnoses.

Author's (end)note

In the title of my thesis the term 'authorship' refers to the process of defining meaning, both in the M E controversy, and in the dialogical construction of my own textual version. To reiterate:

I have indicated my own use of 'alternative literary forms' in certain parts of the text, where they work to (de)construct my own version as reflexive; highlight its intertextual properties; or display the 'rhetorico-responsive' nature of discourse (...) They constitute a form of analysis which can not only highlight the textual and dialogical construction of reality, but can also make explicit the alternative 'voices' that are implicit in a single utterance, account or argument. (Horton-Salway, 1998: 20)

Then there's the question of whether or not we (should) have a dialogue at all. Or indeed of what counts as a dialogue (...) I would guess that you also need to include some notion that the sentences represent different turns by separate speakers. This is what would distinguish it from ordinary connected prose. But then again, you might argue that it is quite possible to arrange what is actually dialogue in the form of connected prose: that is, although it appears

like prose, it is actually dialogue. Or vice-versa. So you could say that this is a dialogue. Or even that it is not! (Woolgar, and Ashmore, 1988)

A (Dialogical) Postscript

- Analyst What do you make of the whole M E thing ?
- Dr Smith In the form of M E, or what we used to know it as ?
- Analyst uh?
- Dr Turner I was sceptical initially..I have to say..for a while it seemed to
 be..y'know this decade's thing..and went along the same sort of lines as
 Total Allergy Syndrome and things like that...
- Dr Walker I think the attitude towards the term M E will probably change..I think
 it's going through a process of becoming..legitimate if you like...we
 may be confused in what we understand about it..but there probably is
 something there that actually is a separate illness of some sort...post-
 viral fatigue is a medically more popular name..in the sense that it
 implies that you know what's causing it...I'm not sure that's
 necessarily true...
- FM M E was used alot initially...alot of writers are changing over to the
 term CFS..because M E implies a particular cause..something to do
 with the nerves and the muscles...and because there's no clear cut
 cause been found...then people are saying 'well let's not give it a label
 that implies a cause'..when we don't actually know what it is yet...
- CR Well I was told by the physician at the hospital..that CFS..or post-
 viral..was what alot of people got after suffering from a very bad
 virus..and this would probably last for about eighteen months..two
 years...and then if that person didn't recover..er and continued with the
 symptoms or got worse..er..they then say you've got M E..er but
 initially it would be diagnosed as CFS or post-viral syndrome...and
 that's how I was led to believe...

- Dr Turner Well syndromes...I think technically a syndrome is...a group of symptoms for which nobody's found a reason for...technically that might be more appropriate for this particular disease...because nobody's found an underlying cause for it..er but I think M E and what it stands for...is making a more definite statement about it..is recognising it more as a disease entity rather than...yeah..than as I say a syndrome (...) M E seems a little more specific...a little less nebulous...
- HK Well my GP says he believes there's something...but he doesn't really understand why it's called M E...he doesn't feel that's the right handle for the illness..
- Dr Kelly It's the label that I don't like...and it's the enforcement of the label ...well myalgic...muscle pain...encephalomyelitis...as a pathological description it's a bit of a nonsense really isn't it? Because you can't really define that..how can you define encephalomyelitis...is there any pathological evidence for it ? I don't think there ever was any evidence...
- Dr North Evidence...mm...I don't really know what to make of it heh still to be honest...it's er...even when you go away and try to find some information on it...what there is is very vague er..and... I don't really understand what it is...I'm still very undecided...you just think 'oh they still haven't made their minds up...they don't know what's going on'..so you reject it as well I suppose...
- Dr Butler The typical one's this viral trigger isn't it ?
- Dr Mason er...that's the one that you...you expect from the literature...true post-viral fatigue...
- EC Well yes..I started with a virus..er which was worse than anything I've ever had before...
- BH Mine started I'm fairly sure...when I had what was classed as Asian 'flu..and er I just had continuous infections for six months...it took me to bed...and that's very unusual for me..and I just didn't seem as if I could really throw it off...it was just one infection after the other (...)

and I just got more and more exhausted...and I thought 'there's something wrong here' y'know 'this is not me at all'..because I'm a very very active person...

JG Well y'know..M E is now recognised as being caused by an enterovirus..it's been called non-paralytic polio in some areas...now that's totally different...totally different from post-viral fatigue..or your chronic fatigue...

FM I don't think...there isn't a virus that's been isolated yet is there ?

Dr Turner Well no..I still think stress plays an important part in it...now whether it's positive or whether it's something which affects the symptoms once you've got them..er I think is er..and area which is probably quite debateable..er certainly people..patients I've seen..patients with quite highly stressed life styles..er stressed jobs...stressful situations...when the diagnosis has been made...

Dr Evans I must admit..I mean in part it tends to be a ...you think they might have a bit of co-existent depression...this sort of pseudo-theory that possibly it is some sort of chemical imbalance of neurotransmitters in the brain...that happens after the viral illness..y'know serotonin and noradrenalin and stuff like that...probably that's how M E works ...but I mean that's more of a hunch than proven fact...

JJ What has upset some people with M E in the past..is some doctors..say M E is caused by mental problems..er that has been disproven...it annoys people with M E..when they hear this said...

FM The problem is..when people have done research with CFS or M E sufferers...they do find...if you give them standard psychiatric interviews..they have a much higher level of depression than say another group with chronic health problems..chronic heart disease or other problems..so..that's why...it's not by any means all people..but it's higher than you'd normally expect...there's a higher incidence of depression...that's one suggestion y'know that...is there some type of

depression..is it?...you see another thing is that chronic fatigue..the actual symptom of fatigue is a symptom of depression...

JJ You see the trouble is...one of the troubles with M E is that nobody knows the answers..nobody can say categorically 'I wouldn't have..it wouldn't have happened to me anyway no matter what state of mind I was in'...

FM But there's something psychological there...why should it affect one personality more than another...if it's a virus ?

JJ Y'know some people say that the depression causes M E...but I think it's the M E that causes the depression..or at least that the two things linked together..they're tied together..but there are some people who believe that M E is caused by depression...that your mind..it's all in the mind y'know...they actually told me that at the hospital...

Dr Butler I suspect there's alot of overlap...and I think some people with genuine M E..get labelled as depression...and I think that some people with just depression either label themselves..or get labelled as having M E...

HK But I think alot of the sort of ...depression side of M E in sufferers..comes from the fact..that we become depressed trying to convince the doctors...the medical profession..there's something wrong with us..

JJ Well I'm convinced there is a psychological element in M E...I'm certain of it...but I don't think..I think it's a consequence rather than a cause (...) what's upset some people with M E..the fact that they've been told ..or they've read ..it's purely a psychological illness...and they know very well it isn't...

FM It depends what you mean when you say psychological...if you're saying that people think there's nothing physically wrong with you at all ..that you're sort of in a way imagining it ..is that what you mean ? (...) it's very difficult to see what you mean when you say something is..psychological...are you saying that it's all imagined..there's nothing particularly wrong with the body..it's all in the mind ?...or are you

saying that the mind affects the body..and therefore things could be partly psychological..y'know I mean..that to me..that's how I think of it..that the mind and the body affect each other...I don't seriously suggest that people imagine the symptoms that they have...they are genuine physical symptoms...

JJ I think it's a bit deeper than that though with M E..I know physical illnesses cause psychological problems but I think with M E there's a closer link...it's not just the fact that you've got M E that makes you feel depressed...it's something affecting the brain itself...

Dr Walker Right..er..okay..for what it's worth..okay it's not my field but..I mean I would have thought it's something to do with the reaction of the immune system...I was going to say 'stresses' ..but not stresses in the sense of mental stresses...stressors in the sense of infections ...things that upset the immune system in some way..and upset the control of that ..and that's some things are going wrong then because it's..I mean the way the immune system works and so on is still not that well understood ..and the more people find out about it the more complicated it looks...

