Society, the body and pain: sociological factors in assessing the meaning and experience of pain in myalgic encephalomyelitis ("yuppie flu") sufferers

A thesis submitted in fulfilment of the

requirements for the degree of

MASTER OF ARTS

of

RHODES UNIVERSITY

by

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January 2002

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MYALGIC ENCEPHALOMYELITIS

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ABSTRACT

This thesis explores the meaning and experience of the bodily states associated with the condition referred to as myalgic encephalomyelitis (ME). It uses as a theoretical point of departure an understanding of the body as a socially constructed phenomenon and, in so doing, offers an interpretation of illness that is seen to differ markedly from those offered by the medical and behavioural sciences.

Using descriptive narrative research analysis, the thesis attempts to elicit personal trajectories of illness experience. In contrast to biomedical and social trajectories of illness, in which the interpretation and meaning given to the condition are imposed externally, personal trajectories are seen to provide unique subjective accounts of illness experience. And the value of using narrative accounts of illness is seen to lie in their ability to bring to light these individualised versions of illness experience. It is shown, in addition, that these narrative accounts of illness are also valuable in exposing the culturally shared knowledge that is employed in the process of assigning meaning to illness experiences. The aim of the thesis, then, in employing the descriptive narrative research method is to describe these shared cultural schemas.

It is suggested that this approach leads to an interpretation of illness experience which sheds light on important links between the body, self and society. It is argued, more specifically, that Western capitalist society is associated with the creation of an "unnatural" environment and social context which is perceived to be inherently damaging and threatening to the well-being of those living in it; and that this assumption is pivotal to the interpretation of the illness experiences narrated and analysed for the thesis. This sociological reading of embodiment provides a basis for understanding the experience of illness, as not one simply embedded in the body or mind of the individual, but as one laden with personal meaning assimilated from, and hence revealing of, the social context in which the illness is experienced. As such, an attempt is made to provide an account of illness experience distinct from the dominant biomedical and behavioural accounts of ME.

ACKNOWLEDGMENTS

I wish to express my sincere gratitude to:

- My supervisor, Professor Jan Coetzee, for his infallible guidance and constructive criticism. I am also deeply indebted to him for his patience, kindness and ceaseless support.
- The four participants who shared their stories with me.
- The Joint Research Fund of Rhodes University for financial assistance.
- The Dean of Humanities, Professor I Macdonald, who, on behalf of the Faculty and on more than one occasion, granted me permission to extend my registration.
- My colleagues in the Department, especially Professor Fred Hendricks and those on the East London Campus: Nyanisile Jack and Derek Mosenthal, in particular, as well as Professor Jimi Adesina since his arrival in 2001.
- Professor HCJ van Rensburg and his wife whose generous hospitality afforded me the opportunity to use the resources at the medical and humanities libraries at the University of the Orange Free State. I am also most grateful to their daughter, Ega, who helped me find my way around the campus and assisted me in sourcing references.
- The long-suffering Bea, Dick and Patrick who will all, I am sure, be relieved to know that this thesis has finally reached a point of abandonment.

GENERAL INTRODUCTION

This thesis attempts to provide a sociological interpretation of the meaning and experience of pain associated with the condition known as myalgic encephalomyelitis (ME). A sociological study is proposed in response to a long standing monopolization of bodily states, such as pain and illness, by the medical and behavioural sciences. The thesis questions the framework most commonly used by the medical and behavioural sciences in which a naturalistic approach to the body is adopted. Within this framework, biochemical and psychological interpretations of pain and illness command attention to the exclusion of almost all others. As such, it is argued that dominant views of illness and pain disregard "...the person as an embodied agent" (Turner, 1992: 169). In other words, by simply treating pain "..as a problem within the sensory system..." attention is not focussed on "...the state of being in pain" which imports "...strong effective, emotional and social responses..." (ibid.). It is reasoned that if pain and illness are states in which we experience our physical bodies, then their meaning and comprehension relates closely to our understanding of the body, which is neither static nor universal. Not only does the meaning of the body alter culturally and socially but "the body" in Western capitalist society has experienced distinct historical transformations (Synnott, 1992: 80; MacSween: 1993: 113-157). It is for this reason that a theory of embodiment is considered essential to the study of illness and pain as socially constructed phenomena. By applying a theory of embodiment to the study of pain and illness, an appreciable departure is taken from dominant approaches. In so doing, this thesis attempts to offer a sociological interpretation of pain and illness that broadens the prevailing medical and behavioural perspectives.

Chapter one develops a theoretical framework for situating the thesis's focus on the meaning associated with illness experience and, in so doing, provides two accounts of the human body. The first, referred to as the naturalistic approach, defines the body as a natural, pre-social entity. This view, which forwards an understanding of the body divided into physical body and rational mind, is dominant in both medical and sociological conceptualisations of the body. As applied to sociology and medical sociology in particular, this naturalist or medicalized view of the body has brought about an "outsider" approach to the study of illness

which focusses on "illness behaviour" or "sickness careers" and is symbolized by Talcott Parsons' notion of the "sick role". These medical and "outsider" approaches, based on a naturalistic understanding of the body, give rise to medical and social trajectories of illness respectively. As such, it is argued that they neglect the subjective, personal trajectories of illness that provide insight into unique, individualised accounts of illness experience.

In rejecting this naturalistic approach, a second account of the body is considered. This account, which is set in opposition to the naturalistic account, is loosely classified as "social constructionist". This approach in sociology is to a large extent indebted to the work of Bryan Turner who, in turn, draws on a wide range of theorists in developing an argument for the body as both a natural, in the Marxist sense of the word, and a socially constructed phenomenon, following the work of Michel Foucault. Turner's sociology of the body is utilised in the chapter to develop an understanding of the body as an historically and socially variable entity. In addition to this structuralist position, which views the body as a socially created outcome of discourse, a phenomenological commitment to the experience of the body is incorporated into the theoretical development of the body as a socially constructed entity. It is indicated that, in accounting for human action and experience, this view provides place for emotions and feelings as well as the body's ability to absorb and reflect social, cultural and historical meaning. It sets forth, as a result, a perspective in stark contrast to biomedical and rationalistic theories of the body and human action. So, in moving beyond a view of the body as biologically determined and historically static, it is argued that the social constructionist approach advances an understanding of pain and illness as embodied experiences that are, furthermore, socially, culturally and historically variable.

In keeping with a theory of embodiment it is argued, furthermore, that in the process of interpreting embodied states such as illness, meaning is sought from dominant discourses of which biomedicine and mind-body dualism are two notable examples. At the same time it is asserted that, as an embodied state, subjective accounts of illness are not necessarily isolated from subjective accounts of health. In order to contribute to an understanding of illness as an embodied experience, then, it is suggested that sociological attention be

extended beyond discourses limited to an exclusive focus on illness, to incorporate those concerned with its "positive" opposition, health. The health promotion discourse of the new public health movement is identified in chapter one as being of particular relevance in this regard. These two points of departure, namely a theoretical focus on the body as a socially constructed phenomenon and the dilation of focus to include dominant discourses of health in understanding illness experience, are developed in chapter one as a framework for the chapters that follow, which detail the analysis and interpretation of the interviews collected from four people suffering with the condition known as myalgic encephalomyelitis.

Chapter two provides an overview of the condition known as myaligic encephalomyelitis or ME. It is identified as an "illegitimate illness" or "non-disease" owing to the controversy surrounding its biomedical status. In other words, no identifiable causative agent has been scientifically linked to the condition which renders it open to speculation and varying interpretations. It is shown that, in accordance with a medicalised view of the naturalistic body, two competing interpretations monopolize explanations regarding ME. One view supports an understanding of ME as an organically-based illness that is caused by a specific disease-producing agent which, although thought to be a virus, has yet to be identified. The second view supports an understanding of ME as a psychologically-based illness which emerges from an understanding of the mind-body dualism characteristic of a naturalistic approach to the body. This is shown to mean that an illness lacking biomedically approved organicity is accounted for in relation to the mind. It is also indicated that the contention evident in this dominant biomedical interpretation of ME, which renders it either physical or psychological, is echoed in controversy regarding symptoms and treatment as well as terminology. It is for this reason, that preference is given in this thesis to an understanding of ME that avoids definitive classification in favour of one that recognises ME as a contemporary label for certain bodily experiences.

Chapter two moves on to consider the bodily state of chronic pain which, in contrast to its earlier identification as a sign indicative of an underlying illness, has more recently been conceptualised as an illness in its own right. It is for this reason that "pain" is used interchangeably with the term "illness", in the thesis, to signify a bodily state associated with the condition presently labelled as ME. From this understanding of

pain-as-illness, it is argued that pain creates a state of bodily dichotomy, not in the simple mind versus body sense epitomized by the medicalized body, but in the sense of a conscious, emotional self separated from the otherwise taken-for-granted body. It is suggested that this division, which disrupts the phenomenological sense of being a body, induces a search for meaning as well as action taken by the self towards the body in an attempt to reach a state in which the self and body are re-aligned. This phenomenological movement from a state of embodiment to one of dys-embodiment and, in the absence of pain-as-illness re-alignment, is shown to mean the experience of bodily states that surpass purely physical or psychological experiences. It is suggested, furthermore, that the meaning associated with these bodily states is derived from specific social and cultural contexts. In other words, if the meaning of ME as an embodied state of pain or illness is to be sought, then a need exists to move beyond explanations derived from dominant physical or psychological accounts of the condition. In this way, it is argued that a theory of embodiment is necessary to understanding the meaning associated with the experience of ME. It is also argued, in closing chapter two, that narrative accounts of illness experience are considered particularly well suited to this purpose.

Chapter three describes and explains the specific narrative research method used in bringing to light the meaning and experience associated with ME. Descriptive narrative accounts of illness experience are identified as the most appropriate method of eliciting the meaning that ME sufferers assign to their embodied experiences. In contrast to an explanatory narrative research method, the adoption of the descriptive narrative research method means that an attempt is made, in this thesis, to ***describe*** the interpretive schemas that individuals use in the process of making sense of illness experiences, rather than ***explain why*** illness events have occurred. It is shown that illness narratives represent the stories that ME sufferers recount in an attempt to understand and give meaning to the event of illness in their lives. From this perspective it is noted that personal, narrative accounts of physical and neurological realities differ from the reasoned accounts of scientific medicine (and the biomedical and sickness trajectories supported by it) by means of a plot or storyline around which events and experiences are organised. It is argued that this plot or storyline, which is set in the context of individual lives and provides unique personal accounts of illness experience is, at the same time, seen to reveal culturally and socially shared understandings of embodied states. And, as indicated

above, it is the description of this latter aspect of the illness experience that is seen to be particularly relevant to fulfilling the goals of this thesis.

Chapter four recounts the findings of the four illness narratives collected and analysed in accordance with the descriptive narrative research method. It is indicated that these personal trajectories of illness impart the individual experiences and difficulties involved in coming to terms, and dealing, with an illness given "illegitimate" biomedical status. They represent, more specifically, narrative re-constructions of past and present biographical details which attempt to re-align the body, self and society and redress the disruption that follows in the event of illness. It will be shown that, in the process of trying to understand and give meaning to this disruption, individuals make use of commonly shared knowledge which, in turn, gives consistency to and connects the single, idiosyncratic, and often dissimilar personalised accounts of illness experience. From this understanding, biomedical discourse is identified as a dominant source of commonly shared knowledge and it will be shown that the narratives documented in chapter four do, indeed, employ it in responding to the onset of illness symptoms. Related to this dominant biomedical discourse is an understanding of the body as divided between mind and body. Evidence of this understanding is also shown to exist in the illness narratives as sufferers attempt to make sense of their "illegitimate" and, hence, medically questionable illness. It is argued that a further source of commonly shared knowledge is also evident in the illness narratives collected for this thesis and, contrary to an understanding of biomedicine as the dominant source of understanding, it appears to provide an equally dominant source of knowledge and meaning. This commonly shared knowledge or cultural model is identified as that associated with the new public health movement's health promotion discourse. Given these findings it is suggested, as it is in chapter one, that sociological accounts of illness experience require attention to dominant discourses imparting meaning to illness as well as those imparting meaning to health.

Chapter five concludes this thesis. It offers, more specifically, a brief overview of the arguments developed in the preceding chapters. It is suggested that the insights provided by the descriptive analysis of the four illness narratives collected for the thesis are indebted to a theoretical approach which views the body, and

our experiences therein and thereof, as socially constructed phenomena. In contrast to the restricted accounts of illness experience and human action that accompany a view of the body as a biological entity divided between rational mind and physical body, a sociology of embodiment provides a basis for extracting the meaning-laden personal trajectories of illness experience.

CHAPTER 1

SOCIOLOGY AND THE BODY

1.1 INTRODUCTION

The purpose of this chapter is to develop a sociological understanding of the body as the specific context for an interpretation of pain and illness as social constructions. Rather than employing the scientifically and medically dominant naturalistic approach which views the body as a pre-social, objective reality, the social constructionist approach views the body as a product of, and existing in, discourses (Shilling, 1993: 70). Discourses, in this context, refer to language aimed at influencing thought and understanding (Senior and Viveash, 1998: 13, 27, 62). So this approach presupposes a conceptualisation of the body as "...a receptor, rather than a generator, of social meanings" (Shilling, 1993: 70). While a number of distinct views exist within the broad social constructionist approach, there is an underlying consensus which places emphasis on the social creation, definition and control of the body within the contexts of culture, history and society. For the most part, the distinction between the different views classified as social constructionist tends to be drawn relative to the extremes to which the body is considered a social product as opposed to a biological phenomenon (ibid.). By analysing the body as a social construction, however, this approach generally brings into sociological focus a previously and commonly accepted notion that the body as a natural phenomenon be the almost exclusive focal point of the natural and medical sciences (Shilling, 1993: 71).

The dominant, allopathic model of medical care that exercises the authority to diagnose and treat illnesses in most Western capitalist societies is called the biomedical model but is also, and sometimes controversially, referred to as "...modern, official, conventional, classical, Western, cosmopolitan, scientific, orthodox or biomedicine..." (van Rensburg et al., 1992: 310). This particular model of medicine, which like many attempts to restore and preserve health, is commonly held to be distinct from other models by virtue of it being firmly "...rooted in the scientifically objective world..." (Jones, 1991: 428). This scientific view of medicine in Western capitalist societies has such prominence that it "...is treated as *the* representation or picture of reality rather than understood as *a* representation" (Misher, 1981: 1). The assumptions

underpinning it are based on an understanding of the human body as a natural phenomenon and it is for this reason that a brief overview of the naturalistic approach is provided below. A discussion of the socially constructed body follows the section on the naturalistic approach and its close association with biomedicine. The two points of departure taken in developing an argument that carries through to the thesis's conclusion are outlined prior to concluding chapter one.

1.2 THE NATURALIST APPROACH TO THE BODY

The naturalist approach represents a broad category of scientific views that have been influential since the eighteenth century and continue to be so regarding common conceptions of the body and its relation to the self and society (Shilling, 1993: 41). Although distinguishable from one another, all views considered "naturalistic" share the common assumption that the self and society are structures founded in, and determined by, a biological substructure. From this perspective, for example, social, political and economic structures in society are ultimately organised around the biological body as a natural and pre-social phenomenon. As such, it is possible to argue as Shilling (ibid.) points out, that "(i)nequalities in material wealth, legal rights and political power are not socially constructed, contingent and reversible, but are given, or at the very least legitimized, by the determining power of the biological body". The naturalist approach, then, is considered influential in justifying and legitimising structures of inequality such as racism and sexism, presenting the unequal social positions of different groups as essentially related to the natural, biological, or genetic in the case of sociobiology, make-up of their respective bodies.

Notwithstanding this, the body as it is accounted for in naturalistic terms underpins the dominant biomedical model of medicine. And it is this "medicalized" view of the body that, furthermore, dominates common conceptions of the body as well as bodily states such as health and illness in Western capitalist society (Frank, 1990: 136; Lupton, 1994: 20; Freund and McGuire, 1995: 5). This medicalized view of the body is defined by the discipline of biology, which developed during the late eighteenth century, and its sub-discipline human anatomy, which evolved during the nineteenth century (Armstrong, 1987: 63). Despite their relatively recent histories, both have established themselves as dominant disciplines which inform medical

knowledge about the human body. According to this view the body is a static, universal phenomenon which is largely devoid of meaning beyond its anatomical and physiological dimensions.

1.2.1 The Naturalistic Body and Biomedical Assumptions

This influential naturalistic view of the body forms the basis for a number of assumptions underpinning biomedical views of bodily states. One such assumption is *the division between mind and body.* Based on this division, it is assumed that disease dwells in the body with the result that the physical body anchors the focus of biomedical attention to the exclusion of the body-as-person (Freund and McGuire, 1995: 6). So, health and illness are first and foremost physical, biological phenomena which, to a large extent, eliminates equally important social and psychological bearings on an individual's health and illness (Freund and McGuire, 1995: 6; Doyal, 1979: 12). Apart from the neglect of the body-as-person in a bio-psycho-social environment, the reduction of health and illness to physical phenomena, furthermore, narrows biomedical attention onto the bodies of individuals exclusively. This often means that relatively little attention is paid to the social, economic, political and ideological factors associated with health and illness.

A second assumption based on this medicalised view of the body considers medicine to be a *natural science* wherein a detached, neutral medical "scientist" observes and treats a passive, neutral body. This is considered to be an impartial process in which the identification and classification of diseases draws on, and contributes to, a body of knowledge that is objective and verifiable. The knowledge and practice of biomedicine, therefore, leaves little room for dispute or negotiation, as the "truth" is revealed in the body of the patient (Senior and Viveash, 1998: 10; Wolinsky, 1988: 79; Doyal, 1979: 12). This "truth" is, furthermore, only identifiable by those who have the specialised training and knowledge to detect it. In other words, it is only the profession practising medicine that may legitimate what is to be considered a state of health or illness through an examination of the body (ibid.).

A third assumption holds that illness is the outcome of a potentially *identifiable cause* lodged in the biological body of the individual (Senior and Viveash, 1998: 10; Wolinsky, 1988). This understanding, which emerged

during the germ theory of disease, has preoccupied biomedicine in the search for distinct illness-provoking agents or organisms (van Rensburg et al., 1992: 311). Although this assumption, known as the doctrine of specific aetiology, has found relative success in dealing with infectious diseases, it came under criticism for its inadequate and narrow explanation of illness and disease causation during the 1950s (Freund and McGuire, 1995: 6). Diseases, for example, in which aetiology is linked to genetic, nutritional or socio-economic factors, are not readily explained by the germ theory. This criticism is considered to be increasingly valid as multi-causal chronic and degenerative illnesses have come to monopolize Western capitalist medical care systems while at the same time curable or treatable infectious diseases are seen to persist as the major cause of mortality and morbidity in Third World or underdeveloped parts of the world (Freund and McGuire, 1995: 17). But based on the understanding that there are identifiable causes, biomedicine also considers illnesses to be *treatable* and *curable* (Senior and Viveash, 1998: 10). Acting as the mediator between bodies and illness, then, biomedicine is seen to hold the promise of health, "...the only problem being that there is not enough of it (medicine) to go round..." (Doyal, 1979:12).

A related assumption, which emerged during the industrial revolution, concerns the *machine metaphor* that is applied to the biomedical understanding of the body (Freund and McGuire, 1995: 6; Lupton, 1994: 59). This analogy which fragments the person and likens the living body to the workings of a machine creates, at the same time, a comparison for the "breaking down" and "blocking up" of body parts. Just as a broken part of a machine can be identified and repaired or replaced, so too can the procedures of biomedicine identify and repair or replace specific problems in different parts of the body. As the dominant approach assigning meaning to the body, this medicalized view of the body with its machine metaphor is remarkably powerful, yet "...at the same time profoundly ideological and often misleading" (Good, 1994: 76).

1.2.2 The Limits of Biomedicine

Owing to the broad acceptance of these assumptions and the scientific approach to health care they advance, a situation of crisis has developed in biomedicine over the past few decades. This "crisis" is explained by Benatar (1992: 30) in the following quote.

> "Until 20 years ago, few would have disputed the value of 'scientific medicine'. Its obvious successes easily attracted private and public funds into medical schools and research institutions in the expectation that this would lead to conquering cancer, heart disease, psychiatric disorders and other afflictions. The money poured into scientific medicine between 1935-1960 gave major returns in terms of medical advances, but a popular view is that the resources spent between 1960-1990 have not led to equivalent objective therapeutic successes nor to an equivalent rise in patient satisfaction."

The "...crisis of confidence in the medical profession" (Benatar, 1992: 31) has led to a recognition of the "limits of medicine" and an attempt to move away from a "biomedical model of disease" (Benatar, 1992: 33). A perceived need, therefore, exists for an interdisciplinary approach to illness and disease that is far more sensitive to the interplay between biology, psychology and society (Turner, 1992: 136-142). And it is this perceived need that provides an opportunity for a sociological contribution to an understanding of illness.

1.2.3 Biomedicine and Sociology

Sociological interest in the area of medicine has traditionally accepted the naturalistic approach to the body and, hence, the same assumptions underpinning biomedicine (Wolinsky, 1988: 79-80; Doyal, 1979: 12; Gerhardt, 1989: xvi; Turner, 1992: 153). But while biomedicine's attention has focussed on diseased states in biological bodies, sociology's attention (in the broad field of medical sociology and the more contemporary sociology of health and illness) has focussed on the social context, construction and interpretation of states such as health, illness and sickness. These concepts, which are fairly central to the specialised areas of sociological study, are somewhat problematic in terms of definitions. Health and illness, for example, are concepts that commonly signify opposing bodily states yet both represent "essentially contested" terms. This means that consensus regarding their meaning is difficult to reach as they vary according to individual and social interpretation as well as over time (Senior and Viveash, 1998: 5-8). "Illness" is, furthermore, commonly seen to encompass concepts such as "disease" and "sickness" which collectively represent "...an interference with health" (Weiss and Lonnquist, 1994: 3). Broad distinctions can, nonetheless, be drawn between those states opposing health and health itself.

1.2.3.1 Sociological Focus on Health and Ill-Health

A commonly cited definition of "health" is the one formulated by the World Health Organization (WHO) in 1947 which considers health to be "...a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (WHO cited in Mishler, 1989: 154). According to this definition, health is seen to be a "positive" state which stands in opposition to a "negative" state of ill-health. So in its more conventional usage, health acts as the ideal bodily state against which those of "illness", "sickness" and "disease" are measured. While no resolution regarding the problematic relationship between health and illness is offered, Bryan Turner (1987: 2) does provide clarification regarding the three representations of ill-health.

> "Whereas disease is a concept which describes malfunctions of a physiological and biological character, illness refers to the individual's subjective awareness of the disorder, and sickness designates appropriate social roles (Susser and Watson, 1971)."

These distinctions, according to Turner, also reinforce a corresponding "prestige ranking of medical activity" and professional division of labour wherein disease is the concern of the medical profession, illness the psychiatrist and sickness the sociologist (Turner, 1987: 2). This distinction implies that for any one bodily state of ill-health, it is possible to obtain three distinct courses or trajectories of illness. Trajectory in this instance refers to "...the course of an illness, and to the work done to control it" (Strauss, 1987: 189) which means that a biomedical course of physical disease, a social course of sickness and a personal course of illness may all exist as detached if not discordant versions of a single condition (Robinson, 1990: 1174-1175).

Turner (1987: 2) argues that value and status have been more readily awarded to the medical profession's interpretation of ill-health as a "disease" condition abiding in a physical body. Even though this biomedical trajectory of physical disease has been privileged over the social and illness trajectories, the social course of sickness, or sickness trajectory, has received some sociological consideration in the form of concepts and research relating to "the sick role", "illness behaviour" and "the sickness career" (Conrad, 1990: 1259).

1.2.3.2 The "Outsider" Perspective

The traditional perspective adopted by sociology in mapping social or sickness trajectories is one Conrad (1990: 1259) refers to as an "outsider" perspective. In other words, the meaning imparted to illness is extraneous and unrelated to the subjective, embodied experience of illness. This "outsider" social trajectory, based on a naturalistic approach to the body, is epitomized by Talcott Parsons' 1951 conceptualisation of the sick role. Accepting the dominant biomedical trajectory of physical ill-health, Parsons views illness as deviance in need of legitimisation, intervention and control by the medical profession (ibid.). The person from this perspective is classified as a "patient" and sociological attention is focussed on the analysis of "patienthood" (ibid.).

This approach is found wanting when it comes to grasping the "...social psychological aspects of illness..." but is, nonetheless, useful in understanding the dominant biomedical assumptions and expectations regarding illness that have dominated the "outsider" approach in sociological research and theory (Conrad, 1990: 1259). As mentioned above, illness for Parsons represents a form of deviance in that the normal functions and obligations of an individual's role cannot be accomplished during periods of ill-health. While sick, an individual retains the right to be temporarily released from their normal role and from assuming responsibility for their condition. In return, however, the individual has an obligation to return to health as quickly as possible which implies consulting a medical practitioner. Parsons' sick role, thus, endorses biomedical intervention as the solution to ill-health, a state from which it is, furthermore, assumed one can recover (Lupton, 1994: 89-90; Freund and McGuire, 1995: 122; du Toit, 1995: 69; Annandale, 1998: 10).

Numerous criticisms have been directed at Parson's sick role theory, but for the purposes of this discussion only one will be dealt with. This particular criticism, relevant to chronic illness (or illness that lasts for a long period of time), suggests that the sick role refers largely to acute illness (or illness that has a short, marked duration) (McCullough, 1982: 14, 148). In other words, "...getting well is the only outcome Parsons considers as acceptable..." (Frank, 1995: 82). The sick role, then, does not apply to the many cases of chronic and disabling conditions, where despite wanting to get well, the illness can conceivably last for the

duration of the individual's life. Furthermore, because chronic illnesses are often permanent and beyond cure, treatment usually involves the management and control of symptoms wherein the success of medical intervention is debatable (Freund and McGuire, 1995: 123; Hart, 1996: 21-25). This criticism of Parson's sick role, and hence the underlying biomedical model of illness, has become increasingly relevant in Western capitalist societies over the past few decades during which time morbidity and mortality profiles, together with population demography, have undergone major changes. At the turn of the twentieth century, for example, death was largely attributed to infectious diseases, but towards the middle of the century, infectious diseases were succeeded by chronic and degenerative diseases as the major cause of death (Freund and McGuire, 1995: 17). In this way, the social trajectory represented by the "sick role" is seen to suffer similar issues of crisis facing biomedicine.

More importantly, though, the sick role represents an example of the "outsider" approach in sociological research and theory which is relatively limited in providing insight into the experiences associated with ill-health. It is for this reason that the "social psychological" or "insider" approach to illness, in the form of a personal trajectory, is of interest in this thesis. This traditional "outsider" approach adopted by medical sociology is, like biomedicine, based on a naturalistic approach to the body and in preference to this view, consideration is given below to the social constructionist approach to the body.

1.3 THE SOCIAL CONSTRUCTIONIST APPROACH TO THE BODY

The social constructionist approach to the body is one that not only challenges the view of the body held by biomedicine, but indeed challenges the view of the body held in sociology. The naturalistic, medicalized view of the body has, in other words, remained a largely unchallenged view in sociology and the social sciences generally (Shilling, 1993: 41; Armstrong, 1987: 63; Lupton, 1994: 20). By way of illustration, Armstrong (1987: 65) argues that "(h)uman anatomy has maintained its hegemony over sociology for too long. Its influence is so pervasive that its dominance has virtually been built into sociological thought." The dominance of this natural, biological body, that is seen to prevail in sociology, is most evident when it comes to defining the body.

1.3.1 Defining the Body

By calling into question the dominant conception of the body, some clarity regarding the specific meaning given to the body in this study is required. Although the body exists as a seemingly obvious phenomenon, its precise meaning within the social sciences is surrounded, to some extent, by ambiguity. In reviewing human and social science literature on the body since 1945, for example, Berthelot (1991: 391) reflects on definitions of the body as follows:

> "Definitions are few and far between. The body seems to be taken for granted and by a sort of inverted spirituality, to constitute a self-evident fact and an obvious benchmark."

So a closer inspection of reference material relevant to the body reveals that a definition of the body is not at hand and the obvious accord employed when referring to the body is seemingly lacking when reference is made to its meaning.

This observation is acknowledged by the social theorist Bryan Turner (1996) in his work on the body. In the "Introduction" to his first edition of "The Body and Society" he states that "(i)n writing this study of the body, I have become increasingly less sure of what the body is" (Turner, 1996: 42). He situates the problem within a number of paradoxes that relate to Peter Berger's distinction between "having" and "being" a body (cited in Turner, 1992: 16, 84). Turner suggests, for example, that it would be ridiculous to make a statement such as "I have arrived and I have brought my body with me", but that this, in essence, depicts the problematic nature of assigning meaning to the body (1996: 42). The physical body is a corporeal organism but, in addition, represents the person. An individual's existence and non-existence are dependent upon embodiment but an individual's experience of embodiment range from that of ruling the body to that of alienation from the body, particularly during periods of illness. Turner (1996: 43) summarises the contradictory nature of the body in the following statement.

> "The body is at once the most solid, the most elusive, illusory, concrete, metaphorical, ever present and ever distant thing - a site, an instrument, an environment, a singularity and a multiplicity."

Notwithstanding this problem encountered in defining the body, a statement of meaning will be pursued in the discussion below which considers the social constructionist approach to the body and that of Turner's in

particular.

1.3.2 The Sociology of the Body

The work of Bryan Turner (1984; 1987; 1992; 1996) has been particularly influential in the recent interest shown by sociology in the body. Turner draws on a wide range of theorists in developing his work, but unlike theories which articulate views on the body his aim, more specifically, has been to theorize the body and produce a sociological understanding or interpretation of it (Shilling, 1993: 88).

1.3.2.1 The Body as a Natural Phenomenon

Turner separates his interest in the body from the naturalistic approach and focuses on the body as it is portrayed in the social sciences more generally and sociology specifically. In short, Turner argues that the body is both a social phenomenon as well as a natural phenomenon. In arguing that the body is a natural phenomenon, he avoids the implication of biological determinism associated with the naturalistic approach by applying the work of Karl Marx (Turner, 1996: 225). According to Marx, nature exists as the context for the satisfaction of human needs and which, in the process of satisfying these human needs through productive labour, is transformed (Turner, 1996: 224; Burkitt, 1999: 72; Shilling, 1993: 27). The fact that humans transform nature in the realisation of their human potential, renders the relationship between nature and humans, historically and socially conditional. In other words, the way in which nature is transformed and the way in which human potential is realised, depend upon a particular mode of production (Turner, 1996: 224). Labour, in this sense, transforms nature into a "product of socio-historical practices" (Turner, 1996: 225). If human beings are part of nature, then the same process of labour which transforms nature will give rise to an understanding of humans as "...contingent, socially constructed phenomen(a)" (ibid.). So while Turner considers the body to be part of an objective, natural reality, human beings are not reduced to a universally fixed and predetermined entity by the objective laws of nature. What is understood by the body is socially and historically reproduced or transformed within a particular mode of production. Turner, therefore, acknowledges a biologically founded embodiment, but does not accept a position of biological reductionism (Turner, 1992: 36).

1.3.2.2 The Body as a Social Phenomenon

In addition to being a natural phenomenon, Turner argues that the body is a social construction (Turner, 1996: 63-64). His argument derives from the work of Michel Foucault (1973; 1977; 1979) whose history of the human body conceptualises it, in Western capitalist society, as an "object of science" (Turner, 1996: 64). In contrast to a naturalist approach to the body which puts forward a "physiologically static" history of the human body, Foucault identifies the Enlightenment as the period during which the body, characterised by mind-body duality and individuality emerged as an object and target of power. In other words, the Enlightenment was accompanied by a re-conceptualisation of the body, rendering it the product of changing social and historical circumstances.

1.3.2.2.1 *Sovereign Power*

According to Foucault's "history of bodies" (cited in Shilling, 1993: 75), structural alterations in knowledge have produced new discourses and forms of control over the body. These structural alterations in knowledge are associated with two systems of power, namely sovereign power and disciplinary power. Sovereign power, the older of the two systems, was visibly vested in a sovereign to whom other bodies were subject (Armstrong, 1987: 67). This repressive system of power was dependent upon its visibility in pageantry, punishment and the prerogative to take life which, in turn, served to demonstrate the relationship between supreme sovereignty and subjugated subjects (Sawday, 1995: 55; Armstrong, 1987: 67; Burkitt, 1999: 17).

1.3.2.2.2 *Disciplinary Power: Target, Object and Scope*

The second system of power, referred to as disciplinary power, emerged during the eighteenth century and ushered in a change in the target, object and scope of discourse (or the language aimed at influencing thought and understanding). Unlike sovereign power which targets and controls the body as flesh, the discourses of disciplinary power target and control the body through its constitution as a "mindful body" (Shilling, 1993: 76). Other than its composition as unembellished flesh, the body is created as an object endowed with "consciousness, intentions and language" (Shilling, 1993: 76). The body, in this way, is transformed into an

"individual" or rational subject requiring control, not in terms of physical persuasiveness, but in terms of surveillance and stimulation (Armstrong, 1994: 21; Shilling, 1993: 76). This means that disciplinary power, rather than being coercive and oppressive, operates by producing knowledge and ways of knowing which, when put into practice through various techniques, amounts to the exercise of power. Discourses, then, are re-directed under disciplinary power towards targeting the mind and correctly producing or constructing bodies as individuals to be controlled through incitement and surveillance.