Dr Turner I'd like there to be a nice acid test that you could do heh heh (...) it's the nebulousness of it that puts alot of doctors off (...) I think even just having er...an accepted disease entity..we could do a test for..that proved it..would be a start...

Dr Evans Right er...there was this one girl..she'd be late teens..very early twenties..when she first started with it..very outgoing and everything..she had a definite...recognisable viral illness...er I think she had a positive monospot at the time for glandular fever..or at least (...) she had a viral picture which er..seemed to go along with that..and then ever since then she has..been a different person really...

Dr Walker Y'know..this is something that I think doctors are sometimes more comfortable with...when they can say 'well this is a bit like glandular fever..it's the aftermath of an infection'..and it's a working model if

you like..which gives some assurance that it isn't in the mind..there is something..there's a possible explanation for it..the problem with that..I'm not at all sure that is the explanation..that may be oversimplistic and I'm not sure how honest it is...

Dr Brown You see..I think the thing is heh I mean obviously..when we don't feel well and we try to make sense of it..and we want a name for it..um..because if you've got a name for it...it makes us feel safer..that we're not at the whims of some random whatever...or we're going mad (...) y'know so I think alot of people want a diagnosis of M E because they then think that's going to...either make it easier or somebody else will be able to cure it..er...

FM I mean it may be that there's a number of sub-illnesses..all with different causes..some caused by viruses..some caused by immune changes..and no-one presents in similar ways..I mean I don't pretend to be an expert anymore than anybody else..er..but I mean that..the psychology approach can still have a role to play..really regardless of what causes it because there's two things...one is what causes it and the other is what helps it to get better...and there's an interest in a wide range of illnesses..looking at how the psychological approach can be used to enhance people's recovery..I mean that's applied to cancer and heart disease or whatever other..regardless of what the actual cause is...

Dr Mason Yeah..if you look at the..mental well being of the rest of the community..it isn't that surprising that people need help..er I mean..the regional figures are..one in eight people working for that service need..psychological outpatient treatment (...) we see so much psychosomatic presentation that it's difficult to pull it apart..and..the other thing is that...it's widely known that..overwhelming tiredness is a symptom of psychological distress...but it may also be a symptom of ..er organelle failure...

Dr Kelly You see..you can't argue with their symptoms..the symptoms are what they perceive and experience..but to actually label it..as 'it is not

depression..it is M E' ..to my mind is er..not right...(...) I suppose you've got to say 'well why do they like the title..of M E rather than depression?' ...I think there is a social class element to it as well..that prefers the title of M E than the title of depression...I think the middle classes prefer to be labelled M E rather than depression (...) it's er..people are picking up on different labels and accepting those they find...palatable..and ignoring those that are unpalatable...it makes the treatment of it very difficult because if people come in with this rigidity of notion that it is M E..and that is it...then that's difficult to treat...

Dr Brown Well yeah...but they also want to be taken seriously ...and there's still this in people's minds...they link nerves with the fact that somehow the doctor's gonna be dismissing it...and that they're being fobbed off..er.. these sorts of things

Dr Turner It's a very frustrating area for everybody involved in it...

"This is what we have so far. I'm afraid things are still very obscure. And I'm not at all sure about this ending. Do we need to start again?"¹

(...)

¹ Woolgar and Ashmore (1988: 11).

APPENDIX

Transcription Conventions

The transcription symbols, used in this thesis are based on the system developed mainly by Gail Jefferson (see Atkinson and Heritage, 1984).

[	A left hand square bracket indicates overlapping speech at the point where the overlap begins.
]	A right hand square bracket indicates where the overlap ends.
=	An 'equals' sign indicates 'latching' of successive talk.
(.)	A dot in brackets indicates a hearable pause that is too short to measure.
(0.3)	Numbers in brackets measure pauses in seconds (for example, three-tenths of a second).
↑↓	Vertical arrows precede rising and falling intonation.
> <	Indicates speeded up talk.
CAPITALS	Mark speech that is obviously louder than surrounding speech.
<u>underlining</u>	indicates emphasis
Ye:ah	A colon indicates elongation of the vowel sound that it follows.
(...)	Indicates where some talk has been omitted from a data extract.
?	Rising intonation.
°speech°	'Degree' signs enclose obviously quieter speech.
Bu-u-	Hyphens mark false-starts.
.hh	A dot before an 'h' indicates speaker in-breath. The more h's the longer the in-breath.
hh	An 'h' indicates out-breath. The more h's the longer the outbreath.
(single brackets)	Utterance unclear, best guess presented.
((double brackets))	Some non-verbal action performed.

REFERENCES

- Abbey, S. (1993). *Somatisation, illness attribution and the sociocultural psychiatry of chronic fatigue syndrome*. In *Chronic Fatigue Syndrome*. Ciba Foundation Symposium 173. Wiley. Chichester: 238- 261.
- Abrams, R.D. and Festinger, J.E. (1953). Guilt reactions in Patients with Cancer. *Cancer* 6: 474-482.
- Acheson, E.D. (1954). Encephalomyelitis associated with a poliomyelitis virus: an outbreak in a nurses' home. *Lancet*. 2, 1044.
- Acheson, E.D. (1959). The clinical syndrome variously called Benign Myalgic Encephalomyelitis, Icelandic Disease and Epidemic Neuromyasthenia. *American Journal of Medicine*. 26: 569-595.
- Ackerknecht, E.H. (1973). *Therapy*. Hafner: New York.
- Ackerknecht, E.H. (1981). Causes and pseudocauses in the history of diseases. In *Fifty Years of the History of Medicine* (ed. L. Stevensen). Johns Hopkins Institute: Baltimore.
- Ackerknecht, E.H. (1982). The history of psychosomatic medicine. *Psychological Medicine*, 12, 17-24.
- Adamson, J.R. (1969). Epidemic neuromyasthenia (cont). *New England Journal of Medicine*, 281: 789.
- Alexander, J.S. (1956). Observations on neuromuscular dysfunction in the Addington outbreak. *South African Medical Journal*. 30: 88.
- Amirkhan, J.H. (1990). A factor analytically derived measure of coping: The coping strategy indicator. *Journal of Personality and Social Psychology*. 59, 1066-74.
- Arber, M. and Macintyre, A. (1994). Chronic fatigue syndrome or myalgic encephalomyelitis. *British Medical Journal*. Jan. 22, 243.
- Archer, M.I. (1987). The post-viral syndrome: a review. *Journal of the Royal College of General Practitioners*, 37, 212-214.
- Aronovitch, R.A. (1992). History of Chronic Fatigue Syndrome. In *Framing Disease*, (Eds.) C. E. Rosenberg and J. Golden. Rutgers University Press. New York.
- Ashmore, M. (1989). *The Reflexive Thesis: Wrighting Sociology of Scientific Knowledge*. Chicago: University of Chicago Press.
- Ashmore, M., Mulkay, M., and Pinch, T. (1989). *Health and Efficiency: A sociological study of health economics*. Milton Keynes: Open University Press.
- Atkinson, J.M. (1984). *Our Master's Voices: the Language and Body Language of Politics*. London: Methuen.
- Atkinson, J.M. and Drew, P. (1979). *Order in Court: the Organization of Verbal Interaction in Judicial Settings*. London: Macmillan.
- Atkinson, J.M. and Heritage, J.C. (Eds.) (1984a). *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press.
- Atkinson, P. (1995). *Medical Talk and Medical Work: The Liturgy of the Clinic*. London: Sage.
- Austin, J.L. (1962). *How to Do Things with Words*. Oxford: Clarendon Press.
- Bakhtin, M.M. (1984). *Problems of Dostoyevsky's Poetics*, ed. and trans. C. Emerson. Minneapolis: University of Minnesota Press.
- Bal, M. (1985). *Narratology: Introduction to the Theory of Narrative*. Toronto: University of Toronto Press.