In addition to the change in discourse target, an associated change in discourse object also exerts disciplinary control over the body. Whereas the object of sovereign power had been the absolute rule over the death of bodies, the object of disciplinary power is transferred to the life and welfare of bodies. So the object of disciplinary control bears less on the body's repression and final destruction than it does on its "...fertility...health and illness, patterns of diet and habitation, and a general concern with...corporeal habits and customs" (Foucault cited in Shilling, 1993: 77; Burkitt, 1999: 17). Illustrating this idea is the desire shown by state and other institutions to stimulate "productive" lifestyles and forms of sexuality as well as to provide "useful" forms of living for such people as prison inmates (Shilling, 1993: 77). So, according to Foucault, the object of disciplinary discourses has overtly adjusted from a governmental concern with death, to one of life.

The third way in which the emergence of disciplinary power has impacted on the control of bodies, relates to the scope of discourse. Government interest in controlling bodies under disciplinary power transfers its focus from disciplining the individual body to regulating the social body. The regulation of bodies by governments, therefore, involves the entire population (Shilling, 1993: 77). This evolved and expansive form of regulation and control is referred to by Foucault as "governmentality" and is defined as "...the coercive and non-coercive strategies which the state and other institutions urge on individuals for their own benefit" (Higgs, 1998: 185). So governmentality is not necessarily coercive or forceful and may, instead, be seen as a means of "directing 'free will'" (ibid.). Repression still exists, then, but in a "better", more "humanised" form. As such, governmentality acts as a new form of government through which the population at large is

regulated and controlled to a far greater extent.

In summary, then, the changes in the target, object and scope of discourse suggest ways in which the human body is marked by and constructed through discourses. According to Foucault, the structural alterations in knowledge that emerged during the Enlightenment saw the emergence of new discourses and hence new forms of control. The bodies of subjects requiring control through sovereign power are, at the emergence of disciplinary power, re-constituted as "mindful bodies" or individuals in need of control through surveillance and the stimulation of desire. In this way, the body is seen to be a socially created outcome of power and knowledge, or discourse. And, based on this argument, it is suggested that the body is not an objective reality that exists as a fixed pre-social, natural entity, but is instead the construction of external, determining forces.

1.3.2.2.3 *The Body as a Structuralist and Phenomenological Concern*

Foucault's socially constructed body, while useful in examining discourses aimed at controlling and regulating the bodies of individuals and populations, is not accepted without caution by Turner. He objects, for example, to Foucault's structuralist perspective which reduces conscious human action to the outcome of discourses. According to Foucault's approach, humans are determined by all that discourses enable them to know, which ignores the potential for the construction of meaning and action (Shilling, 1993: 80-81; Turner, 1996: 229). In this way, the phenomenology of embodiment is overlooked by reducing the body to an effect of discourse. The sensory experience of possessing, occupying and controlling a body is diminished and neglected to the benefit of a view emphasising external discursive control and regulation (Turner, 1996: 230).

So, in forwarding a view of the body as socially produced, Turner rejects the idea of a body that is exclusively "...constructed by ideology / in discourse" (MacSween, 1993: 116). Rather, he argues for the incorporation of a "phenomenology of embodiment" in the sense of "...immediate and first-order possession..." or experience of the body (Turner, 1996: 229, 221). It is, after all, through embodiment that humans exercise "corporeal government" or personal control of the body-environment (Turner 1996: 230). This issue of rulership is important to the phenomenology of embodiment, but it is also problematic when located within

the context of the individual. An individualistic understanding of governmentality or rulership does not, for example, account for the impact of social structures which distribute control over bodies irregularly. Not only are certain categories of individuals denied full control over their embodiment, in cases for example of the elderly, or those labelled "insane", but in addition bodies are increasingly the object of professional and governmental control and surveillance. Turner (1996: 81) argues this point in the following quote.

> "To talk about our phenomenological rulership of our bodies is to miss the crucial sociological point, namely the regulation of the body in the interests of public health, economy and political order."

So in effect, Turner sees a sociology of the body embracing both the phenomenological concern with "being a body (the body as capacity)" as well as the structuralist concern with "having a body (the body as constraint)" (Turner, 1992: 95). Such an understanding of embodiment, although neglected in sociology, is for Turner crucial, in that it transcends rationalistic theories of action by respecting the capacity of emotions and feelings in human action (Turner, 1992: 162-164). Human action and experience thus signify an intercourse between "embodiment, society and culture" (Turner, 1992: 380). In this way, a sociological theory of the body represents a significant departure from the naturalistic approach by demanding attention to the embodiment of a person who feels, experiences and ascribes meaning to the body and different bodily states.

In attempting to understand the experience of bodily states such as pain and illness, then, the social constructionist approach to the body offers sociology an opportunity to move beyond the confines of the naturalistic approach which dominates biomedicine. It also offers an opportunity to move beyond those sociological approaches to health and ill-health based on a naturalistic, and hence "outsider", understanding of the body. In short, it provides the basis for an understanding of meaningful, embodied experiences and action which are, furthermore, situated within the broader social context.

1.3.3 Points of Departure

The social constructionist approach to the body, as outlined above, lends itself towards an "insider" account of illness experience. And it is an "insider" or personal, subjective account of illness experience that is of interest in this thesis. So, in pursuing this interest the thesis takes as a point of departure an understanding of the body as a socially constructed phenomenon.

A second point of departure, concerns the focus of attention. As indicated above (cf. 1.2.3 and 1.2.3.1), illness as well as health remain "essentially contested" terms that are commonly understood as opposing bodily states. Health is, for example, defined by Georges Canguilhem (a medical philosopher) as "...something we cannot know positively; or at least we can only know it, so to speak, in its absence" (cited in Osborne, 1997: 179). This definition suggests that a mutually inclusive relationship exists between health and ill-health in so far as they are bodily states available to our experience only through the presence or absence of one or the other. Subjective accounts of illness, from this understanding, are to some extent dependent upon the "opposing" subjective experience of health. For this reason, it is being suggested that a sociological focus on illness experience be broadened to incorporate a focus on health and, more specifically, dominant discourses on health for which a theory of embodiment provides a suitable framework.

It is assumed, in reaching this point of departure, that dominant discourses conveying an understanding of the body in naturalistic and medicalized terms will influence understandings and experiences of bodily states such as illness and pain. To be anticipated in accounts of illness, then, are references to the naturalistic body and mind-body dualism which are gleaned from biomedical trajectories of physical illness. Dominant discourses on illness, however, implicate health and in order to understand illness it is being suggested that dominant discourses on health, too, be the focus of sociological attention.

Although Turner has reservations about the unqualified adoption of Foucault's socially constructed body, it remains useful in examining discourses aimed at controlling and regulating the bodies of populations. In accepting, for example, Foucault's argument that an understanding of the body as a natural, biological entity

only emerged during the eighteenth century, it is possible to identify the naturalistic, medicalized view of the body as a dominant discourse directing and influencing understanding and experience not only of the body, but also of bodily states such as health, illness and pain. This dominant biomedical discourse may, however, be seen as one of a number of competing discourses aimed at controlling and regulating the bodies of populations. Indeed, it is to be suggested in the section that follows, that equally relevant and influential discourses may be found in those associated with public health.

1.3.4 Public Health

Public health broadly "...implies a focus on the health states of populations rather than individuals..." (Petersen and Lupton, 1996: 3). A significant shift, in this focus on the health states of populations, has been witnessed during the twentieth century which loosely corresponds to the changing morbidity and mortality profile in Western capitalist societies. This movement, then, from "public health" to what "...has come to be known as 'the new public health'" (Petersen and Lupton, 1996: ix), represents a repositioned public health focus, from that controlling the spread of infectious diseases, to that controlling and preventing non-infectious chronic illnesses and, at the same time, promoting health.

1.3.4.1 Risks To Health

This shift in focus is reflected, to a large extent, in public health's concern with risks to health. The meaning of the term "risk" as it is applied to public health has evolved from a neutral conceptualisation as "...the mathematical likelihood of an event occurring", to one identified with negativity and danger (Lupton, 1995: 78; Lupton, 2001: 395; Fox, 1999: 12). As such, the interpretation of risk as "something to avoid" dominates understanding in contemporary capitalist society to the point where "(a)ny risk is now negative; it is a contradiction in terms to speak of something as a 'good risk'" (Douglas cited in Lupton, 2001: 395). This interpretation is evidently reinforced by biomedicine. In drawing the distinction between a hazard and a risk, for example, Fox (1999: 12) cites a description given by the British Medical Association which explains that a hazard is "...'a set of circumstances which may cause harmful consequences', while risk is 'the likelihood of its doing so'". So risks to health are associated with particular entities or conditions that are seen

to threaten or jeopardize health. In the development of public health, however, perceptions of what entities or conditions constitute risks to health have undergone fundamental change (Bunton, 1997: 228).

In the earliest model of public health referred to by Armstrong (cited in Williams and Bendelow, 1998: 70, 71) as the "quarantine model", risks to health were initially embodied in dangerous individuals and groups who were controlled by means of physical confinement. In the later "sanitary science" model, risks to health were controlled by preventive medical interventions, epitomized in England from the mid 1800s onwards by the obligatory appointment of doctors to "sanitary districts", whose role it was to "...monitor health conditions through inspection and report" (Porter, 1999: 138). The priority given to controlling the risky *individual,* shifted during the twentieth century and was instead placed on the anticipation and prevention of risk *factors* (Petersen, 1997: 193). Petersen citing Castel (ibid.) explains that this relocation of risks, from individuals to factors, proliferates the number of risks that are seen to encroach on health by placing them "anywhere and everywhere" (Williams and Bendelow, 1998: 71). This, in effect, provides an abundance of opportunity for institutional intervention and regulation by means of which certain behaviour and practices are encouraged and normalised while the existence of others is curtailed (Tyler, 1997: 79). So, the shift to what is referred to as "the new public health", "...represents the imposition of a far more subtle and effective mode of population regulation..." (Petersen, 1997: 193).

1.3.4.2 Health Promotion: Lifestyle and Behaviour

This control and regulation is associated, more specifically, with the new public health's discourse of health promotion (Petersen, 1997: 193-7; Lupton, 1995: 51). Health promotion is an "extremely broad" (Lupton, 1995: 50) concept which encompasses

> "...fostering 'positive health', preventing illness and disease rather than treatment, developing performance indicators based on specified objectives, the use of mass media to 'market' health-enhancing behaviours and attitudes, and a focus on working with 'communities' to develop health-enhancing environments" (Lupton, 1995: 51).

One of the aims of health promotion, as this definition suggests, is to re-conceptualise health as "health-as-

wellbeing" (O'Brien, 1995: 193-194) and, in so doing, offer an alternative to biomedicine's negative interpretation of health (the absence of disease). Indeed, considerable effort has been undertaken to dissociate health promotion from biomedicine (Bunton and Burrows, 1995: 206; Kelly and Charlton, 1995: 79; O'Brien, 1995: 193). As such, health promotion is seen to extend well beyond the limited biomedical focus on the "ill-health" and treatment of sick individuals, to address instead "...all individuals at all levels of the population" (Lupton, 1995: 51). Although directed at the entire population, Lupton (1995: 139) does indicate that in it's application to certain Western capitalist societies, health promotion discourse is found more appealing to certain groups. It is possible that her description, below, might also be applicable to South Africa.

> "In Britain, North America and Australia, health promotion is a middle-class movement dominated by women from English-speaking backgrounds. While their appeals to rationality and self-control may strike a chord with others of a similar socio-economic and cultural background, different social groups receive and interpret health promotional discourses in different ways." (Lupton, 1995: 139)

So, in re-conceptualising health as "health-as-wellbeing", this predominantly middle-class movement has also broadened the narrow biomedical preoccupation with organically caused ill-health, to include an understanding of "...ill-health as a product of society" (Lupton, 1995: 51). Lifestyles, more specifically, and their associated range of "risky" behaviours, are seen to be the cause of illness. In this way, illness is perceived to be "...'a symptom of the pathology of civilization', an outcome of the stresses and poor lifestyle choices of the members of modern societies, a sign that modern life is inherently damaging to health" (ibid.). The suggestion that "poor lifestyle choices" are responsible for ill-health implies, in turn, that individuals are in a position to control their state of health. The new public health movement has, thus, given rise to a "behavioural" approach to health (Taylor, 1993: 49-51) which has encouraged the creation of an "entrepreneurial self" who is tasked with the responsibility of managing their own risky behaviour and lifestyle (Bunton and Petersen, 1997: 9).

So, far from being linked to structural inequalities or even the control of infectious diseases, the factor which

is seen to contribute most to health and ill-health in Western capitalist society today is associated with particular lifestyles. This understanding has encouraged an intensified public health effort since the 1970s to educate the population into adopting healthier lifestyles and healthier behaviour (Taylor, 1993: 49; Petersen and Lupton, 1996: 15). This educational effort does not, however, discriminate between healthy and non-healthy members of the population. Instead, the all-inclusive nature of health promotion discourse targets the population as a whole with the result that it "...moves the attention of medicine from pathological bodies to each and every member of the population" (Gastaldo, 1997: 116). This extended mode of surveillance, referred to by Armstrong (cited in Gastaldo, 1997: 116) as "surveillance medicine", is blind to the distinction between healthy and non-healthy members of the population and, as such, suspends the distinction between health and illness. Gastaldo (1997: 116 / 117) explains this shift in the quote below.

> "The categories of health and illness give way to the notion of risk - illness is not a problem per se, but a significant portion of health is redefined as an 'at-risk state' (Armstrong 1995: 400; Petersen 1996: 45-51). The borders between health and illness have also been reshaped - healthy people can become even healthier, and a person can be healthy and ill at / the same time..."

So, the conventional distinctions between health and illness, as the quote above indicates, fade away under the discourse of health promotion and are replaced by an all-encompassing state of being "at risk". At the same time, the duties and obligations associated with being sick and occupying the sick role are seen to advance to new and further obligations and duties associated with what Bunton and Burrows (1995: 208) refer to as "the health role".

1.3.4.3 The Health Role

The health role, unlike the sick role, applies to everyone regardless of their state of "health" or "ill-health". All individuals, according to this discourse, have a "moral responsibility" (MacDonald, 1998: 28) to protect themselves and others from risks to health. This responsibility involves assuming a lifestyle that places priority on "risk-minimisation" which, in turn, requires that individuals pay attention to bodily boundaries. Illness, from the perspective of the health role, is no longer simply understood as "...an invasion from outside" (Annandale, 1998: 52). The body is instead perceived to be vulnerable and open to attack from both the

exterior as well as the interior (Petersen and Lupton, 1996: 112). So in order to reduce the risk of illness, the individual is required to monitor both the external and internal environments, ensuring that greater vigilance over the boundary between the two is maintained and that the body is protected from the possibility of ill-health. Central to this process, is the body's defence mechanism or immune system.

1.3.4.4 The Immune System

The immune system, which was identified by the relatively recent scientific discipline of immunology during the 1960s, is considered to be a complete, yet complex "homoeostatic, self-regulating system" which defends the body against foreign microscopic invasion (Martin, 1992: 123, 126). The idea of an immune system has had important implications for the body as a bounded entity. Prior to the 1960s and the notion of an immune system, the exterior surface of the body was seen to be the boundary between internal and external and the shell that protected the inner body. From this earlier perspective, "...the boundary between the body ('self') and the external world ('nonself')..." was fixed and definite (Martin, 1992: 126). With the development of immunology, however, the ultimate check in distinguishing between the "self" and "nonself" has been seen to reside in the immune system. So, it is the body's internal defence system, rather than the outer surface of the body, that serves to define and affirm what constitutes "self" and "nonself" as Martin (1992: 125) explains below.

> "The self has retreated inside the body, it is a witness to itself, a tiny figure in a cosmic landscape, which is the body...The 'I' who used to wear the body like a closely fitting set of clothes is miniaturized, and is dwarfed by its body. The 'I' is made a passive and powerless witness to the doings of the components of the body. Somewhere in the system lies agency; the 'I' can only watch."

In drawing and monitoring the boundaries of the body, then, the individual has to, by and large, rely on the autonomous workings of the immune system. The precarious nature of this situation is compounded by the perception that the body is under constant threat from the external environment over which the individual has little control. This situation has, furthermore, lent itself well to the military or war metaphor in which the body is seen to be under attack from an external foreign invader.