- Balla, J.I. (1985). *The Diagnostic Process: A Model for Clinical Teachers*, Cambridge University Press, Cambridge.
- Bard, M. and Dyke, R.B. (1956). The Psychodynamic Significance of Beliefs Regarding the Cause of Serious Illness. *Psychoanalytic Review*. 43: 146-162.
- Barthes, R. (1974). *S/Z*. London: Jonathan Cape.
- Bartley, M. (1985) Coronary heart disease and the public health 1850-1983. *Sociology of Health and Illness*, 7, 289-313.
- Baumeister, R.F. and Newman, L.S. (1994). How stories make sense of personal experiences: Motives that shape autobiographical narratives. *Personality and Social Psychology Bulletin*. 20, 674-690.
- Beard, G. (1869) Neurasthenia, or nervous exhaustion. *Boston Medical and Surgical Journal*, 3 (new series): 217-20.
- Becker, H.S. (1963) *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press.
- Behan, B.O. and Bakheit, A.M.O. (1991). Clinical spectrum of post-viral fatigue syndrome. *British Medical Bulletin*, 47: 793-808.
- Berger, P. and Luckmann, T. (1966). *The Social Construction of Reality*. Garden City, NY: Doubleday.
- Billig, M. (1987). *Arguing and Thinking: a Rhetorical Approach to Social Psychology*. Cambridge: Cambridge University Press.
- Billig, M., Condor, S., Edwards, D., Gane, M., Middleton, D. and Radley, A.R. (1988). *Ideological Dilemmas*. London: Sage.
- Blisset, M. (1972). *Politics in Science*, Boston: Little, Brown and Co.
- Bogen, D. and Lynch, M. (1989). Taking account of the hostile native: plausible deniability and the production of conventional history in the Iran-Contra hearings, *Social Problems*, 36: 197-224.
- Boring, E.G. (1929). *History of Experimental Psychology*, New York, Century.
- Breakwell, G.M. and Canter, D.V. (1993). *Empirical approaches to social representations*. Oxford: Clarendon.
- Brodsky, C.M. (1983). "Allergic to everything" - a medical subculture. *Psychosomatics*, 24: 731-42.
- Bruner, J.S. (1990). *Acts of Meaning*. Cambridge, MA: Harvard University Press.
- Bruner, J.S. (1991). The Narrative Construction of Reality. *Critical Inquiry*, 18, 1-21.
- Burke, K. (1945). *A Grammar of Motives*. New York: Prentice Hall.
- Butler, S., Chalder, T., Ron, M., and Wessely, S. (1991). Cognitive Behaviour Therapy in the Chronic Fatigue Syndrome, *Journal of Neurology, Neurosurgery, Psychiatry* 54: 153-158.
- Button, G. and Lee, J.R.E. (1987). *Talk and Social Organisation*. Clevedon: Multilingual Matters.
- Carver, C.S., Pozo, C., Harris, S.D., Noriega, V., Scheir, M.F., Robinson, D.S., Ketcham, A.S., Moffat Jr, L. and Clark, K.C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65, 375-90.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5, 168-195.
- Chomsky, N. (1965). *Aspects of the theory of syntax*. Cambridge, MA: MIT Press.
- Chomsky, N. (1966). *Cartesian linguistics: A chapter in the history of rationalist thought*. New York: Harper and Row.

- Chomsky, N. (1968). *Language and mind*. New York: Harcourt, Brace and World.
- Clinical Meeting of the Natal Coastal Branch. (1955). The Durban mystery disease. *South African Medical Journal*. 29: 997.
- Cohen-Cole, S.A. (1991). *The Medical Interview: the three function approach*. St Louis MO: Mosby.
- Collins, H.M. (1985). *Changing Order: Replication and Induction in Scientific Practice*. London: Sage.
- Compston, N. (1956). (correspondence) *British Medical Journal*. 2. 157.
- Creed, F., Mayou, R., and Hopkins, A. (eds.) *Medical Symptoms not explained by organic disease*. London: Royal College of Psychiatrists and Royal College of Physicians of London. 1992.
- Crowley, N. Nelson, M. and Stovin, S. (1957). Epidemiological Aspects of an Outbreak of Encephalomyelitis at the Royal Free Hospital, London, in the Summer of 1955. *Journal of Hygiene*. Cambridge. 55, 102.
- Da Costa, J.M. (1871). On irritable heart: a clinical study of a form of functional cardiac disorder and its consequence. *American Journal of Medical Science*, 121: 17-52.
- Daikos, G.K. Paleologue, A. Garzonis, S. Bousvaros, G.A. Papadoyannakis, N. (1959). Benign Myalgic Encephalomyelitis. An outbreak in a Nurses' School in Athens. *Lancet*, 2, 693-696.
- David, A. Wessely, S. and Pelosi, A. (1988). Postviral fatigue: time for a new approach. *British Medical Journal*, 296, 696-699.
- David, A. and Wessely, S. (1993). Chronic fatigue, ME and ICD-10. *British Medical Journal*. Nov. 13.
- Dawes, B. (1991). What does M.E. mean to m?: A holistic viewpoint. *Maternal Child Health*, Dec: 380-384.
- Delamothe, T. (1994) Look at M.E. *British Medical Journal*. March 19, 798.
- Derrida, J. (1977b). Limited inc abc. . . . *Glyph*, 2: 162-254.
- DiGiacomo, S.M. (1992). Metaphor as Illness: Postmodern Dilemmas in the Representation of Body, Mind and Disorder. *Medical Anthropology*, Vol.14, 109-137.
- Dilthey, W. (1972). The Rise of Hermeneutics. *New Literary History*, 3, 229-44.
- Dimsdale, H. (1957b). Acute encephalomyelitis of virus origin. *Modern Trends in Neurology*. ed. D. Williams. London: Butterworths.
- Drew, P. (1990). Strategies in the contest between lawyers and witnesses. In J.N. Levi and A.G. Walker (Eds.), *Language in the Judicial Process*. New York: Plenum.
- Dunbar, F. (1943). *Psychosomatic Diagnosis*. Hoeber: New York.
- Easton, C. (1989). *Jacqueline Du Pre. A Biography*. London: Hodder and Stoughton.
- Easton, H.G. (1978). Epidemic Malaise. *British Medical Journal*. 2, 1696.
- Edwards, D. (1997) *Discourse and Cognition*. London: Sage.
- Edwards, D. (1995). What's in a word? Bring on the seals and the sheep (In response to Hofmann). *Journal of Pragmatics*, 23, 451-453.
- Edwards, D. (1991). Categories are for talking: On the cognitive and discursive bases of categorization. *Theory and Psychology*, 1 (4), 515-542.
- Edwards, D. and Middleton, D. (1986a). Joint Remembering: Constructing an account of shared experience through conversational discourse. *Discourse Processes*, 9, 423-459.

- Edwards, D., Ashmore, M., and Potter, J. (1995). Death and furniture: The rhetoric, politics, and theology of bottom line arguments against relativism. *History of the Human Sciences*, 8 (2), 25-49.
- Edwards, D., and Potter, J. (1992a). *Discursive psychology*. London: Sage.
- Eisenberg, L. (1977). Disease and Illness: Distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry* 1: 9-24.
- Elder, R.G. (1973). Social Class and Lay Explanations of the Etiology of Arthritis. *Journal of Health and Social Behaviour* 14: 28-38.
- Endler, N.S. and Parker, J.D.A. (1990). Multidimensional assessment of coping: A critical evaluation. *Journal of Personality and Social Psychology*, 58, 844-54.
- Engel, G.L. (1977). The need for a new medical model: a challenge for biomedicine. *Science* 196: 129-136.
- Engel, G.L. (1980). The Clinical Application of the Biopsychosocial Model. *American Journal of Psychiatry* 137: 5, 535-544.
- Erikson, K.T. (1962). Notes on the sociology of deviance. *Social Problems*. vol.9, 307-14.
- Evans, A.C. (1947). Brucellosis in the United States. *American Journal of Public Health*, 37: 139-51.
- Fabrega, H. (1973). *Disease and Social Behavior*. Cambridge, Mass: MIT Press.
- Fabrega, H. (1975). The need for an ethnomedical science. *Science*. 189: 969-975.
- Farr, R. (1985). *Some reflections on the historical development of psychology as an experimental and social science*. London: London School of Economics and Political Science.
- Farr, R. and Moscovici, S. (Eds.). (1984). *Social representations*. Cambridge: Cambridge University Press.
- Fog, T. (1953). Neuritis vegetativa epidemica. *Ugesk. f. laeger*, 115: 1244.
- Folkman, S., and Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour*. 21, 219-39.
- Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A. and Gruen, R. (1986a). The dynamics of a stressful encounter. *Journal of Personality and Social Psychology*. 50, 992-1003.
- Folkman, S., Lazarus, R.S., Gruen, R.J. and DeLongis, A. (1986b). Appraisal, coping, health status and psychological symptoms. *Journal of Personality and Social Psychology*. 50, 571-9.
- Foucault, M. (1973). *The Birth of the Clinic: An Archaeology of Medical Perception*. trans. A.M. Sheridan Smith. London: Tavistock.
- Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings 1972-77*, trans. C.Gordon, Hemel Hempstead: Wheatsheaf.
- Frank, A.W. (1993). The rhetoric of self-change: illness experience as narrative. *Sociological Quarterly*, 34, 39-52.
- Frank, A.W. (1997). Illness as moral occasion: restoring agency to ill people. *Health*. 1(2) 131-148.
- Freeman, M. (1993). *Rewriting the Self: History, Memory, Narrative*. London: Routledge.
- Fromkin, V. and Rodman, R. (1998). *An Introduction to Language* (sixth edn.). Fort Worth, TX: Harcourt Brace College Publishers. p. 158.
- Frye, N. (1957). *Anatomy of Criticism*. Princeton, NJ: Princeton University Press.

- Galen (1821). *Opera* (ed. L.S. Kuehn). *Ars medica*, vol. 1, 367. *De sanitate tuenda*, vol. 2, 78. Lipsiae.
- Galpine, J.F. and Brady, C. (1957). Benign Encephalomyelitis. *Lancet*. April 1957, pp.757-758.
- Galpine, J.F. (1958). Benign myalgic encephalomyelitis. *British Journal of Medical Practice*. 12, 186.
- Gantz, N.M. and Holmes, G.P.(1989). Treatment of patients with chronic fatigue syndrome. *Drugs*, 38, 855-862.
- Garfinkel, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.
- Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.
- Geertz, C. (1988). *Works and Lives: the Anthropologist as Author*. Oxford: Polity.
- Geffen, D. and Tracy, S.M. (1957). An outbreak of Acute infective Encephalomyelitis in a Residential Home for Nurses in 1956. *British Medical Journal*, October 1957, pp.904-6.
- Gergen, K.J. and Gergen, M. M. (1986). Narrative form and the construction of psychological science. In T.R. Sarbin (Ed.), *Narrative psychology*. (22-44) New York: Praeger.
- Gergen, M.M. (1994). The social construction of personal histories: Gendered lives in popular autobiographies. In T.R.Sarbin and J.I.Kitsuse (Eds.), *Constructing the Social*. London: Sage.
- Gilbert, N.G. and Mulkay, M. (1984). Opening Pandora's Box: A sociological analysis of scientist's discourse. Cambridge University Press. Cambridge.
- Gill, C.H. (1970). Epidemic medicine. *British Medical Journal*, 1, 299.
- Gilliam, A.G. (1938). Epidemiological 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, U.S. Treasury Dept. No. 240.
- Glaser, B. and Strauss, A.L. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine Press.
- Goffman, E. (1971;1990). *The Presentation of Self in Everyday Life*. London: Penguin.
- Gordon, D.R. (1988). Tenacious Assumptions in Western Medicine, In *Biomedicine Examined*. M. Lock and D.R.Gordon (Eds.) Kluwer Academic Publishers: 24.
- Gosling, P. (1970). Epidemic Malaise. *British Medical Journal*, 1, 499-500.
- Goudsmit, E.M. and Gadd, R. (1991). All in the Mind? The psychologisation of illness. *The Psychologist*, 4, 449-453.
- Grice, H.P. (1975). Logic and conversation: In P. Cole and J. Morgan (eds), *Syntax and Semantics 3: Speech acts*. New York: Academic Press.
- Gsell, O. (1958). Encephalomyelitis myalgic epidemics, eine poliomyelitisahnliche Krankheit. *Schweizerische Medizinische Wochenschrift*, 88, 488.
- Guggenbuhl-Craig, A. and Micklem, N. (1988). No answer to Job: Reflections on the limitations of meaning in illness. In M. Kidel and S. Rowe-Leete (Eds.), *The meaning of illness* (pp. 141-153). London: Routledge.
- Harre, R. (1983). *Personal Being: a Theory for Individual Psychology*. Oxford: Blackwell.
- Heider, F. (1958). *The Psychology of Interpersonal Relations*. New York: Wiley.

- Heider, F. and Simmel, M. (1944). An experimental study of apparent behaviour. *American Journal of Psychology*, 57, 243-259.
- Heritage, J.C. (1984). *Garfinkel and Ethnomethodology*. Cambridge: Polity.
- Hermann, C.F. (ed.) (1919). Charmenides. In *Dialogs*, Vol. 9, 5. Lipsiae.
- Herzlich, C. (1973). *Health and Illness: A social psychological analysis*. trans. D. Graham. London: Academic Press.
- Hill, R.C.J. (1955). Memorandum on the outbreak amongst nurses at Addington Hospital, Durban. *South African Medical Journal*. 29, 344.
- Hill, R.C.J. Cheetham, R.W.S. Wallace, H.L. (1959). Epidemic Myalgic Encephalomyelopathy. The Durban Outbreak. *Lancet*. 2, 690-693.
- Himmelhoch, J. Pincus, J. Tucker, G. and Detre, T. (1970). Sub-acute encephalitis: behavioural and neurological aspects. *British Journal of Psychiatry*, 116, 531-538.
- Holmes, G.P., Kaplan, J.E., Gantz, N.M., Komeroff, A.L. et al (1988) CFS: a working case definition. *Annals of Internal Medicine*, 108: 387-9. International Federation of ME Associations et al. (1993). London Criteria.
- Holquist, M. (1981). (Ed). *The Dialogical Imagination: Four Essays by M.M. Bakhtin*. trans. Caryl Emerson and Michael Holquist. Austin: University of Texas Press.
- Hope Pool, J. Walton, J.N. Brewis, E.G. Uldall, P.R. Wright, A.E. and Gardner, P.S. (1961). Benign Myalgic Encephalomyelitis in Newcastle Upon Tyne. *Lancet*, 2, 733-737.
- Hopkins, E.J. (1970). Epidemic Malaise. *British Medical Journal*, 1, 501.
- Howard, G.S. (1991). Culture tales: A narrative approach to thinking, cross-cultural psychology, and psychotherapy. *American Psychologist*, 46, 187-197.
- Ho-Yen, D.O. (1990). Patient management of post viral syndrome. *British Journal of General Practice*, 40, 37-39.
- Hume, M.C. (1992). Self-help organisation's advice on myalgic encephalomyelitis. *The British Medical Journal*, vol.305, 12 Sept, 649.
- Huxley, A. (1952). *The Devils of Loudun*. London, Chatto and Windus.
- Jefferson, G. (1990). List construction as a task and resource, in G. Psathas (ed.), *Interaction Competence*. Lanham, MD: University Press of America.
- Jelinek, J.E. (1956). Benign Encephalomyelitis. *Lancet*. September 1956, pp.494-5.
- Jenkins, R. Aggett, P. and Newall, B. (1988a). *Teaching medical students and registrars: a multidisciplinary team approach to the management of chronic pain and abnormal illness behaviour*. Association of University Teachers of Psychiatry Newsletter, London.
- Jenkins, R. Smeeton, N. and Shepherd, M. (1988b). *Classification of Mental Disorder in Primary Care*, Psychological Medicine Monograph No. 1, Cambridge University Press, Cambridge.
- Jenkins, M. (1989). Thoughts on the management of myalgic encephalomyelitis. *British Journal of Homeopathy*, 78, 6-14.
- Jenkins, R. (1991). *Introduction*. in Jenkins R. and Mowbray, J. (eds.) (1991). *Post-Viral Syndrome*. Wiley.
- Jenkins, R. and Mowbray, J. (eds.) (1991). *Post-Viral Syndrome*. Wiley.
- Jones, J.F., Ray, C.G., Minnich, L.L., Hicks, M.J., Kibler, R., Lucas, D.O. (1985). Evidence for active Epstein-Barr virus infection in patients with persistent, unexplained illnesses: elevated anti-early antigen antibodies. *Annals of Internal Medicine*, 102: 1-7.