1.3.4.5 External Risks to Health

The environment external to embodied individuals is, according to health promotion discourse, seen to harbour risks to health. Although the environment, or "nature", has always acted as a threat or risk to health, the new public health movement is seen to be distinct from earlier models of public health in its concern regarding nature. Whereas earlier models deem nature itself to be a risk to health, the new pubic health discourse suggests that "...it is because of the way in which humans have spoiled nature (for example through pollution) that it has become dangerous" to health (Nettleton and Bunton, 1995: 46). Within this discourse, the urban, industrial environment is seen to be "unnatural" and at odds with the needs of a healthy and risk-free lifestyle (Petersen and Lupton, 1996: 112). In contrast, a country, rural, or more "natural" environment is prized for being less contaminated by culture and society and, hence, seen to be desirable for a healthy lifestyle. Nature and all that is considered to be natural is thus valued over that which is seen to be urban, industrial and "pathologizing" (Lupton, 1995: 90). According to this discourse, then, one of the few options available to individuals, in the control of external threats to health, is to pursue a lifestyle that eradicates as many factors and activities perceived to be unnatural as possible, in favour of those perceived to be natural.

1.3.4.6 Internal Risks to Health

While external risks may act as a relatively unmanageable threat to the health of the body, an obligation does accompany the health role to manage and reduce internal risks. Apart from the continuous surveillance of "body boundaries" (Bunton and Burrows, 1995: 208) "risk-minimisation" behaviour, aimed at managing internal risks, involves engaging in practices such as "...moderation, abstention, attention to diet and exercise" (Petersen, 1997: 199; also Bunton and Burrows, 1995: 208). Such practices are considered valuable to the maintenance of bodily balance in terms of "...'inputs' (e.g. attention to diet, sleep and consumption of such 'unhealthy' products as tobacco, alcohol, fast foods) and 'outputs' (time-management, heart rate, muscle size, body shape and weight)" (Petersen, 1997: 200). So based on an understanding of lifestyle as pathological and the cause of ill-health, individuals are encouraged to adopt internal risk-minimisation practices and behaviours in pursuit of an ideal, risk-free state of health (Lupton, 1995: 142).

1.3.4.7 Risk Minimization: Stress

Risk-minimisation practices and behaviours often target the reduction and control of stress. Stress can broadly be defined "...as 'a reaction to an observable event (stressor) that influences the person in a harmful way'" (Engel, 1993: 346). The harm that stress induces is seen to impact directly on the health of an individual as a result of physiological changes that ultimately weaken the immune system (Engel, 1993: 347). The body's ability to fight off invasions of foreign microorganisms is, therefore, seen to be compromised by the presence of stress. This commonly held understanding is given credibility by research such as that done in 1991 by American psychologist, Sheldon Cohen, who provided evidence linking stress and susceptibility to colds (Houlder, 2000: 11). So in order to guard against weakening the immune system, individuals are encouraged to adopt risk-minimisation practices that involve the management and reduction of stress (Petersen, 1997: 198).

1.3.4.8 Risk Minimisation: Fitness

Other than attention to stress, one of the most widely advocated means of avoiding risks to health and thereby fulfilling one's "moral responsibility" is through "fitness" (Petersen, 1997: 200). Physical fitness is considered essential to building-up one's immune system and as the body's internal "defence" against outside "invasion" it is, in turn, considered vital to the protection of the body from dangers to health. This idea is illustrated in a popular guide by Conley (1995: 22) called "Be Slim! Be Fit!".

> "Remember, getting physically fit means more than just losing weight and looking better. WE fight infection more easily, we have lots more energy and we enjoy life much, much more! So do it!" (Emphasis added)

In addition to protecting the body from risks, fitness is also associated with the "construction of subjectivity" (Lupton, 1995: 143). Lupton (ibid.) explains this relationship in the quote below.

> "Fitness activities represent the attempt of individuals to find their 'true selves', to uncover the 'fit' and lean individual hiding beneath the layers of flesh, to bring together the mind and the body, to cope with the seemingly chaotic nature of life in the late twentieth century by mastering the body."

As a form of self-regulated and purposeful action, then, fitness represents "...a conduit of agency and self-expression" in the endeavour to create an "integral biography" (Lupton, 1995: 143). In this way, physical fitness acts as the visible expression of an inner disposition towards self-discipline, control, morality and commitment to the common good (ibid.).

1.3.4.9 "Experts" and "Authorities"

Such "practices of the self", which health promotion discourse encourages individuals to adopt in the health role, are not by definition coercive and oppressive. Rather, as the reference to fitness above indicates, the potential exists to re-create and reinforce a self-identity (Lupton, 1995: 148). It is this productive and non-oppressive nature of health promotion discourse that has led to its association with "...the development of a new form of governance, one that has moved well beyond the walls of the hospital and involves not just the physician and the patient, but a whole range of agencies dispersed throughout society..." (Bunton and Burrows, 1995: 208). As this quote suggests, the health role acts as a form of surveillance which is, furthermore, associated with a glut "...of 'experts' and 'advisers' located in a range of diffuse institutional and cultural sites" (ibid.). In this way the health role is removed, unlike the sick role, from the exclusive authority of the biomedical professionals and, instead, individuals are encouraged to listen to and adopt the sometimes contradictory advise given to them by a host of "experts". As Bury (1998: 11) argues, this has dissolved the distinction between the "lay every-day world" and that of "the expert". So although health promotion discourse is premised on the idea that "...science can discover objective, ultimate truths about risk and provide a basis for making ethical decisions about personal conduct...", it is often the case that disparate and incompatible "scientific" evidence is used to support advice regarding health risk minimisation (Petersen, 1997: 201; Nettleton, 1997: 216; Williams and Bendelow, 1998: 70). As a result, health promotional discourse is, at times, seen to hold questionable assurance of security against dangers to health.

If it is to be accepted that some insight can be gained by broadening the focus of attention from illness to include health, then, as it has been argued above, the need exists to consider dominant discourses that not only surround illness, but also health. The aspects of the new public health movement discussed above will,

therefore, be used to establish a point of focus in the interpretation of the meaning and experience of the embodied states associated with the condition myalgic encephalomyelitis. The chapter that follows, however, provides an overview of myalgic encphalomyelitis before attention is turned to an interpretation of the embodied states associated with it.

1.4 CONCLUSION

In developing a theoretical frame of reference for a sociological study of pain and illness, this chapter has discussed two approaches to the body, namely the naturalistic and the social constructionist approaches. The naturalistic approach is manifest in common conceptions of the body as well as the dominant and official model of medicine, referred to throughout this thesis as biomedicine. It also informs biomedical assumptions regarding health, illness and disease. These are in short, that disease and illness are regarded as biological phenomena that reside in the bodies of individuals; that a scientifically identifiable disease may be diagnosed, treated and cured by a scientifically neutral medical practitioner; and by implication that health may be restored by biomedicine. These assumptions, in turn, generate a particular illness trajectory that follows the course of disease in a physical body. Certain sociological approaches to the study of illness, referred to as "outsider" approaches and typified by Talcott Parsons' notion of the "sick role", are furthermore supported by the same assumptions. This "outsider" perspective also locates illness and its meaning within the medicalized physical body and gives rise to a sickness trajectory, or social course of sickness, in keeping with the biomedical trajectory. By underwriting the naturalistic approach to the body, these two trajectories are considered ill-suited to an understanding of pain and illness as embodied states. A personal trajectory of illness experience requires that the perception of the body as a biologically determined and pre-social given, be dispensed with or at least modified, in favour of an approach that appreciates the body's ability to absorb and reflect meaning beyond biology, from its variable social and historical context.

The position adopted in this thesis can be seen to depart from dominant approaches to the study of pain and illness in two significant ways. Firstly, based on the assumption that pain and illness heighten our awareness of our physical bodies together with the assumption that conceptions of the body, be they physical or

otherwise, are socially, culturally and historically variable, it is reasoned that interpretations of embodiment are fundamental to understanding pain and illness experiences. An analysis of pain and illness as social constructions, therefore, demands an analysis of the body as a socially constructed phenomenon. It is for this reason, that a sociological interpretation of the body as a socially defined and controlled entity is adopted in favour of the naturalistic approach which views the body as a biologically determined and historically static entity.

A second and related point of departure from dominant approaches to the study of pain and illness, concerns the scope of attention. It has been argued that the body as a socially constructed phenomenon is subject to the exercise of disciplinary power aimed at the regulation and control of the social body, comprised of mindful individuals. Discourses, which have been defined as the knowledge and language directing and modifying thought and understanding (Senior and Viveash, 1998: 13, 27, 62), are central to this process of regulation and control. For this reason, an examination of those discourses seen to impart meaning about illness, is deemed appropriate to understanding the meaning that individuals give to their experiences of embodiment during periods of illness. Apart from discourses relevant to illness, it is argued, further, that discourses relevant to health are equally significant in understanding illness experiences. If it is to be accepted that health is a state, defined by the medical philosopher Georges Canguilhem (cited in Osborne, 1997: 179), of "... 'life lived in the silence of the organs'", then health remains "...something we cannot know positively; or at least we can only know it, so to speak, in its absence". According to this understanding, the knowledge and experiences associated with illness are intimately entwined with those of health and accessing the meanings associated with illness necessitates attention to the meanings associated with health. So, the second point of departure involves expanding the focus of attention to those discourses affiliated with health and, of particular importance, the health promotion discourse associated with the new public health movement.

CHAPTER 2

MYALGIC ENCEPHALOMYELITIS (ME)

2.1 INTRODUCTION

The previous chapter presented an argument for the conceptualisation of the body as a socially constructed phenomenon. In contrast to the naturalistic approach (which views the body and its status, states and experiences as biological or physical) the sociological interpretation of the body, as proposed by Turner, argues for an understanding of the body which articulates the social experience of "being" and "having" a body. In employing this perspective to study the body in a state of chronic pain and illness an attempt will be made, in this chapter, to offer an understanding of pain and illness that moves away from the biomedically mediated physiological or neurological explanation. In so doing, it responds to the need, recognised by both biomedicine and sociology, to advance from a biomedical model of disease and develop "...a new way of thinking" (Benatar, 1992: 33) about the body and its states of health, illness and pain. In the discussion that follows, then, the dominant conceptualisations of myaligic encephalomyelitis will be explored as a backdrop to the argument of this chapter, which calls for a sociologically informed understanding of the body as a socially constructed phenomenon, in the interpretation of meaning and experience associated with myalgic encephalomyelitis.

2.2 MYALGIC ENCEPHALOMYELITIS

This thesis seeks to understand the embodied experience of chronic pain and illness and uses as a specific case in point, people diagnosed with the condition referred to as myalgic encephalomyelitis (ME), but also known as chronic fatigue syndrome, chronic pain syndrome, panic anxiety, sleep disorder, epidemic neurasthenia, postviral fatigue syndrome, chronic Epstein-Barr virus syndrome, chronic mononucleosis-like syndrome, Royal Free disease, postinfectious neuromyasthenia, sero-negative glandular fever, Los Angeles Flu, Addington's disease, vegetative neuritis, Akureyri disease, chronic hyper-fatigability syndrome as well as the more popular "yuppie flu" (Kleinman and Straus, 1993: 3; Berne, 1992: 16; Smith, 1991: x). This sizable list of terms all, essentially, refer to a state of chronic ill-health or illness characterized by "...a set of symptoms occurring

together...", as the frequent reference to "syndrome" implies (McCullough, 1982: 654). It is the syndrome's close association with chronic pain that provides the basis for its experiential analysis as a state of chronic pain.

Apart from it being considered a form of chronic pain, in this thesis, ME lends itself well to a sociological study of pain because of its contested biomedical nature and status. Conrad (cited in Encandela, 1993: 787), for example, argues that medical diagnoses often impede a comprehensive investigation of a phenomenon because they are "too narrow". By using an ambiguously defined and understood illness, the potential exists to elicit lay interpretations that do not rely, to an overwhelming extent, on biomedical interpretations of the condition (ibid.). It is, furthermore, suggested by Encandela (1993: 788) that "special attention" be paid to the pain associated with "emerging phenomena". That is "...conditions...about which we are still learning..." which "...may help illuminate the physical, psychological and social aspects related to them" (ibid.). It is the intention of the following discussion to indicate that ME is a controversial condition over which there is little biomedical consensus regarding its aetiology, diagnosis and treatment. Despite this, the debates and issues relevant to ME take place, to a large extent, within biomedical discourse based on the assumptions of a naturalistic body that is divided between rational mind and biological body. As such, the following discussion will highlight the mind-body distinction evident in biomedical discussions of ME.

2.2.1 TERMINOLOGY

ME, in its literal translation, means "...*mya* - muscles; *algic* - painful; *encephalo* - brain; *myel* - nerve; *itis* - inflammation." (Smith 1991: 20). The name, then, describes in biomedical terms a disease in which the symptoms are muscular pain and inflammation of the nervous system (brain and spine). Myalgic encephalomyelitis is the term that evolved from an condition referred to earlier as epidemic neuromyasthenia, but was abandoned in favour of the former term on account of it being more accurate in its reflection of the condition. The terminology remains problematic, however, because myalgia or muscular pain, although very common, need not be a symptom and there is rarely evidence of encephalomyelitis or nervous system inflammation (Smith, 1991: 20; Macintyre, 1992:20). At the same time, a large number of commonly

experienced symptoms are excluded from the term. These include muscle fatigue, exhaustion and general malaise, loss of memory and concentration, periodic sore throat and glands, as well as depression (Smith, 1991: 21; Macintyre, 1992: 21-27). In addition, an array of minor secondary symptoms may or may not be experienced during the course of the condition. These include, amongst others, "...headaches; dizzy spells; visual focusing problems; disturbed sleeping patterns and nightmares; chest pain; palpitations; a feeling of shortness of breath; gastro-intestinal upset, including indigestion, flatulence, distension and wind (collectively termed 'irritable bowel')" (Smith, 1991: 21). Further to the variation in symptoms, their actual onset is also inconsistent. Symptoms may appear in an acute and sudden manner or they may involve a far more surreptitious process that develops over a prolonged period of time. In either case it is commonly held that the condition follows a viral infection and, for this reason, it is also sometimes referred to as "post-viral fatigue syndrome" (Macintyre, 1992: 20-21).

The controversy surrounding the condition, and its terminology, symptoms and onset, attest to a fundamental problem surrounding the "disease" itself and those similar to it. These diseases which include amongst others, temporomandibular joint dysfunction, chronic fatigue syndrome, total allergy syndrome, sick-building syndrome, Gulf War syndrome and repetitive strain injury (Garro, 1994: 775, 776; Cooper, 1997: 187; Engel, 1993: 322-324, 324-328, 345, 360-363) all carry a questionable biomedical status. The reason for this relates to the lack of scientific certainty regarding medical testing, aetiology and subsequent diagnosis and treatment. In the case of ME, for example, diagnosis, prognosis and treatment are sometimes based entirely on the symptoms identified and reported by the patient with little or no commonly-held biomedical verification. The disputable organic nature of such "diseases", and lack of assured legitimation as an illness, has disposed these conditions to classification as "non-disease" or "illegitimate illnesses" (Cooper, 1997: 186-7). Following Cooper (1997: 186), it is this classification of ME as a "non-disease" or "illegitimate illness" that holds preference in this thesis.

2.2.2 The Division between Body and Mind

The contention surrounding ME is to a large extent associated with the biomedical discourse which divides

the body into distinct organic and psychological components. This division between mind and body also represents the two constituencies most commonly associated with debates regarding ME. Those who defend the position that ME is organically located include, to a large extent, those individuals suffering from ME, associations for and representing ME sufferers, and certain members of the medical profession and scientific and research communities (Cooper, 1997: 189). The prominence given to ME, as an organic disease, within the medical profession followed a symposium held during 1978 by a group of doctors in London with the expressed purpose of drawing the medical profession's attention to ME or "epidemic neuromyasthenia" as it was referred to then (Lyle and Chamberlain, 1978).

This symposium instituted a heightened biomedical awareness of the condition which, in turn, intensified the associated process of medicalisation. Medicalisation is a term used to indicate that "(c)ertain behaviours or conditions are given medical meanings and thus medical practice becomes the appropriate vehicle for their elimination and control" (Levinson, 1998: 75). This process of medicalisation is seen to be an important means of authorizing and legitimating a condition, particularly to those suffering from it (Beechey, 1989: 18). At the same time, however, it implies that debates and issues relevant to the condition become defined by, and confined to, biomedical interpretation. This is evident in issues discussed at the symposium - many of which remain issues of contention in more contemporary debates surrounding ME. As a point of reference, then, this symposium will be referred to in the section below which provides a brief overview of the "organic" and "psychological" interpretations of ME which are frequently held by medical professionals and lay individuals alike.

2.2.2.1 Organically-Based Accounts of ME

For those in support of the organicity of ME, reference is commonly made to the relationship between ME and viral infections and enteroviruses, more specifically (of which polio, echo and coxsackie are all examples). The earliest outbreaks of ME are, for example, more often than not associated with outbreaks of poliomyelitis. The 1934 outbreak of ME at the Los Angeles County General Hospital and the fourteen that followed this one between 1934 and 1959, in places such as Iceland, Australia, the United Kingdom, Ireland, Switzerland

and South Africa (Parish, 1978: 711-717; Ramsay, 1978: 710), are all associated with outbreaks of poliomyelitis. As such, they are often described as "abortive poliomyelitis" or as a "disease resembling or simulating poliomyelitis" (Parish, 1978: 711). An identifiable association with outbreaks of poliomyelitis thus characterises the earlier outbreaks of ME. Although this link is recognised, it is one closed to further investigation "...for the simple reason that there are no more epidemics of poliomyelitis on which to base such an investigation" ([Ramsay in "Discussion"] in Dillon, 1978: 730). Despite this, the connection between ME and viral infections is one commonly recognised and often cited as a precursor to the onset of ME by medical practitioners and individuals suffering from ME.

Discussion documented at the symposium certainly acknowledges and supports an identifiable connection between outbreaks of ME and poliomyelitis. It is also acknowledged that this connection is not without contention. A question is, for example, raised about the existence of an apparent pattern between earlier outbreaks of ME and hospital, as well as a few cases of military, personnel. The hospital outbreaks are, in these cases, seen to disproportionately affect nursing staff, as the following question appearing in a "Discussion" at the symposium indicates.

> "Why is it so unlike poliomyelitis where you get hundreds of cases in the community and perhaps one or two nurses? In this the ratio is, broadly speaking, the other way round. How does one explain that?" ([Easton in "Discussion"] in Dillon, 1978: 730)

One of the explanations proposed in response to this question, suggests that "...muscular or physical activity plays some part in the susceptibility to infection" (Dillon, 1978: 730). This explanation is substantiated by reference to an outbreak that took place in North Finchley, as the following quote indicates.

> "It was noticeable that no sedentary persons were affected in that outbreak which included about 270 cases altogether. That might explain, too, the fact that no patients were affected in the Royal Free outbreak within the hospital." (Dillon, 1978: 730)

The reasoning that the disease affects active, rather than sedentary, people is also used to explain an outbreak in Frohburg which affected a women's-only section of the St Gall hospital. In this outbreak, both staff and patients were affected and the explanation offered surmises that "...in the separate women's section, one

would expect at least some of the women to be in labour (and consequently more physically active than other hospital patients)" ([Parish in "Discussion"] in Dillon, 1978: 730). Although no evidence is provided to show that those women in labour during the outbreak were the ones affected by the condition, the understanding that activity increases susceptibility to ME is, to all appearances, accepted at the symposium, and continues to influence more contemporary and popular conceptions of the condition today.

The association, then, between ME and women, and those working in hospitals particularly, is a further issue identified at the symposium. Although not confined to those working in hospitals, the linkage between ME and women is one that persists. Current estimates confirm this particular pattern of prevalence wherein women are seen to comprise seventy percent (70%) of the affected population, as opposed to men who comprise the remaining thirty percent (30%) (Cooper, 1997: 192). An effort was made at the symposium to dispel the idea that ME is only associated with "young adult females in hospitals and nursing homes" (Parish, 1978: 711). A paper by Parish (1978), for example, documents outbreaks of the epidemic that have affected children, males and females equally, as well as males alone in military establishments (Parish, 1978: 711-717). Despite the evidence produced by Parish, which suggests that ME affects members of the population at large, he nonetheless concludes that "(a) strange feature of this disease is the frequent occurrence among young female nurses in hospital epidemics, while patients usually remain unaffected" (Parish, 1978: 716).

Apart from its association with outbreaks of poliomyelitis, then, papers presented and discussions documented at the symposium, identify a number of possible social, economic, political and ideological characteristics specific to the condition now referred to as ME. These include its geographically localised incidence, prevalence in young women and particularly those working in hospitals as well as military personnel, and the susceptibility of active as opposed to sedentary people. It is, however, the association with poliomyelitis and other viral infections that directs the main focus of deliberation. This is consistent with the biomedical assumption that a distinct, organic disease-producing agent can be identified through scientific means in the bodies of individuals. It is not surprising, then, that the relationship between ME and viruses remains an area

of research and one of the factors accounting for the occurrence of ME today.

Contemporary research relevant to the relationship between ME and viral infection is, however, controversial and remains inconclusive. On the one hand, the cause of ME is seen to be a persistent viral infection while on the other, damage to the immune system caused by a persistent viral infection and other "environmental toxins" is seen to be the causative agent accounting for the occurrence of ME (Cooper, 1997: 189). Despite the lack of consensus, preoccupation with a biologically bound disease remains primary for the supporters of the organic interpretation of ME. Psychological factors associated with the condition, such as depression, are, therefore, explained as secondary and consequential to the organic nature and progression of the disease (ibid).

2.2.2.2 Psychologically-Based Accounts of ME

Psychologically based accounts of ME are seen to exist in opposition to those that favour an organically based explanation. This division, which epitomises dominant naturalistic and biomedical assumptions about the body, is brought to the fore in accounting for illness such as ME where no "pathognomonic signs or diagnostic tests" are supported by scientific and biomedical research studies (Fukuda et al., 1994: 953). Lacking scientifically-credible organicity tends to dispose conditions such as ME towards "psychological" explanations. In other words, the fact that ME does not have any biomedically acceptable cause, places it at risk of being seen, from a biomedical perspective, as an "all in the mind" condition.

An example of this thinking is illustrated in papers published during 1970 by two London psychiatrists on the outbreak of ME at London's Royal Free Hospital. The hypothesis offered to account for this particular outbreak which occurred in 1955, was one of "mass hysteria" (Macintyre, 1992: 36; Compston, 1978: 724). The Chairperson of the symposium, referred to above and a supporter of the organically based explanation of ME, refers, in his concluding comments, to this hypothesis of "mass hysteria" and the medical profession's apparent readiness to accept it.

> "Ours is a most remarkable profession in that we pride ourselves in being highly critical and yet one

> of the most astounding things to me is that the profession as a whole seems to swallow a hypothesis of mass hysteria (McEvedy and Beard, 1970) hook, line and sinker." (Ramsay, 1978: 743)

The readiness to accept the explanation of mass hysteria is not altogether surprising given the association of hysteria with women and the prevalence of the condition amongst women (Beechey, 1989: 18; Cooper, 1997). But without any organic verification, biomedicine's seal of approval is reserved in favour of the only other apparent explanation available to it. This explanation is based on the assumption of bodily duality which means that if a condition is not physiological, it must be psychological. As Macintrye (1992:38) indicates in the following quote, ME is a condition that illustrates the highly contested nature of the division between mind and body.

> "Much excellent research is being done, looking at the evidence of persistent virus and at immune dysfunction. However, every time some new evidence of the organic nature of M.E. appears, someone writes an indignant letter pointing out flaws in the research, and providing a psychological explanation for the results."

Psychological explanations clearly stand in opposition to organically-based accounts of ME. As such, psychological and psychosomatic conditions resembling depression, for example, take priority in psychological accounts of ME. From this perspective, the manifestation of organic symptoms is explained as secondary to, and as a result of, a particular psychological state (Cooper, 1997: 189). Depression, it could be argued then, is seen to be responsible for suppressing immune responses which, in turn, accounts for heightened and persistent susceptibility to infections of which viral infections are one possibility. This psychological account of ME is often held by members of the medical profession including psychiatrists who "...argue that such diagnoses as ME are 'fashionable' labels, self diagnosed by individuals who wish their emotional and psychological distress to be legitimised as an organic illness" (Cooper, 1997: 189). The suggestion, made in this quote, that individuals attempt to have conditions legitimised by recourse to organic illness, highlights the biomedical value placed on body duality and physiological or organically-based illness, as opposed to psychological illness.

It is apparent, then, that in those conditions such as ME where the organic nature of the illness is held in some doubt, the assumption of bodily duality underpinning a biomedical explanation of illness will be brought to the fore. Although contested, it is also apparent that the position of the body in such conditions will be overtly privileged over all other considerations, including the mind. This bias is illustrated by Veronica Beechey (1989: 18) who argues that there is

> "...the tendency within medical thinking for the illness to be abstracted from other, non-medical factors. It is almost as if in order to qualify as a 'real' illness any connections between mind, body and environment must be severed. The links between mind and body are also strenuously denied by many people who have campaigned for ME to be taken seriously as an illness."

In relating her own experiences of ME, Beechey (1989: 18) challenges such reductionist interpretations of the condition. She indicates this in the following quote (ibid.).

> "I have spent a good deal of time over the past 18 months trying to make sense of the interplay of physical, environmental and psychological factors in my own illness...It is also likely that other 'non-medical' factors may have played a part."

Beechey's intimation of an interplay between mind, body and society in her experience of ME counters the dominant biomedical discourse and points to the need for an interpretation of ME that takes into account far more than the physical or psychological construction provided by a naturalistic understanding of the body. Before pursuing this line of thinking, however, one final area of concern, that requires clarification with reference to ME, relates to the terminology surrounding it.

2.2.3 ME AND CHRONIC FATIGUE SYNDROME(CFS): TERMINOLOGICAL CONTROVERSY

The mind-body duality that dominates debates and issues surrounding ME's diagnosis, aetiology and treatment is evident, too, in the controversy surrounding its terminology and "name" to be more specific. As a "non-disease" or "illegitimate illness" consensus regarding a suitable label for the symptoms considered to be representative of ME has been difficult to reach. While its suitability is questioned, for example, myalgic encepahlomyelitis has remained the term of choice in the United Kingdom unlike its American counterpart which is referred to as chronic fatigue syndrome (CFS) (Simpson, 1993: 211). Based on a recommendation

made to the United States Centres for Disease Control in 1988, myalgic encephalomyelitis together with epidemic neuromyasthenia, chronic Epstein-Barr virus disease and chronic fatigue immune dysfunction syndrome were absorbed under the umbrella term "chronic fatigue syndrome" (Holmes, 1991: 53-55).

This distinction in terminology has, however, become a matter of more recent debate and has generated problems for medical practitioners involved in diagnosing and treating the conditions, as well as researchers who have attempted to generalise research findings to the conditions, without recognising apparent distinctions and differences between them (Goudsmit and Sheperd, 1992: 127; Fukuda et al., 1994: 953-959; Welsby, 1992: 63). Apart from the problems experienced by medical practitioners and researchers, controversy surrounding terminology has also created frustration for sufferers of ME. In the United States, for example, specific attempts have been made by sufferers of ME and their associated organisations to have the name CFS changed, without success. One such endeavour in 1996 involved the appointment of a United States government committee whose task it was to investigate and recommend "...a new scientific name or eponym..." for the syndrome (Burns, 1997: 8). The recommendation made by this committee was that no change was necessary and "...that any change should wait until there might be more scientific evidence about the nature of CFS" (ibid).

The rationale for changing the name relates, amongst other issues, to the stigma and trivialising effect associated with CSF, which is captured in an editorial appearing in the Wall Street Journal (cited in Burns, 1997: 11).

> "'Myalgic Encephalomyelitis.' Sounds pretty serious doesn't it? Serious as in: put your papers in order, the Grim Reaper's coming. 'Chronic Fatigue Syndrome' just doesn't have the same poly-syllabically scary sound, does it? Say Chronic Fatigue Syndrome to most sensible people and they think it's something they might like to sign up for if they just had time to take a long break. Then they go about their day, getting out of bed, putting bread on the table, dealing with the often very tedious minutiae of daily life..."

As this quoted section of the editorial suggests, CSF not sounding as grave or severe, is not taken as seriously

as ME which has implications for its authenticity, as well as the resources allocated to it. In the December 1997 edition of "CSF News", for example, a comparison is made between the Unites State's budgets of $125 million for an estimated 118 000 sufferers of Gulf War Syndrome and $6 million for the estimated half a million CSF sufferers (Burns, 1997: 12). Within this context, it is reasoned that a change in name would sanction greater legitimacy and a larger budget.

More importantly, though, this distinction between ME an CSF reiterates the mind body distinction evident in biomedical discourse surrounding the conditions. CFS is more specifically associated with an attempt, by supporters of the psychologically-based explanation of ME, to "psychologise" the condition by reconstructing it as CFS. ME is, in turn, associated with the organically-based explanation which favours terminology that points to the organic nature of the disease as illustrated by the term "myalgic encephalomyelitis" (Cooper, 1997: 188). The implications of this contention regarding terminology is illustrated by a "Task Force" report commissioned by the British Government in 1987 (Cooper, 1997: 187). This report, far from finding the debate regarding nomenclature one of "sematics", indicates that it "...encompasses serious disagreements, which have sadly led to ill will and abusive remarks, on such questions as whether the syndrome or some form of it exists, whether it is 'real' or 'organic' or 'merely' psychological" (cited in Cooper, 1997: 188).

As the discussion above indicates, it is not only the issues and debates surrounding ME that are considered controversial. As a construction itself, the very term ME reflects discrepant ideological and political concerns and constituencies. It is for purposes of clarity, then and following Cooper (1997: 188), that this thesis elects to "bracket the label ME". The implication that this has for relating the experiences of people diagnosed with and suffering from ME, is that "sufferers" does not by definition "...mean sufferers of *ME*, but sufferers of such bodily experiences of pain and incapacity, which have presently been *labelled* as ME..." (ibid.). This distinction, while not necessarily specified in discussions to follow, nonetheless, directs attention towards bodily experiences of symptoms, such as pain, which are associated with the condition currently labelled and understood as ME.

2.3 ME: PAIN-AS-ILLNESS IN EMBODIED EXPERIENCE

The interpretation of pain employed in this thesis draws on the particular theory of embodiment developed by Bryan Turner (cf. 1.3.2). This view challenges the dominant, yet narrowly defined, biomedical interpretation of pain as a physiological condition "...caused by stimulation of specialized nerve endings" (McCullough, 1982: 514). This naturalistic approach to pain is premised on the same assumptions that underpin the "medicalised" view of the body. The assumption, more specifically, that a division exists between the mind and the body, and the value awarded to the body in this division, is of particular relevance. "'Real' pain" according to this view, "means physical pain, anchored in visible tissue damage" (Williams and Bendelow, 1998: 157). In short, pain is seen to be "...symptomatic of an underlying disorder or lesion" which "disappears with the repair of that lesion" (Csordas and Clark, 1992: 384).

This narrow physiological definition of pain has, however, been broadened over the past two decades in response to the growth of chronic pain which is increasingly "...viewed as a medical condition in itself, separate and different from acute pain..." (Baszanger cited in Hekster, 1991: 353). While the conventional biomedical view makes the distinction between acute and chronic pain based on the period of time that pain is experienced in relation to tissue pathology, the more recent conceptualisation of chronic pain considers it to be "...a real condition in itself...a real illness and not only as the possible symptom of an underlying illness" (Baszanger cited in Hekster, 1991: 354). This re-conceptualisation of chronic pain has opened the way for psychosocial involvement in the study and treatment of pain, as well as sociological accounts of chronic pain as embodied experience "...within the broader sociocultural contexts of meaning and action..." (Williams and Bendelow, 1998: 158). So, this understanding of pain-as-illness is given preference in understanding the pain associated with the bodily experiences currently labelled as ME.

Embodiment is considered central to the analysis of pain-as-illness because it is precisely during such episodes that "...the body becomes a central aspect of experience, albeit in an alien, dysfunctional sense" (Williams and Bendelow, 1998: 159). Day-to-day life and activities are usually characterised by a state of embodiment in which individuals are unmindful of their bodies until confronted by pain, illness or injury. As Williams and

Bendelow (ibid.) argue, this phenomenological experience of bodily "disappearance" or embodiment is replaced by bodily "dysappearance" or dys-embodiment in the presence of pain and illness. They explain (citing Vrancken, 1998: 159) that pain brings about a "dichotomy" in which the "'I' and my body become two separate entities". So the dichotomy, referred to in the experience of pain, extends beyond a simple dualistic division between mind and body and incorporates, instead, a dichotomy between a conscious, emotional self and the body. As Williams and Bendelow (1998: 161) continue, the physical discomfort that accompanies pain "...is inseparable from its cognitive and emotional significance", which means that the "...mind, body and self are thoroughly interfused in pain, albeit in a problematic way...".

This state, then, of bodily dysappearance or dys-embodiment is not simply physical or psychological. It is, importantly, an emotional state. This emotional element is evident in Kleinman's description (cited in Williams and Bendelow, 1998: 160) of the body in pain or illness which he argues

> "...menaces. It erupts. It is out of control. One damned thing follows another...The fidelity of our bodies is so basic that we never think of it - it is the grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair."