- Judge, B. (1970). Epidemic Malaise. *British Medical Journal*. Jan. 1970, p. 171.
- Katon, W. Reis, R. and Kleinman, A. (1984). The prevalence of somatisation in primary care. *Comprehensive Psychiatry*, 25(2): 208-215.
- Kennedy, H.G. (1987). Fatigue and fatiguability. *The Lancet*, May 16, 1145.
- Kerckhoff, A.C. and Back, K.W. (1968). *The June Bug*. New York, Appleton-Century-Crofts.
- Kety, S. (1974). *American Journal of Psychiatry* 131, p.957.
- King, S.H. (1962). *Perceptions of Illness and Medical Practices*. New York: Russell Sage Foundation.
- Kirmayer, L. J. (1988). Mind and Body as Metaphors: Hidden Values in Biomedicine. In *Biomedicine Examined*, (Eds.) M. Lock and D.R. Gordon, Kluwer Academic Publishers. pp 57-93.
- Kitsuse, J.I. (1962). Societal reaction to deviant behaviour: problems of theory and method. *Social Problems*. vol. 9, 247-56.
- Kleinman, A.M. (1973). Towards a Comparative Study of Medical Systems: An Integrated Approach to the Study of the Relationship of Medicine and Culture. *Science, Medicine and Man* 1: 55-65.
- Kleinman, A.M. (1988). *The Illness Narratives: Suffering Healing and the Human Condition*.
- Kleinman, A.M. and Kleinman, J.(1985). *Somatization*. In *Culture and Depression*. Edited by A.Kleinman and B.Good, 429-90. Berkeley: University of California Press.
- Kleinman, A. and Straus, S.E. (1993). *Introduction*, in CIBA Foundation Symposium: 173. (Eds. G.R. Bock and J.Wheelan), Chichester, Wiley.
- Kress, G. and Hodge, R. (1979). *Language as Ideology* London: Routledge and Kegan Paul.
- Labov, W. (1972). *Language of the Inner City*. Philadelphia: Philadelphia University Press.
- Lain Entralgo, P. (1956). *Heilkunde in geschichtlicher Entscheidung*. Salzburg.
- Laing, R.D. (1967). *The Politics of Experience*. New York: Ballantine Books.
- Latour, B. (1980). The three little dinosaurs or a sociologist's nightmare. *Fundamenta Scientiae* 1, 79-85.
- Latour, B. (1987). *Science in action*. Milton Keynes: Open University Press.
- Latour, B., and Woolgar, S. (1979). *Laboratory life: The social construction of scientific facts*. London: Sage.
- Leading Article.(1954). Not Poliomyelitis. *Lancet*. 2: 1060.
- Leading Article. (1956). A New Clinical Entity? *Lancet*, 1: 789.
- Leading Article. (1957). Epidemic myalgic encephalomyelitis. *British Medical Journal*. 2: 927.
- Lemert, E.M. (1951). *Social Pathology*. McGraw-Hill.
- Lemert, E.M. (1967). *Human Deviance: Social problems and Social Control*. Prentice-Hall.
- Lemert, E.M. (1962). Paranoia and the Dynamics of Exclusion. *Sociometry*, 25:2-20.
- Levinson, S.C. (1983). *Pragmatics*. Cambridge: Cambridge University Press.
- Lewis Price, J. (1961). Myalgic Encephalomyelitis. *Lancet*, 2, 737-738.
- Lipowski, Z, J. (1969). Psychosocial Aspects of Disease. *Annals of Internal Medicine* 71: 1197-1206.

- Lipowski, Z.J. (1974). Physical Illness, the Patient and his Environment: Psychosocial Foundations of Medicine. In *American Handbook of Psychiatry*, vol. iv., second edition, (Eds.) S. Arieti, M Reiser, New York: Basic Books.
- Lipowski, Z.J. (1979). Physical Illness, the Individual and the Coping Process. *Psychiatry in Medicine* 1: 91-102.
- Lloyd, G.G. (1986). Hysteria: a case for conservation. *British Medical Journal*, 293, 1255-1256.
- Lloyd, A.R. Wakefield, D., Boughton, C., Dwyer, J. (1988). What is myalgic encephalomyelitis? *The Lancet*. June 4.
- Lloyd, A.R., Hickie, I., Broughton, C.R. et al (1990). Prevalence of chronic fatigue syndrome in an Australian population. *Medical Journal of Australia*, 153: 524-528.
- Lock, M. and Gordon, D.R. (eds.) (1988) *Biomedicine Examined*. 11-16, Kluwer Academic Publishers.
- Mabry, J. H. (1964). Lay Concepts of Etiology. *Journal of Chronic Disease* 17:371-386.
- MacMillan, K. (1995). Giving voice: The participant takes issue. *Feminism and Psychology*, Vol 5 (4), 547-552.
- MacMillan, K. (1996). *Trance Scripts: The Poetics of a Reflexive Guide to Hypnosis and Trance Talk*. Ph.D.Thesis: Loughborough University.
- MacMillan, K. and Edwards, D. (in press). Designer Families: A discourse analysis of fact and accountability. *Journal of Sociolinguistics*.
- MaCrae, A.D. and Galpine, J.F. (1954). An illness resembling poliomyelitis observed in nurses. *Lancet*, 2, 350.
- Maines, D. (1993). Narrative's moment and sociology's phenomena: Toward a narrative sociology. *Sociological Quarterly*, 34, 17-38.
- Mandler, J.M. (1984). *Scripts, Stories and Scenes: Aspects of Schema Theory*. Hillsdale, NJ: Erlbaum.
- May, P.G.R., Ashton, J.R., Donnan, S. P. B., Ogilvie, M.M. and Rolles, C.J. (1980). Personality and medical perception in benign encephalomyelitis. *The Lancet*. Nov. 22, 1122.
- Manningham, R.(1750). The symptoms, nature, causes and cure of the febricula or little fever: commonly called the nervous or hysteric fever; the fever on the spirits; vapours, hypo, or spleen. 2nd ed. London: J.Robinson, 52-3.
- Markson, E.W. (1971). Patient Semiology of a Chronic Disease. Rheumatoid Arthritis. *Social Science and Medicine* 5: 159-167.
- McEvedy, C.P. Griffith, A. and Hall, T. (1966). *British Medical Journal*. 2, 1300.
- McEvedy, C.P. and Beard, A.W. (1970). Royal Free Epidemic of 1955: A Reconsideration. *British Medical Journal*. 1, 7-11.
- McEvedy, C.P. and Beard, A.W. (1973) A controlled follow-up of cases involved in an epidemic of 'Benign Myalgic Encephalomyelitis'. *British Journal of Psychiatry*, 122, 141-150.
- McKenzie, K. (1997). *In the Gulf between Prejudice and Culture: Talking the Experience of Western Expatriates in the Middle East*. Ph.D.Thesis: Loughborough University.
- Medical Staff of the Royal Free Hospital, London. (1957). An outbreak of Encephalomyelitis in the Royal Free Hospital Group, London, in 1955. *British Medical Journal*. October, 1957. pp.895-904.