As Kleinman illustrates fairly vividly in this quote, the chronic pain that so often accompanies chronic illness is an emotional experience. And it is an appreciation of this "...'mindful', emotionally 'expressive' body..." (Williams and Bendelow, 1998: 161) that provides an opportunity for pain and illness to be accounted for in terms other than those that are purely physical or psychological. It is, indeed, an appreciation of the embodied person that makes possible an account of the "alienation" of body and self that accompanies dys-embodiment. It also makes possible the associated search for "meaning, legitimacy and understanding" and the attempt to overcome dys-embodiment by action directed "*towards*" the body rather than "*from*" it (Williams and Bendelow, 1998: 160).

Drawing on Turner's (1992) work, Williams and Bendelow (1998: 161) call for an understanding of pain and illness experiences which move beyond a focus on physical and psychological states, to the state of dys-

embodiment. It is this dys-embodied state that, importantly, induces a search for meaning, as well as action, aimed at reducing dys-embodiment. And it is the search for meaning which, in turn, paves the way for a sociological interpretation of pain and illness experiences in so far as the individual derives meaning from specific social and cultural contexts. Williams and Bendelow (citing Kleinman 1998: 162) explain this in the quote below.

> "It is culture..that fills the 'existential space' between the immediate embodiment of disease as a physiological process and its 'meaning-laden character as experience'."

So, socially and culturally filtered meaning is central to understanding pain and illness experiences. It is also central to understanding the action taken towards the body in an attempt to "re-align" the body and self. The relationship between society, the body and self, then, is again central to understanding "re-alignment" which involves "...a sort of 'negotiated settlement'...one that, although never quite able to return the individual to their former embodied state, none the less attempts an approximation to it" (Williams and Bendelow, 1998: 162).

Although Williams and Bendelow (1998) identify the vital role that society and culture play in understanding pain and illness experiences, they do recognise the dominant position held by biomedical discourses in assigning meaning to those experiences. Biomedicine and its underlying assumptions could, for example, be seen to reinforce an understanding of pain and illness as physical states confined to a biological body, which remains detached from a rational mind. The value placed, by biomedicine, on a pain- and illness- free society provides, furthermore, relatively infertile soil for reaping an abundance of cultural meaning associated with the experience of illness and pain. Despite this, Williams and Bendelow (1998: 169) argue that

> "...the dominant medico-scientific discourse on pain represents only part of a broader sociocultural canvas upon which the true nature and reality of pain needs to be painted...The medical discourse of pain is just one amongst many other voices."

It, nonetheless, needs to be acknowledged that biomedicine has been a dominant voice and one that has drowned out "other voices" especially "...the subjective voice of the patient" (Williams and Bendelow, 1998: 169). It is for this reason that Williams and Bendelow (1998: 163) see the necessity for narrative as a way of abstracting the "other voices" that give meaning to pain and illness. As they argue (1998: 163),

it is through narratives "...that the dialectical relationship between nature and culture, meaning and significance is played out...". Narratives, then, represent an "*analytical*" as well as "*experiential*" challenge to the dominant dualistic thinking that separates mind from body (ibid.). As such, narratives represent the particular method of investigation that directs this study of ME and the interpretation of embodied experiences associated with it.

2.4 CONCLUSION

The discussion in this chapter has focussed on the condition referred to as ME. It indicates, more specifically, that ME does not enjoy the status of being seen as a "legitimate" illness because it lacks the necessary scientific "proof" required by biomedicine. While this has led to its classification as a "non-disease" or "illegitimate illness", it has not prevented a process of medicalisation which interprets and explains ME from a dominant biomedical perspective. The dualistic divide between mind and body, underpinning this perspective, is imposed on ME with the result that its aetiology, diagnosis and treatment are interpreted as being either organically or psychologically based. This debate, which has intensified since the 1970s, is reflected in terminology surrounding the condition as well as in interpretations and explanations of it, be these lay or professional. In an attempt to avoid, as far as possible, identifying with the ideological and political concerns and constituencies associated with the debate, this thesis favours an approach which "brackets" the term ME and simply focusses on the bodily experiences associated with a condition that is, at present, "*labelled* as ME" (Cooper, 1997: 188).

In an attempt to avoid, furthermore, the mind-body dualism that dominates accounts of "illegitimate" illnesses such as ME, it has been argued that an approach supporting the view of pain and illness as embodied experiences has been adopted. This approach, which focusses on the state of dys-embodiment during illness and pain experiences, draws attention to the meaning given to the embodied state as well as the action taken to overcome that state. And it is suggested, by Williams and Bendelow (drawing on the work of Turner) in the discussion above, that the most appropriate way in which the meaning associated with ME can be extracted is through narrative accounts of illness experience.

CHAPTER 3

SOCIOLOGICAL RESEARCH: NARRATIVE ACCOUNTS OF ILLNESS

3.1 INTRODUCTION

In this chapter the research method employed and followed in this thesis will be described. In attempting to explain the experience of illness and pain sociologically, the relationship between society and the meaning and experience of these bodily states has been pursued. As such, this study employs a qualitative research design which endeavours to analyse and explain the meaning that ME sufferers attach to their state of pain within a particular social context. As Bryan Turner argues, illness should be regarded "...as a text or story which requires interpretive skills..." suggesting that pain be seen as "...an inner story of personal experience and neurological realities" (Turner, 1987: 213). For this reason, the personal narratives of four people suffering from ME have been documented. This particular method in the qualitative research tradition has been employed in an attempt to reveal the meaning that ME sufferers attach to their experiences.

3.2 QUALITATIVE AND QUANTITATIVE RESEARCH

Narrative research, which is essentially concerned with "...the interpretation of experience" (Josselson and Lieblich, 1995: ix), falls within the broad category of qualitative research. A conventional, although controversial, distinction is often drawn between qualitative and quantitative research (Silverman, 1993: 20, 22; McCracken, 1988: 16; Robson, 1993: 6, 20, 304; Bryman, 1988: 5, 105; Bryman and Burgess, 1994: 222-223). Underlying much of the controversy and distinction are debates concerning positivist and qualitative methodologies (Silverman, 1993: 2).

Quantitative and qualitative approaches to the study of social phenomena are based on assumptions that give rise to specific research questions, techniques and outcomes (ibid.). Positivism is, for example, based on the assumption that all knowledge derives from the scientific or systematic study of the social world as an objective entity and is disposed, in consequence, towards the detection of general laws and the empirical

testing and measurement of social phenomena (Jones, 1993: 124; Silverman, 1993: 2, 20-21). In practice, this means setting apart a limited number of clearly defined categories before investigating the correlation between them (McCracken, 1988: 16). Quantitative methods and techniques, such as surveys and experiments, are used in this process for the purpose of producing quantifiable or statistical data that can be applied to a broad population (Silverman, 1993: 91).

Qualitative methodology, by contrast, is based on the assumption that social reality is constructed through the meaningful actions of human beings (Denzin and Lincoln, 1998 a and b: 8; Henwood and Pidgeon, 1993: 14; Jones, 1993: 118, 137). Rather than attempting to verify or falsify theory and explain the causal relationship between social phenomena, qualitative research attempts to understand and describe the meanings and interpretations given to the social world by people living in it. And it is from research data or findings that concepts and theories are then generated (Henwood and Pidgeon, 1993: 15, 16).

The researcher in qualitative research does not assume the role of an objective scientist, but rather acts as an "instrument" in the research process (McCracken, 1988: 18-20; Babbie and Mouton, 2001: 273). In other words, "...the investigator cannot fulfill qualitative research objectives without using a broad range of his or her own experience, imagination, and intellect..." (McCracken, 1988: 18; Atkinson, 1998: 64). This is because the ability to arrive at an understanding of meaning and action relies on the human potentiality to put "... oneself in the place of the other" (Jones, 1993: 138). The fundamental task of the researcher, then, is to imaginatively reconstruct "...a version of the respondent's view of the world by taking up and trying on his or her underlying assumptions and categories" (McCracken, 1988: 20). And it is only through the active and subjective participation of the researcher in this process that an understanding of the social world can be gained.

The findings of such research are clearly influenced by the individual researcher which calls attention to a further facet of qualitative research. Although the aim of quantitative research is to produce a set of findings that can be replicated by other researchers in similar settings, the aim of qualitative research "...is to

produce a coherent and illuminating description of and perspective on a situation that is based on and consistent with detailed study of that situation" (Ward Schofield, 1993: 202). It is apparent, then, that questions of replicability, which apply to the measurement of external validity, are not seen to be as relevant as those of internal validity, which concern credibility or the accordance between conclusions and original descriptions and details (ibid.; Babbie and Mouton, 2001: 276).

A fundamental concern of external validity in quantitative research is, however, the issue of "generalizability". In other words, the aim of quantitative research is to produce a set of results that can be generalized from a representative sample to the population from which the sample was drawn. In contrast, the aim of qualitative research is to produce a rich or "thickly described" account of the entity studied (Denzin cited in Ward Schofield, 1993: 201; Babbie and Mouton, 2001: 277; Robson, 1993: 46). With this as their aim, qualitative researchers have often treated questions of generalizability with "disdain" but more recent trends indicate a movement towards "...redefining the concept in a way that is useful and meaningful for those engaged in qualitative work" (Ward Schofield, 1993: 220, 221). So although it might not be employed in exactly the same way as it is in quantitative research, Janet Ward Schofield (1993: 221) suggests that it is possible to conceptualise "...generalizability...as a matter of the 'fit' between the situation studied and others to which one might be interested in applying the concepts and conclusions of that study". This re-conceptualisation of "generalizability" as a "matter of fit" relies on the "thick descriptions" that epitomize qualitative research, thus offering the potential to transfer understanding to "other situations" (Ward Schofield, 1993: 221). As such, the term "transferability" is often applied in the context of qualitative research (Babbie and Mouton, 2001: 277).

The broad and generalised distinctions drawn between quantitative and qualitative research in the discussion above are indicative of two well-defined research traditions in the social sciences. The qualitative research tradition which informs and directs this thesis is not, however, associated with a single approach or method but is instead a broad category that encompasses a range of approaches and methods. Some of these will be outlined in the discussion below which focuses more specifically on qualitative research relevant to chronic illness.

3.3 QUALITATIVE RESEARCH AND CHRONIC ILLNESS

According to the differentiation Turner (1987: 2) draws between "disease", "illness" and "sickness" it is possible to obtain three distinct courses or trajectories of an illness (cf. 1.2.3.1). As outlined in chapter one (cf. 1.2.3.2), the social course of sickness has been an area of sociological research and interest. This approach, however, is traditionally referred to as an "outsider" approach and it is largely considered inappropriate to the study of personal accounts of illness and pain experience. It is for this reason that the thesis adopts what is referred to as an "insider" approach. While the social course of sickness is more applicable to the study of acute illness, this "insider" approach is seen to be more relevant to the study of chronic illness.

Chronic illnesses, which are illnesses lasting for a long period of time, are commonly distinguished from infectious or acute illness which have a short, marked duration (McCullough, 1982: 14, 148). The growth of chronic illnesses has had implications for sociology's involvement in matters relevant to health and illness (Turner, 1992: 155). In point of fact, Annandale (1998: 256) suggests that "(w)ith illness no longer swiftly followed by death in most cases, individuals need to make sense of their experience; to learn from it in order to move forward and, importantly, to 'tell their stories' to others". So the need to extract and interpret the meaning and experience of chronic illness, extends beyond the bounds of the social trajectory characterised by an "outsider" perspective.

Conrad (1990: 1259) distinguishes the "outsider" perspective from the "insider" perspective which "...typically focuses directly and explicitly on the subjective experience of living with and in spite of illness". Such "insider" perspectives, which started to emerge within a largely humanist tradition during the 1960s and 70s, gained momentum as dissatisfaction grew with the inability of the "outsider" social trajectory, and its quantitative social survey methods, to adequately capture the qualitative, subjective experience of personal suffering and chronic illness (Conrad, 1990: 1260; Gerhardt, 1990: 1152-3).

The qualitative methods adopted by the "insider" sociological perspective in researching chronic illness are broadly and loosely categorized by Gerhardt (1990: 1155) into three main approaches, namely, social interactionism, ethnomethodology / narrative analysis and biographical constructionism. Although the methods in these categories are distinct and numerous, they are alike in "...that their methods of data elicitation are usually intensive interviews, mostly tape-recorded, and their methods of data interpretation refrain from using statistical evidence while relying on words..." (Gerhardt, 1990: 1155). In addition to commonalities in data collection and analysis, these methods have also, as a collective, been employed to investigate the experiences of chronic illness, the work involved in managing illness, and modifications in the chronic illness sufferer's identity (Strauss, 1990: v). The efforts of such qualitative research respond to the specific need for an "insider" perspective that captures the "social psychological" aspects and experiences of chronic illness which are seen to be lacking in biomedical and social trajectories of illness. And it is an "insider" perspective that has been employed in this thesis in an attempt to realise personal trajectories of ME. It responds, more specifically, to Turner's (1987: 213) and Williams and Bendelow's (1998: 158, 163, 164, 169) call for narrative accounts of embodied pain and illness experiences.

3.4 NARRATIVE ACCOUNTS OF ILLNESS

The popularity of narrative accounts of illness has grown in sociology since the 1980s and is congruent with the prevalence of chronic as opposed to acute illnesses in Western capitalist society (Gerhardt, 1990: 1155; Hydén, 1997: 50). As indicated above, the identifying pattern of acute illnesses is one of sudden onset followed by either recovery or death. This pattern does not follow in the case of chronic illness which has given rise to the notion of a "sick person" (Annandale, 1998: 256) living in "the remission society" (Frank, 1995: 8). The "remission society" is a term used by Arthur Frank (1995: 8-13) to describe a situation in which people suffering from chronic illness are not cured, but recover to an insecure state in which they are "effectively well" (Frank, 1995: 8). This experience of illness, which Frank argues has been "colonized" by biomedicine, is not catered for in the remission society (Frank, 1995: 10). This has, in turn, initiated a period of "post-colonialism" wherein ill people "...demand to speak rather than being

spoken for..." (Frank, 1995: 13). Illness can, thus, be seen as "a call for stories" (Frank, 1995: 53). Such stories are, in the event of illness, seen to provide the sufferer with an opportunity to voice their experiences, as well as "...*repair* the damage that illness has done..." by attempting to make sense of the life interrupting experience (ibid.).

Narrative accounts of illness, which are seemingly well-suited to the study of chronic illness, are set in opposition to "...abstract, propositional or scientific modes of thought..." (Mattingly and Garro, 1994: 771). As a distinct mode of thought "...grounded in the particulars of human action" (ibid.), narratives are seen to offer

> "...what is perhaps our most fundamental way to understand life in time. Through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped to shape our history; we try to understand who we are becoming by reference to where we have been." (ibid.)

In attempting to understand chronic illness, then, narratives focus on the discursive or digressive processes through which meaning is attached to illness experiences. In the event of illness, for example, a person will attempt to explain and make sense of his or her situation with reference to social and cultural models of knowledge, and historical and biographical contexts. These models and contexts may or may not include biomedical knowledge of the illness, but either way the meaning associated with the illness event will extend beyond a biomedical explanation. And it is this meaning which is expressed and captured in the form of narrative.

3.4.1 Narrative Reconstruction

The analysis of illness narratives documented in this thesis is concerned, more specifically, with what Gareth Williams (1989: 267-368; also cited in Riessman, 1990: 1196; Robinson, 1990: 1175) calls "narrative re-construction". He defines this concept as "...an attempt to reconstitute and repair ruptures between body, self, and the world by linking-up and interpreting different aspects of biography in order to realign

present and past and self with society" (Williams, 1989: 287). This means that the disruption that illness creates in the taken-for-granted existence of embodiment often leads to a situation in which personal narratives undergo "radical surgery and reconstruction" as a means of illuminating the disruptive experience (Williams, 1989: 270). In so doing they rely on what Rubin (cited in Garro, 1994: 776, 786) refers to as "autobiographical memory". The implication of this reliance on autobiographical memory is that past events, rather than being considered "reproductions", are more appropriately considered "reconstructions" (Garro, 1994: 776). As such, the narrative accounts of illness collected for this thesis represent attempts by the participants to make sense of the present by reconstructing the past.

In contrast to the explicit logic of scientific accounts, narrative reconstructions of illness reside in stories or fiction (Polkinghorn, 1988: 13; Denzin, 1989: 41; Mattingly and Garro, 1994: 771). This means that in addition to an individual's or narrator's life experiences, a narrative is seen to hold an autonomous "plot" or "storyline" with "...a beginning, a middle, and an end" (Denzin, 1989: 41). The plot is, in the words of Robert Musil (cited in Williams, 1989: 269), "...the simple order that consists in one's being able to say: 'When that happened, then this happened'". The plot, then, acts as the "organizing theme" around which individual, social and historical events can be structured in a coherent way (Polkinghorn, 1988: 19). So, rather than being considered in relation to specific categories, for example, parts of the narrator's life and illness experiences are considered in relation to the plot (Polkinghorn, 1988: 19; Mattingly and Garro, 1994: 771; Riessman, 1990: 1195). In this way, the structure of the story adjoins seemingly discordant parts of a narrative in similar fashion to that of metaphor and it is for this reason that narratives are referred to as "extended metaphor" (Ricoeur cited in Mattingly and Garro, 1994: 771).