- Middleton, D. and Edwards, D. (1990b). *Collective Remembering*. London: Sage.
- Molotch, H.L. and Bogen, D. (1985). Talking social structure: discourse, domination and the Watergate hearings, *American Sociological Review*, 50: 273-88.
- Monteiro, L. (1979). *Societal Views of the Cardiac Patient*. In Cardiac Patient Rehabilitation. New York: Springer-Verlag.
- Montgomery Hunter, K. (1991). Doctor's Stories: The Narrative Structure of Medical Knowledge. N.J. Princeton University Press.
- Morson, G.S. and Emerson, C. (1990). *Mikhail Bakhtin: Creation of a Prosaics*. Stanford, CA: Stanford University Press.
- Moscovici, S. (1984). The phenomenon of social representations. R.M. Farr and S.Moscovici (eds.) *Social Representations*. Cambridge: Cambridge University Press.
- Moss, P.D. and McEvedy, C.P. (1966). *British Medical Journal*, 2, 1295.
- Mulkay, M. (1984). The Scientist talks back: A one act play, with a moral, about replication in science and reflexivity in sociology. *Social Studies of Science*, 14, 265-82.
- Mulkay, M. (1985). *The word and the world: Explorations in the form of sociological analysis*. London: Allen and Unwin.
- Murray, M. (1997). A Narrative Approach to Health Psychology. *Journal of Health Psychology*. 2 (1) 9-20.
- Neimeyer, R.A. (1995b). Constructivist psychotherapies: Features, foundations and future directions. In R.A. Neimeyer and M.J. Mahoney (Eds.), *Constructivism in psychotherapy*. (11-38). Washington, DC: American Psychological Association.
- Nicholson, G.A. Wilby, J. and Tennant, C. (1986). Myasthenia gravis: the problem of a "psychiatric" misdiagnosis. *Medical Journal of Australia*, 144, 632-638.
- Ogden, J. (1997). The rhetoric and reality of psychosocial theories of health: A challenge to biomedicine? *Journal of Health Psychology*. 2(1) 21-29.
- Parker, I. (1992). *Discourse Dynamics: Critical Analysis for Social and Individual Psychology*. London: Routledge.
- Parsons, T. (1951a) *The Social System*. Glencoe, Ill: Free Press.
- Parsons, T. (1951b) Illness and the role of the physician: a sociological perspective. *American Journal of Orthopsychiatry*, 21, 452-60.
- Parsons, C.D.F. and Wakeley, P. (1991). Idioms of Distress. *Culture, Medicine and Psychiatry*. 15: 111-132.
- Peat, F.D. (1993). Science as story. In C. Simpkinson, and A. Simpkinson (Eds.), *Sacred stories*. 53-62. San Francisco, CA: Harper.
- Pels, D. (1996). The Politics of Symmetry. *Social Studies of Science*. 26: 277-304.
- Pellow, R.A.A. (1951). Clinical description of a disease resembling poliomyelitis seen in Adelaide, 1949-51. *Medical Journal of Australia*. 1, 944.
- Pfohl, S. (1977). The 'discovery' of child abuse. *Social Problems*, 24: 310-24.
- Pfohl, S. (1985). Toward a Sociological Deconstruction of Social Problems - Comment. *Social Problems*, vol.32 (3) 228-232.
- Pinch, T. and Pinch, T. (1988). Reservations about reflexivity and new literary forms or why let the devil have all the good tunes? In S. Woolgar, (ed.) *Knowledge and Reflexivity: New frontiers in the sociology of science*. London and Beverly Hills, CA: Sage. 178-198.
- Plummer, K. (1995). *Telling sexual stories*. London: Routledge.

- Polkinghorne, D.E. (1988). *Narrative Knowing and the Human Sciences*. Albany, NY: State University of New York Press.
- Pollner, M. (1974). Mundane reasoning. *Philosophy of the Social Sciences*, 4, 35-54.
- Pollner, M. (1987). *Mundane reason: Reality in Everyday and Sociological discourse*. Cambridge: Cambridge University Press.
- Pomerantz, A.M. (1984a). Agreeing and Disagreeing with Assessments: Some Features of Preferred/Dispreferred Turn Shapes. In J.M. Atkinson and J. Heritage (Eds.) *Structures of Social Action: Studies in Conversation Analysis* (55-101). Cambridge: Cambridge University Press.
- Pomerantz, A.M. (1984b). Giving a source or basis: The practice in conversation of telling 'how I know'. *Journal of Pragmatics*, 8, 607-25.
- Pomerantz, A.M. (1986). Extreme Case Formulations: A New Way of Legitimizing Claims. *Human Studies*, 9, 219-29.
- Poskanzer, D.C. Henderson, D.A. Kunkle, E.C. Kalter, S. S. Clement, W.B. and Bond, J.O. (1957). Epidemic neuromyasthenia. An outbreak in Punta Gorda, Florida. *New England Journal of Medicine*. 257: 356.
- Poskanzer, D.C. (1970). Epidemic Malaise. *British Medical Journal*, 2, 420-421.
- Potter, J. (1984). Testability, flexibility: Kuhnian values in psychologists' discourse concerning theory choice, *Philosophy of the Social Sciences*, 14, 303-30.
- Potter, J. (1987). Reading repertoires: A preliminary study of some techniques that scientists use to construct readings. *Science and Technology Studies*, 5, 112-21.
- Potter, J. (1988a). Cutting cakes: a study of psychologists' social categorisations, *Philosophical Psychology*, 1: 17-33.
- Potter, J. (1988b). What is reflexive about discourse analysis? The case of reading readings, in S.Woolgar (ed.), *Knowledge and Reflexivity: New frontiers in the sociology of knowledge*, London: Sage.
- Potter, J. (1996) *Representing Reality: Discourse, Rhetoric and Social Construction*. London: Sage.
- Potter, J. and Mulkay, M. (1985). Scientist's interview talk: Interviews as a technique for revealing participants' interpretative practices. In M.Brenner, J. Brown, and D. Canter (Eds.), *The Research Interview: Uses and Approaches*. London: Academic Press.
- Potter, J. and Wetherell, M. (1987). *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.
- Potter, J. and Wetherell, M. (1988a). Accomplishing attitudes: Fact and evaluation in racist discourse, *Text*, 8, 51-68.
- Potter, J. and Wetherell, M. (1995). Natural Order: Why Social Psychologists Should Study (a Constructed Version of) Natural Language, and Why They Have Not Done So. *Journal of Language and Social psychology*, 14: 216-222.
- Prince, G. (1982). *Narratology: The Form and Function of Narrative*. The Hague: Mouton.
- Propp, V.J.(1928/1968). *Morphology of the Folktale*. Austin, TX: University of Texas Press.
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: Sage.
- Radley, A. and Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. *Sociology of health and Illness*. 18, 220-240.

- Ramsay, A.M. (1957). Encephalomyelitis in North west london. An endemic infection simulating poliomyelitis and hysteria. *Lancet*. December 1957, pp.1196-1200.
- Ramsay, A.M., Dowsett, E.G. Myalgic Encephalomyelitis then and now; an epidemiological introduction. In: Hyde, B.M., Goldstein, J. and Levine, P.H. (eds) *The Clinical and Scientific Basis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*, Nightingale Research Foundation, Ottawa, p.81-84.
- Ramsay, A.M. and O'Sullivan, E. (1956). Encephalomyelitis simulating poliomyelitis. *Lancet*, May 1956. pp.761-4.
- Ray, C., Phillips, L., and Weir, W. (1993). Quality of attention in chronic fatigue syndrome: subjective reports of everyday attention and cognitive difficulty, and performance on tasks of focused attention. *British Journal of Clinical Psychology*, 32: 357-64.
- Reid, J. Ewan, C. and Lowy, E. (1991). Pilgrimage of Pain: The Illness Experiences of Women with Repetition Strain Injury and the Search for Credibility. *Social Science and Medicine*. 32, 5, 601-612.
- Reissman, C.K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science and Medicine*, 30, 1195-1200.
- Reissman, C.K. (1993). *Narrative Analysis*. London: Sage.
- Richardson, A.T. (1956). Some aspects of the Royal Free Hospital epidemic. *Annals of Physical Medicine*, 3, 81-89.
- Richmond, C. (1989) Myalgic encephalomyelitis, Princess Aurora, and the wandering womb. *British Medical Journal*, vol. 298, 1295-1296.
- Rippere, V. (1991). The Mental State of Dismissed Patients- An Enquiry into Dismissal Injury V. Repercussions of Psychogenic Dismissal. *Newsletter for the Society for Environmental Therapy*. 11, 2, 138-148.
- Robinson, I. (1988). *Multiple Sclerosis*. London: Routledge.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, 30, 1173-1186.
- Robinson, J.A. and Hawpe, L. (1986). Narrative thinking as a heuristic process. In T.R. Sarbin (Ed.), *Narrative psychology*. New York: Praeger.
- Royal Colleges of Physicians, Psychiatrists, and General Practitioners. (1996). *Chronic Fatigue Syndrome*. Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists, and General Practitioners. CR54.
- De Saussure, F. (1974). *Course in General Linguistics*. London: Fontana.
- Sacks, H. (1984). On doing 'being ordinary'. In J.M. Atkinson and J.Heritage (Eds.), *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press.
- Sacks, H. (1987). On the Preferences for Agreement and Contiguity in Sequences in Conversation. In G. Button and J. Lee (1987). *Talk and Social Organisation*. Clevedon: Multilingual Matters. 54-69.
- Sacks, H. (1989). *Harvey Sacks - Lectures 1964-1965* (Ed. G. Jefferson). Special issue of *Human Studies*, 12(3-4), 183-404.
- Sacks, H. (1992). *Lectures on conversation*. Vols. I and II, edited by G. Jefferson. Oxford: Basil Blackwell.
- Sacks, H. Schegloff, E.A. and Jefferson, G. (1974). A simplest systematics for the organisation of turn-taking for conversation. *Language*, 50 (4), 696-735.

- Samoral, J. Saunders, L. and Larson, R.F. (1962). Knowledge about Specific Diseases in Four Selected Samples. *Journal of Health and Human Behaviour* 3:176-185.
- Sarbin, T.R. (1986b). The narrative as a root metaphor for psychology. In T.R. Sarbin (Ed.), *Narrative Psychology: The Storied Nature of Human Conduct*. New York: Praeger.
- Scambler, G. (ed.) (1991). *Sociology as Applied to Medicine*. (3rd edition) London: Bailliere Tindall.
- Schank, R.C. and Abelson, R. (1977). *Scripts, Plans, Goals and Understanding*. Hillsdale, NJ: Erlbaum.
- Schegloff, E. A. (1997). Whose Text? Whose Context? *Discourse and Society* 8(2): 165-187.
- Schluederberg, A. et al (1992) Chronic fatigue syndrome research: definition and medical outcome assessment. *Annals of Internal Medicine*, 117: 325-331.
- Schneider, J.W. (1985) Defining the Definitional Perspective on Social Problems. *Social Problems*, vol 32, No. 3, 232-234.
- Scott, B. (1970). Epidemic Malaise. *British Medical Journal*. Jan. 1970, p.170.
- Searle, J.R. (1969). *Speech Acts*. Cambridge: Cambridge University Press.
- Seligman, M.E.P. (1975). *Helplessness: On depression, development and death*, San Francisco: W.H. Freeman.
- Shapiro, M. (1988) *The Politics of Representation: Writing practices in biography, photography and policy analysis*. Madison, WI: University of Wisconsin Press.
- Sharpe, M.C., Archard, L., and Banatvala, J.(1991). A report - chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine*, 84: 118-121.
- Sharpe, M.C., Hawton, K., Seagroatt, V. and Pasvol, G. (1992). Follow up of patients presenting with fatigue to an infectious diseases clinic. *British Medical Journal*. 305: 147-52.
- Shaver, K.G. (1975). *An Introduction to Attribution Processes*. Cambridge: Winthrop Publishers, Inc.
- Shelokov, A. Habel, K. Verder, E. and Welsh, W. Epidemic neuromyasthenia. An outbreak of poliomyelitis-like illness in student nurses. *New England Journal of Medicine*. 257: 345.
- Shepherd, M. (1978). Epidemiological perspective of psychosomatic medicine. *International Journal of Epidemiology*, 7, 201-204.
- Shepherd, C. (1992). Outcome in the chronic fatigue syndrome. *British Medical Journal*, August 8, 365.
- Shilts, R. (1988). *And The Band Played On*. London: Penguin.
- Shotter, J. (1993b). *Cultural Politics of Everyday Life: Social Constructionism, Rhetoric, and Knowing of the Third Kind*. Buckingham: Open University Press.
- Shotter, J. and Gergen, K. J. (Eds.) (1989). *Texts of Identity*. London: Sage.
- Sigurdsson, B. and Gudmundsson, K.R. (1956). Clinical findings six years after outbreak of Akureyri Disease. *Lancet*, May 1956, pp.766-767.
- Sigurdsson, B. Sigurjonsson, J. Sigurdsson, J.H. Thorkelsson, J. and Gudmundsson, K.R. (1950). Disease epidemic in Iceland simulating poliomyelitis. *American Journal of Hygiene*. 52, 222.
- Skinner, B.F. (1971). *Beyond Freedom and Dignity*. New York: Knopf.