In relating the "storifying experience" of individuals, narratives provide an original, personalized account of illness (Riessman, 1990: 1195). This is seen to be particularly relevant in understanding experiences of illness in light of the biomedical "outsider" account which translates illness into a stereotypical occurrence grounded in biology and physiology. It should not, therefore, be assumed that a standard biomedical

explanation of illness encompasses the experience of illness in its entirety as Sacks (cited in Garro, 1994: 775) suggests in his observation that "(b)iologically, physiologically, we are not so different from each other; historically as narratives, we are each of us unique". So narrative accounts of illness move away from the stock experience founded in a similar biological and physiological state and direct attention towards the personalized story of that state. At one level, then, narratives concern the "social psychological" experiences of the individual.

Narratives relate the meaningful stories of individuals but these stories are, in turn, imbued with social and cultural knowledge and values. So, at another level, narratives are concerned with the constantly changing social and cultural medium through which personal accounts of experiences are created, exchanged and transformed (Polkinghorn, 1988: 16; Garro, 1994: 775). In this way, an illness narrative is understood to present an individually and socially entwined interpretation of events relevant to the illness. It is through the analysis of narratives, then, that the socially infused meaning implicit to the experience of personal illness is elicited.

3.4.2 Descriptive Narrative Research

The specific narrative method employed in this thesis follows what Polkinghorn (1988: 161) refers to as descriptive research. Polkinghorn (ibid.) divides narrative research into two broad categories, namely, descriptive and explanatory. While the purpose of explanatory research is to provide narrative accounts which disclose causal links between events, descriptive research is interested in describing the "interpretative schemes" used in the process of appending meaning to events (ibid.). In accordance with the descriptive category of research, this thesis is interested in describing the narrative event of illness in relation to broad socially and culturally shared understandings or "interpretative schemes" which impart meaning to that event. Individual narratives are, therefore, analysed in relation to themes apparent in socially shared knowledge of illness and the body. The descriptive narrative research report is not, however, as Polkinghorn (1988: 169) points out "...simply the presentation of the story of some person or organization. It is an

argued essay that conforms to the rules of a scholarly presentation." As such, the argument developed in presenting the research findings serves as one possible interpretation of the collected narrative material, which is, furthermore, reliant upon detail from the narrative interviews for its substantiation (ibid.).

3.5 THE PARTICIPANTS

Illness narratives were collected for this study by means of extensive interviews with four people living in East London who had suffered from the chronic symptoms associated with ME for a period of at least six months. Babbie and Mouton (2001: 277), citing Lincoln and Guba's notion of credibility, indicate that qualitative research should strive for "...compatibility between the constructed realities that exist in the minds of the respondents and those that are attributed to them". So in order to reach this point of "compatibility" qualitative researchers should, amongst other "procedures", remain active in the collection of data to the point that "data saturation" occurs (ibid.). This is taken to mean (in the collection of narrative interviews) that a small number of comprehensive interviews is preferable to an extensive collection of less comprehensive data that might be preferable in quantitative research methods. So, although a small number of participants were interviewed, the aim in collecting data was to do so as comprehensively as possible.

The first participant was a referral from a University librarian who took an interest in this research topic. She arranged an introductory meeting with a student who had been diagnosed with ME and with whom she was well acquainted and who was, furthermore, willing to participate in the research. A second participant was, in turn, referred by the first participant and contacted telephonically prior to the interview. In addition, the local ME Society was approached for potential volunteer participants willing to relate their experiences of the illness. This led to telephonic contact with a further three sufferers, two of whom were willing and available to be interviewed, although neither was actively involved in the ME Society.

All four participants were white English-speaking females who ranged in age from twenty seven to sixty

three years of age at the time of the interviews. All the participants had some form of tertiary education and work experience although none were formally employed at the time of the interviews. Two of the participants were professional nurses, one being a retired matron and the other having left formal employment three years prior to the interview. Three of the four participants were married and two of these had children. The fourth participant was single.

The interviews involved topical histories, focussing in each case on the participant's spoken account of their illness experience (Denzin, 1989: 41). A list of focussed, open-ended questions concerning the participant's experience of ME, as well as biographical events and details, was drawn up. Participants were initially asked to "Tell me about your illness" and the remaining questions on the schedule were conditional to what was covered in the participant's response. In addition, questions of clarification and detail that arose from the participant's narrative, were asked during the course of the interview. All the interviews were tape recorded and took place in the participants' homes. The length of the interviews ranged between one and three hours. In one case, subsequent contact was maintained after the initial interview and a second interview was arranged and conducted three years after the initial interview.

3.6 THE NARRATIVE INTERVIEW

Narrative interviews are, according to Elliot Mishler (cited in Polkinghorn, 1988: 163-164; Gerhardt, 1990: 1155), not only distinct from survey interviews but differ too from written narratives and fictional narratives of chronic illness. Of relevance to the narrative interview context, specifically, is the "production" of narrative, as Polkinghorn (drawing on Mishler, 1988: 164) explains in the following quote.

> "...the story is the result of the total situation - the teller of the story, the codes of the story, and the hearer of the story. The interviewee is the teller of the story, the interviewer the hearer. In this context, the story selected to be told can function to present a particular image of the teller; and the kind of interview the hearer undertakes can affect the kind of story told."

So, the story or narrative is produced in the context of the interview and the neutral role of the interviewer

in that production cannot be assumed. An apt illustration of the point Polkinghorn makes above, relates to a comment made by one of the participants during the course of an interview. In this case, the participant, having recounted certain events relevant to her illness ends by saying: "I'm not really sure if this is the sort of thing you want to know". This comment highlights the extent to which the presence of the interviewer is able to influence the production of the interview narratives. While acknowledging the role of the interviewer in the story production, an attempt was nonetheless made to reduce the extent to which the organization of the interviews was prescribed (Cooper, 1997: 192). For this reason, the interview structure favoured an approach wherein participants were invited to relate their illness experiences in a manner of their choosing with as little interruption from the interviewer as possible.

Full verbatim transcriptions of the interviews were made and analysed as narrative accounts of chronic illness experience. As outlined above, the interviews were directed by questions relating to the participants' experiences of myaligic encephalomyelitis. As such, the entire interview transcripts were considered relevant to the analysis of the narratives contained therein. One of the ways in which credibility in qualitative research is seen to be strengthened is by asking participants to go through their transcribed and analysed interviews for comment on their accuracy (Babbie and Mouton, 2001: 275-276, 277). This valuable check for credibility was frustrated in this thesis, by the period of time that had elapsed between conducting and transcribing the interviews and was not as a result carried out. The transcribed interviews were instead checked and re-checked in their entirety against the recorded interviews and the analysis proceeded only once a precise correlation between the two had been achieved. In certain instances, words remained inaudible and are reflected as such in the findings.

3.7 NARRATIVE ANALYSIS

Narrative analysis may be classified as a form of qualitative data analysis which entails "...developing an organizing system, segmenting the data, and making connections" (Miller and Crabtree, 1998: 302). Although it shares similarities with other qualitative methods, narrative analysis is discernable in its treatment

of the transcribed text. In ethnomethodology and grounded theory approaches, for example, the text is dissected and coded according to various content categories (Riessman, 1990: 1195). Narrative analysis, on the other hand, deals with larger sections of text identified as narrative. Involved in the analysis, then, is the recognition and demarcation of narrative and the extraction, in turn, of the plot from these narrative sections (Riessman, 1990: 1195; Polkinghorn, 1988: 164). In addition to identifying the plot, which is referred to as the structural or form analysis, individual sections of narratives are analysed independently and as they relate to the whole by means of unifying ideas or themes (Riessman, 1990: 1195; Polkinghorn, 1988: 165; Tuval-Mashiach, 1998: 88).

3.7.1 Classification and Organization of Narrative Analysis

Lieblich et al. (1998: 12) propose, more specifically, "(a) model for the classification and organization of types of narrative analysis". The model identifies four, or a combination of four, workable ways in which narrative material may be analysed. The distinctions in classification and organization are drawn along two independent continua. The first of the two continua refers to the unit of analysis and its extremes are defined in terms of holistic as opposed to categorical approaches. The application, in practice, of one or the other extreme is explained by Lieblich et al. (1998: 12) as follows:

> "The categorical approach may be adopted when the researcher is primarily interested in a problem or a phenomenon shared by a group of people, while the holistic approach is preferred when the person as a whole, that is, his or her development to the current position, is what the study aims to explore."

The second continuum's extremes are defined in terms of the content as opposed to the form of the story or narrative. On the "content" side of the continuum, approaches may focus on either the explicit or implicit content of the narrative. What this means, in the first instance, is that the analysis focusses on the content itself, as it is expressed by the narrator, providing an explicit or "phenomenological" reading of the narrative (Lieblich et al., 1998: 12; Lieblich, 1998: 76). In the second instance and by contrast, an

implicit reading of the content attempts to elicit the unspoken or symbolic meanings conveyed by the narrator in the content of their narrative. Lieblich (1998: 76) describes the implicit approach as one in which the researcher "...is armed with a variety of theoretical assumptions (unknown to the interviewee, of course)". These theoretical assumptions direct the analysis which "...is searching for silences, gaps, contradictions, symbols, and other clues to the underlying or implicit contents that the interviewer is concealing, often also from him- or herself" (ibid.).

Lying at the opposite extreme of the second continuum are those approaches that focus on the form or structure of the narrative as opposed to the contents thereof. Such approaches accept that the form or structure of a story can bring to light as much of the narrator's "...identity, perceptions, and values..." as can its contents (Lieblich et al., 1998: 88; Riessman, 1990: 1196). In some instances, these aspects are seen to be more revealing than the contents because it is considered more difficult to bring pressure to bear upon a narrative's form or structure than it is its contents. So formal or structural approaches focus on "...the structure of the plot, the sequencing of events, its relation to the time axis, its complexity and coherence, the feelings evoked by the story, the style of the narrative, the choice of metaphors or words...and so forth" (Lieblich et al., 1998: 13).

The categorization and organization of narrative analyses along these two continua, provide at their intersection, "...a matrix of four cells, which consist of four modes of reading a narrative..." (Lieblich et al., 1998: 13). In other words, the intersection of the holistic-categorical continuum with the content-form continuum allows for "holistic-content" and "holistic-form" narrative analysis, as well as "categorical-content" and "categorical-form" narrative analysis. Although of value in stipulating four distinct treatments for the analysis of narrative material, Lieblich et al. (1998: 14, 168 - 170) point to limitations and difficulties in applying their model. In the first place, the separation of narrative analysis into four clear-cut methods stands the risk of concealing or losing "...finer distinctions and combinations" (Lieblich et al., 1998: 169). In the second place, the distinctions drawn by their model tend to "...oversimplify the

practice of conducting narrative research" (ibid.). They mention, in particular, the difficulty involved in detaching the form or structure of a narrative from its contents. Similarly when dealing with the unit of analysis, the detachment of smaller sections or categories of the narrative from the whole, is often found to be more difficult than their model might suggest (ibid.). Notwithstanding the limitations mentioned above, Lieblich et al.'s model will be referred to in the section below which outlines the process of analysis followed in the course of doing this thesis.

Apart from identifying a plot or storyline (discussed in the paragraph to follow) the analysis did not focus specifically on the structure or form, in part (categorical-form analysis) or in whole (holistic-form analysis). In other words, the analysis did not involve classifying the narratives into commonly accepted typologies such as the one identified by Frye in which "...comedy, romance, tragedy and irony-satire..." (Robinson, 1990: 1176) serve as the four main plot types (also cited in Tuval-Mashiach, 1998: 89; Polkinghorn, 1988:15, 71, 73-76, 168). Neither were the plots analysed according to the approach developed by Gergen and Gergen (cited in Robinson, 1990: 1176; Tuval-Mashiach, 1998: 89; Polkinghorn, 1988: 15, 168-169), which allows for the classification of a plot's direction. Such analyses typically trace the narrator's movement towards a goal over time in one, or a combination of, three main plot directions, namely, progressive, stable or regressive. A further type of form or structural analysis, which was also not set about in this thesis, involves the narrative's cohesiveness. In this type of analysis, the extent to which a narrative develops as a "good story" is seen to be of importance (Tuval-Mashiach, 1998: 89). In other words, the narrative should ideally include "...clear and logical organization of structure, objectives, and plot movement..." (Tuval-Mashiach, 1998: 105). This type of analysis has been useful in autobiographical and oral research which suggests that males and females construct narratives differently and it is the narratives of males, as opposed to those of females, that are typically seen to conform to the structure and cohesiveness of a "good story" (Tuval-Mashiach,1998: 89-105). Such gender comparisons are clearly not suited to this thesis's collection of female-only narratives, but a structural or formal analysis, or even a feminist reading of the structure or form, is nonetheless possible using the transcribed narratives collected for this study.

3.7.2 IDENTIFYING THE PLOT

Although the methods used for structural or formal plot analysis as outlined above were not employed, the first part of the analysis did involve the identification of a plot. This formal aspect of the narratives was informed by sociological theory and narrative research relevant to the body and chronic illness. Sociologists have, for example, identified a number of "ideal typical genres" in analysing accounts of illness (Annandale, 1998: 257). "Restitution", "chaos" and "quest" are, more specifically, narrative types identified by Arthur Frank, that tell different stories of illness and the ideal typical change in self identity that accompanies these different stories of illness (Frank 1995: xii; also cited in Annandale, 1998: 257). Hawkins (cited in Hydén, 1997: 60), in turn, refers to the organising genre of illness narratives, and the concept of "regeneration" inherent to them, as "pathographies". Pathographies relate an individual's experience of illness and her or his attempt to overcome it, but are according to Hawkins (ibid) drawn from "...an ancient Christian narrative pattern". According to this genre the story relates how a "sinner", in recognizing his or her sinfulness and showing remorse for it, proceeds in life as a regenerated, converted individual. The point that Hawkins makes in drawing this parallel is that the narrator is able "...to make use of established genre and narrative techniques in order to configure his or her life and illness in culturally recognisable and acceptable patterns" (cited in Hydén, 1997: 60).

In relating stories of embodied experience, then, it was assumed that the analysis of the interview texts would reveal a particular plot based on "established genre and narrative techniques". A biomedical understanding of illness, for example, typically gives rise to a "restitution" plot which Frank (1995: 77) describes as follows: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again". Although attempts to employ this restitution storyline are to be expected in accounts of illness, it applies more readily to acute rather than chronic illnesses. Frank's (1995: xii; also cited in Annandale, 1998: 257) "chaos" and "quest" narrative plots are possibly more applicable to narratives of changing self identity in chronic illness, but the attempt in this thesis to focus on illness as an embodied experience

favoured a reading of the narratives in keeping with the plot identified by Simon Williams (cited in Annandale, 1998: 258; Williams and Bendelow, 1998: 159-164) and mentioned in chapter two (cf. 2.3). This plot involves an "ideal typical movement" of the ill person from a state of "embodiment" to "dys-embodiment" and finally "re-alignment" of self and body. So in attempting "...to make sense of bodily disruptions" (Annandale, 1998: 258), it was expected that individuals would reconstruct their narratives in accordance with an identifiable pattern or plot (Hawkins cited in Hydén, 1997: 60). It was, furthermore, assumed that the movement of bodies through the stages of "embodiment", "dys-embodiment" and "re-alignment" would be structured by "epiphanies" or "...the significant, turning-point moments in a subject's life" (Denzin, 1989: 22).

Although the structured movement of individuals through "culturally recognisable and acceptable patterns" of narrative reconstruction was assumed, Hydén (1997: 60) indicates that "(l)ike many life histories, illness narratives are by nature ambiguous because they do not have a clear and foreseeable *end*". Despite the fact, then, that narratives are understood in relation to a plot containing a beginning, a middle and an end, illness narratives are considered problematic because they are often in want of an ending. The reason for this relates to the indefinite nature and outcome of illness which is not always apparent during the illness. This means that illness narratives are "...forever in search of meaning" (Hydén, 1997: 61) and are often open to change, renegotiation and uncertainty. The "ideal typical movement" of the ill person, then, from dys-embodiment to re-alignment "...can be precarious, fragile and in need of constant repair work..." (Simon Williams cited in Annandale, 1998: 259). Indeed, as Williams (ibid.) indicates, "...even to suggest processual stages in the relationship between mind and body in chronic illness imposes significant order on what is likely to be a far more ambiguous and fraught experience". Notwithstanding this problem of "ending", illness narratives remain "...an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society" (Williams, 1989: 287).