- Smith, D. (1978). K is mentally ill: The anatomy of a factual account. *Sociology*, 12, 23-53.
- Spracklen, F.H.N.(1988). The chronic fatigue syndrome (myalgic encephalomyelitis) - myth or mystery? *South African Medical Journal*. 74, 448-452.
- Stanton, A.L. and Snider, P.R. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12, 16-23.
- Stimson, G.V.(1976). General Practitioners, 'Trouble' and Types of Patients. In Stacey, M. (ed.) *Sociology of the NHS. Sociological Review Monograph*. 22: 43-60.
- Stoeckle, J.D. and Barsky, A.J. (1981). Attributions: Uses of Social Science Knowledge in the 'Doctoring of Primary Care. In L.Eisenberg and D.Kleinman (eds.), *The relevance of Social Science for Medicine*, 223-240. D. Reidel Publishing Company.
- Straus, S.E. (1991) History of Chronic Fatigue Syndrome. *Review of Infectious Diseases*, 13 (Suppl 1): S2-7.
- Stringer, P. (1985). You decide what your title is to be and [read] write to that title. In D.Bannister (ed.), *Issues and approaches in personal construct theory*. London: Academic Press.
- Stroebe, W., and Stroebe, M. (1995). *Social Psychology and Health*, Open University Press.
- Sumner, D.W. (1956). Further Outbreak of a Disease Resembling Poliomyelitis. *Lancet*. May 1956, pp.764-766.
- Tan, E.S. (1963-4). *Medical Journal of Malaya*. 18, 72.
- Tannen, D. (1989). *Talking Voices: Repetition, Dialogue and Imagery in Conversational Discourse*. Cambridge University Press.
- Todorov, T. (1969). *Grammaire du Decameron*. The Hague: Mouton.
- Truss, C.O. (1981). The role of *Candida Albicans* in human illness. *Journal of Orthomolecular Psychiatry*, 10: 228-38.
- Twaddle, A.C. (1969). Health decisions and sick role variations: an exploration. *Journal of Health and Social Behaviour*, 10, 105-15.
- Van Economou, C. (1931). *Encephalitis Lethargica; Its Sequelae and Treatment*. Translated by Newman, K.O. London. Oxford University Press.
- Von Bertalanffy, L. (1968). *General Systems Theory*. New York. Braziller.
- Von Bertalanffy, L. (1969). *Chance or Law*. in *Beyond Reductionism*. Koestler, A., Smythies, J.R. New York. Macmillan.
- Ware, N. (1992). Suffering and the social construction of illness: the delegitimation of illness experience in the chronic fatigue syndrome. *Medical Anthropology Quarterly*. 6(4):347-61.
- Ware, N. (1993). Society, mind and body in chronic fatigue syndrome: an anthropological view. In *Chronic Fatigue Syndrome*. 62-82 (Ciba Foundation Symposium 173) Wiley, Chichester.
- Ware, N. and Kleinman, A. (1992). Culture and Somatic Experience: The Social Course of Illness in Neurasthenia and Chronic Fatigue Syndrome. *Psychosomatic Medicine* 54:546-560.
- Weiss, P. (1959). Animal behaviour as system reaction: orientation toward light and gravity in the resting posture of butterflies. *General Systems: Yearbook of the Society for General Systems Research* 4: 1-44.

- Weiss, P. (1969). *The Living System: determinism stratified*. in Beyond Reductionism. Koestler, A., Smythies, J.R. New York. Macmillan.
- Wessely, S. (1990). Old wine in new bottles: neurasthenia and 'ME'. *Psychological Medicine*, 20, 35-53.
- Wessely, S. and Powell, R. (1989). Fatigue Syndromes: a comparison of chronic 'post-viral' fatigue with neuromuscular and affective disorders. *Journal of Neurology, Neurosurgery, Psychiatry* 52: 940-948.
- Wessely, S., Butler, S., Chalder, T., and David, A. (1991). The cognitive-behavioural management of the post-viral syndrome. In *Post-viral Fatigue Syndrome*. R.Jenkins and J. Mowbray (eds.) 305-334. Wiley, Chichester.
- Westcare (1994). Report from The National Task Force on Chronic Fatigue Syndrome (CFS) Post Viral Fatigue Syndrome (PVFS) Myalgic Encephalomyelitis (ME).
- Wetherell, M. and Potter, J. (1992). *Mapping the Language of Racism: Discourse and the Legitimation of Exploitation*. London: Harvester Wheatsheaf.
- Whalen, M.R. and Zimmerman, D.H. (1990). 'Describing trouble: practical epistemology in citizens calls to the police', *Language in Society*, 19: 465-92.
- White, D.N. and Burtch, R.B.(1954). Iceland Disease; a new disease simulating acute anterior poliomyelitis. *Neurology*, 4, 506.
- White, H. (1973). *Metahistory: the Historical Imagination in Nineteenth Century Europe*. Baltimore: Johns Hopkins University Press.
- White, H. (1978). *Tropics of Discourse*. Baltimore, MD: Johns Hopkins University.
- White, H. (1980). The value of Narrativity in the Representation of Reality. *Critical Inquiry*, 7, 5-28.
- White, G.M. (1982). The role of cultural explanations in 'somatization' and 'psychologization'. *Social Science and Medicine*, vol.16: 1519-30.
- White, M. and Epston, D. (1990). *Narrative means to therapeutic ends*. New York: North.
- Widdicombe, S. and Wooffitt, R. (1995). *The Language of Youth Subcultures: Social Identity in Action*. London: Harvester Wheatsheaf.
- Williams, G. (1984). The Genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness*, 6, No.2, 175-200.
- Wittgenstein, L. (1953/1958). *Philosophical Investigations*. Trans. G.E.M. Anscombe. Oxford: Blackwell. (2nd Edn). 1958.
- Wittgenstein, L. (1967). *Zettle*, ed. G.E.M. Anscombe and G.H. von Wright, trans. G.E.M. Anscombe. Oxford: Basil Blackwell.
- Wittgenstein, L. (1978). *Remarks on the Foundations of Mathematics*. (3rd Edn). Oxford. Oxford University Press.
- Woods, T.O. and Goldberg, D.P.(1991). Psychiatric Perspectives - An Overview. *British Medical Bulletin*, vol. 47 (4) 908-18.
- Wooffitt, R. (1992) *Telling Tales of the Unexpected: The Organization of Factual Discourse*. Hemel Hempstead: Harvester Wheatsheaf.
- Wookey, C. (1978). Epidemic myalgic myalgic encephalomyelitis. *British Medical Journal*, 2, 202.
- Woolgar, S. (1980). *Discovery: Logic and sequence in a scientific text*. In Knorr, Krohn, and Whitley 1980: 239-68.
- Woolgar, S. (1982). Laboratory studies: A comment on the state of the art. *Social Studies of Science* 12: 481-98.

- Woolgar, S. (1983). Irony in the social studies of science. In K.D. Knorr-Cetina and M. Mulkay (eds.), *Science observed: Perspectives on the social study of science*. London and Beverly Hills, CA: Sage. pp.239-66
- Woolgar, S. (1988). Time and documents in researcher interaction: Some ways of making out what is happening in experimental science. *Human Studies*, 11, 171-200. Reprinted in M. Lynch and S. Woolgar (Eds.), (1990). *Representation in scientific practice* (pp. 123-152). Cambridge, MA: MIT Press.
- Woolgar, S. (1988b). *Science: The very idea*. Chichester: Ellis Horwood./ London: Tavistock.
- Woolgar, S., and Pawluch, D. (1985). Ontological Gerrymandering: The anatomy of Social Problems Explanations. *Social Problems*, vol.32, No. 3, 215-225.
- Woolgar, S. and Ashmore, M. (1988). The next step: An introduction to the reflexive project. In S. Woolgar, (ed.) *Knowledge and reflexivity: New frontiers in the sociology of science*. London and Beverly Hills, CA: Sage.
- Wundt, W. (1900-20). *Volkerpsychologie*. Volumes 1-10. London: Allen and Unwin.
- Yardley, L. (1996). Reconciling discursive and materialist perspectives on health and illness: A reconstruction of the biopsychosocial approach. *Theory and Psychology*. 6(3) 485-508.
- Yunus, M.B. (1988). Diagnosis, etiology, and management of fibromyalgia syndrome: an update. *Compr Ther*, 14 (4): 8-20.