So a number of pre-existing assumptions informed the process of identifying the structural or formal aspect of the narratives. The transcripts were read and re-read and sections that related to the movement of the body from a state of embodiment to one of dys-embodiment, as outlined by Simon Williams (cited in Annandale, 1998: 258; Williams and Bendelow, 1998: 159-164), were identified and highlighted. In reading the transcripts for descriptions of this movement, for example, it was anticipated that participants would recount the onset of symptoms or experiences associated with the onset of the illness. In other words, they would recount experiences of perceiving and observing an otherwise taken-for-granted body. The same process was followed for identifying sections of narrative that related to bodily re-alignment. In this case, for example, attempts to adjust to, and overcome, the experience of dys-embodiment were identified as relevant to bodily re-alignment. This plot of bodily movement was evident in all four narratives and was used as the main theme for organizing the content and the analysis thereof.

Identifying the plot in this way confirmed Hydén's (1997: 60) argument that narratives of illness do not always have a clear ending and are, thus, considered problematic. In only one of the narratives used for this thesis, for example, was there a point at which an end to the illness, and hence bodily re-alignment and narrative closure, had been reached. It was also evident in identifying the plot that bodily movement from the states of embodiment, to dys-embodiment and again to re-alignment did not, as Williams predicts, occur in a particularly methodical or systematic way (Williams cited in Annandale, 1998: 259). The movement instead appeared to be more complex and, although not set about in this thesis, an holistic or categorical form analysis holds the probability of shedding light on this aspect of the narrative structure.

3.7.3 Categorical-Content Analysis

Having identified the plot and using it as the main storyline, the focus of the analysis turned to the content which involved the reading and re-reading of the transcripts. Although the transcripts were read in their entirety, the approach that was adopted is more appropriately classified as "categorical-content" in contrast

to an "holistic-content" approach (Lieblich et al., 1998: 112-113, 62-63). In other words, the analysis did not attempt to unravel each participant's narrative as a whole and in isolation from the other participants' narratives. Instead, the main area of focus concerned the embodied experience of myalgic encephalomyelitis as a phenomenon shared by the four participants. As such, the reading and re-reading of the transcripts was undertaken as a means of generating content themes.

These content themes were identified in two main ways. In the first, a number of pre-existing assumptions directed the reading and identification of themes (Lieblich et al., 1998: 113). It was anticipated, for example, that dominant discourses, of which biomedicine is primary, would direct action and meaning in response to the onset of ME. Based on this assumption, it was foreseen that the experience of dys-embodiment would be accompanied by action aimed at bodily re-alignment which would involve stories recounting visits to medical practitioners and the adoption of various forms of treatment. It was also anticipated that socially and culturally filtered meaning would be attributed to pain and illness experiences and accounts would, as a result, draw on biomedical interpretations and mind-body dualism as principal explanations of ME. The transcripts were, therefore, read with several preconceived ideas and evidence drawn from this reading confirmed the identification of biomedicine and mind-body dualism as two main themes. Applying the method used by Brown et al. (cited in Lieblich et al., 1998: 63), coloured markers were used to highlight these themes. Hard copies of the transcripts were used during this process but at times highlighting was also put to use electronically when working with disk copies of the transcripts.

Identifying and highlighting the two themes in this way left a relatively large proportion of all the transcribed narratives unaccounted for and this was possibly the first indication that an understanding of the body and illness based on biomedical interpretation was not as predominant as originally assumed. The second way in which the content themes were identified, then, was through a reading that remained uncommitted to pre-existing theory and assumptions (Lieblich et al., 1998: 113). In other words, the

reading involved identifying themes that arose through the process of reading and re-reading the transcripts with no foreknowledge or expected outcomes. The question: "What is being said about the body and embodiment?" was used to direct the reading of the illness experiences and stories related in the un-highlighted sections of the transcripts. Words or sentences that appeared repeatedly and related in some way to the question cited above were useful in identifying potential themes. Notes were made regarding all ideas and hunches throughout this process which involved the repeated reading of potential themes in isolation to, and as part of, other sections and the whole narrative. Those themes and sub-themes that were found to appear in all the narratives were identified as important clues to understanding the meaning given to the participants' illness experiences and were used to guide and focus a literature search.

The literature search based on possible themes and sub-themes directed attention towards public health and health promotion discourse. This body of literature had not, up until this point, been considered particularly relevant to the thesis due to its emphasis on "health" as opposed to "illness". Contrary to earlier assumptions, however, it was found to be useful in informing the analysis and refining the themes and sub-themes.

The identification of themes using the two methods described above, produced three main themes that were used to sort and organise the narrative content. Sections of all four narratives, then, that related to these three themes, namely, biomedical discourse, mind-body dualism and health promotion discourse, were highlighted and used to give descriptive form to an understanding of the illness experience. In this way, the themes are seen to act as the "interpretive schemes" (Polkinghorn, 1988: 161) or socially shared models of knowledge that satisfy the search for meaning during episodes of illness. And it is these themes that require identification and description in accordance with the descriptive narrative research method adopted in this thesis (Polkinghorn, 1988: 161-163).

The analysis of the narrative content, as described above, was designed to elicit the meaning associated with the illness experience. As such, it is classified by Lieblich et al. (1998: 12, 76) as an "implicit" rather than "explicit" approach. This distinction in interpretive level marks the difference between a "naive" reading, as opposed to a theoretically loaded reading, of the narratives. Although positioned in opposition to one another, Lieblich (1998: 76) does indicate that "(v)arious shades of interpretive levels can be characterized between these two extreme poles"; and in the analysis described above, "various shades" of interpretation are evident. The first method of identifying content themes, for example, relies on several pre-existing assumptions and theory whereas the second method relies on a "naive" reading of the narratives which then directs the search for theory. But the fact that the analysis is motivated by an attempt to extract meaning rather than report events from the narrator's point of view, places it on the "implicit" side of the divide. Notwithstanding its implicit status, the analysis does not display a high degree of suspicion or doubt with regard to the narrators and their stories (Lieblich, 1998: 76). In other words, a more critical reading of the same narratives, wherein a greater degree of interpretive depth can be attained, is possible in narrative research. An effort was, however, made in this thesis to suspend "judgement" (ibid.) in the reading of the narratives which remains, as such, one among a number of potential analyses.

In summary, then, the analysis of narratives is considered to be a particularly appropriate means of fulfilling the goals of this thesis on account of its concern with that aspect of human existence "...we call meaning" (Polkinghorn, 1988: 157). In addition to relating events concerning the material or organic reality and experience of illness, it is assumed that these events are at the same time voicing significance and meaning. It is for this reason that narrative analysis is deemed to be well-suited to the purpose of understanding the embodied experience of ME. At the same time, however, narratives represent only one of the "voices" that give meaning to the illness experience. Although providing the opportunity to elicit the "insider" personal "voice", it should be noted that narratives represent subjective versions of an illness or event as seen by the narrator and their value can only be appreciated as such. In light of this, "(a)mbiguity of

meaning and alternative readings of the same material are permitted with this kind of perspective" (Cooper, 1997: 193).

3.8 DESCRIPTIVE NARRATIVE RESEARCH EVALUATION

Central to the evaluation of descriptive narrative research is "...the accuracy of the researcher's description in relationship to the operating narrative scheme" (Polkinghorn, 1988: 161). A number of criteria and procedures can be taken into account in response to this need for research "accuracy". They are associated, more broadly, with two related concepts relevant to the evaluation of qualitative research. The first concerns Smaling's notion of "objectivity" (cited in Babbie and Mouton, 2001: 274), which is defined as "*...doing justice to the object of study*" and the second concerns Lincoln and Guba's related concept of "trustworthiness" (cited in Babbie and Mouton, 2001: 276). When applied to qualitative research, "trustworthiness" is taken to mean the "...neutrality of its findings or decisions" (ibid.). Both "objectivity" and "trustworthiness" require attention to a similar set of criteria and procedures. A number of these will be discussed below with reference to the accuracy called for in "...describing the narratives held in or below awareness that make up the interpretive schemes a people or community uses to establish the significance of past events and to anticipate the consequences of possible future actions" (Polkinghorn, 1988: 162).

One of the ways in which accuracy can be enhanced in qualitative research is through triangulation, "...or the use of multiple methods..." (Babbie and Mouton, 2001: 275). In other words, the shortcomings of one research method can be compensated for by the use of another and in this way research findings can be substantiated or invalidated. Although not embarked upon, the single method used in this thesis could, for example, have been supplemented through the use of a survey, or the collection of data from sources other than sufferers of ME in order to enhance the accuracy of the interpretive schemes identified and described in this thesis.

A further way in which accuracy can be refined is through the use of extensive field notes. Babbie and Mouton (2001: 275) suggest that field notes should include descriptions and observations of the research setting as well as "theoretical memoranda". Rather limited use was made in this thesis of field notes concerning the research setting, but extensive note taking was fundamental to the process of analysing the transcribed narratives. This strategy of continual observation that is noted during the research process serves to "...contradict or enhance...original theoretical ideas" (ibid.). In the process of attempting to identify themes, for example, notes were made during and after every reading. The following extract is taken from notes made after an early reading of one narrative in which possible themes were being considered:

> "Emotions - maybe need to look at this. The body - a lot being said about the body. What exactly? Health / illness - things being said about health as well as illness. Religion? Morality? Is disease / illness being linked to one's moral qualities? 'I am healthy = I have high moral standards.' If you don't care for your health (sin?), you deserve to get ill (punishment?). Illness as work? 'Doing' -people who 'do' becoming people who can't 'do'."

At another point notes were made after a literature search, which dealt specifically with gender and the bodies of women. The following issues and questions were amongst those noted and used in a subsequent reading of the transcribed narratives:

> "The feminine body - seen as the only environment over which women have control ie self acts on the body rather than the external environment, self living in rather than through the body. So is health that which makes activity possible or is health an activity in itself? What is being said about individual rulership and ownership of the body? Do they say anything about being women? Are there any ideals of 'good wife' or 'good woman' to which they conform? Any contradictions?"

As the findings reported in the following chapter will imply, many of the issues, comments and questions mentioned in the notes were made to no avail. Very little, for example, was said about issues of gender or the feminine body and it is possible that these issues are more appropriately attended to through the

use of another research method, such as life stories, or a more implicit analytic approach, such as a feminist reading of the transcripts. What these notes do indicate, however, is an attempt to engage in, or at least pay attention to, a range of different interpretations and possibilities; an issue considered important to strengthening "objectivity" and "trustworthiness", and hence accuracy, in qualitative research.

Another notable factor in the evaluation of qualitative research is that of "transferability" (Babbie and Mouton, 2001: 277). Although the aim of quantitative research, as discussed above, is to generalize research findings from a sample to a larger population, the aim of qualitative research is to produce findings specific to a particular context. Unlike the quantitative researcher's responsibility in demonstrating generalizability, "...the obligation for demonstrating transferability [in qualitative research] rests on those who wish to apply it to the receiving context (the reader of the study)" (ibid., [Brackets added]). But in order for transferability to be at all feasible, descriptions need to be recognized as accurate. And such recognition is subject, in turn, to the provision of "thick description" in the reporting of research findings. In the chapter that follows, then, an attempt is made to report the findings as comprehensively and accurately as possible, thus allowing for the possibility of transferability (ibid.).

Although by no means exhaustive, these issues represent a few of the criteria considered important to the evaluation of qualitative research. So, the need to pay attention to accuracy in the process of descriptive narrative research, in particular, requires attention to a number of criteria and procedures more broadly associated with objectivity and trustworthiness in the qualitative research tradition. As the discussion above indicates, consideration was given to several of these in the process of undertaking, and reporting on, the research for this thesis. But a more deliberate and extensive application of them and others remains, as Babbie and Mouton (2001: 276) suggest, "...a goal, something to be striven towards, although never to be fully attained".

3.9 CONCLUSION

This chapter has provided an overview of the particular research method used in this thesis as a means to eliciting an "insider" personal account of the illness experiences of four individuals diagnosed with ME. While sharing similarities to other qualitative research methods in sociology, the narrative analysis of unstructured interview texts is considered particularly useful to the study of chronic illness experiences. It is through narrative accounts of illness that individuals are, for example, seen to make sense of their bodily experiences and in so doing imbue their experiences with meaning. As such, illness narratives are seen to move beyond the bland and limiting confines of biomedical accounts of illness and pain as physiological phenomena by providing personal, embodied accounts of pain and illness as lived, meaningful experiences. At the same time, narratives recount meaningful experiences within specific social, cultural and historical contexts and, it is for this reason, that they provide a valuable lens for understanding the interplay between personal trajectories and socially shared knowledge of pain-as-illness.

CHAPTER 4

FINDINGS

4.1 INTRODUCTION

The previous chapter identifies narrative accounts of illness as a specific method of qualitative research relevant to the study of chronic illness and the method that has, furthermore, been employed in this thesis. The four in-depth interviews collected and analysed, in accordance with this method, attempt to provide descriptive accounts of illness experience with the purpose of gaining insight into what it means to have ME. The narrative re-constructions that follow in this chapter are, therefore, not intended to provide a comprehensive account of ME, nor a comprehensive account of the illness experiences of the four participants. Instead, they aim to consider particular issues relevant to the illness experience which bring to light aspects of ME, as well as the broader social and cultural context in which ME occurs. Although this analysis depicts only one possible reading of illness narratives, the value of using this method rests in the potential it offers to render insight and understanding that are unavailable in quantitative modes of research. Such narrative accounts, as this chapter will indicate, illustrate unique subjective experiences of illness that simultaneously represent aspects of socially informed and shared knowledge and understanding.

Chapter two classified ME as an "illegitimate" illness which does not readily allow sufferers to relate their experiences in biomedical terms. In other words, the suitability of the body (in the first instance and the mind failing that) as the main loci for identifying, treating and explaining illness, is held in some doubt. The illness narratives detailed in this chapter, nonetheless, provide evidence of attempts to make sense of the bodily experiences associated with ME in conformity with the biomedical trajectory and the mind-body dualism underpinning it. At the same time, the physical and neurological realities of the illness generate stories of personal experience drawn from competing social discourses and, of particular relevance, is the health promotion discourse of the new public health movement. The inclusion of health promotion discourse

in the illness narratives suggests that illness is not only socially constructed, but is also interpreted in terms distinct from the biomedical discourse dominant in Western capitalist society. All four illness narratives abandon, to varying degrees, the biomedical discourse and instead supplement their search for meaning and interpretation with health promotion discourse. The chapter content has been organised according to these themes evident in the illness narratives, namely, the biomedical trajectory and its associated assumption of mind-body dualism, followed by the health promotion discourse which imparts distinguishable interpretations of the body and illness experience.

In presenting extracts from the transcribed narratives, priority has been given to verbatim accounts as expressed by the narrators. Grammatical accuracy has, therefore, been overlooked in favour of word-for-word accounts as given by the participants themselves. Virtually no editing of the transcribed narratives has been undertaken except in one or two instances where speech utterances were found to be unintelligible. For the sake of convenience during transcription, all utterances such as "eh", "er", "ah", "uuh", "um" were recorded as "um" and appear in this chapter as "um". Following Lieblich et al. (1998: 30), a number of symbols have been included in the presentation of narrative sections. They include the following:

- Brackets [-] have been used to signify all words and phrases added by myself.
- Three full-stops -...- have been used to indicate a break in the flow or direction of narration.
- Three full-stops in brackets [...] have been used to indicate the omission of a sentence.
- Words and phrases emphasised by the narrator, have been underlined.
- Quotation marks have been used to indicate dialogue that is described by the narrator, or understood within the context of the narrative.

In addition, all the names of the participants, as well as names mentioned in the course of their narratives, have been changed.

4.2 THE MOVEMENT FROM EMBODIMENT TO DYS-EMBODIMENT

4.2.1 BIOMEDICINE AND ILLNESS NARRATIVES

In attempting to understand pain and illness experiences, it has been argued that meaning will have been drawn

from available social and cultural contexts. It follows, then, that those discourses perceived to be dominant in particular social and cultural contexts, will be the ones referred to, and drawn on, in explaining and understanding phenomena. In the context of South Africa, and amongst white South Africans in particular, the model of medicine that tends to prevail over any other, in accounting for illness and disease, is the official, biomedical or allopathic model (van Rensburg et al., 1992: 312-313). Narratives based on a biomedical understanding of illness, and the "sick role" trajectory it supports, are what Frank (1995) refers to as "restitution narratives". The restitution plot, as mentioned in chapter three (cf. 3.7.2), is described by Frank (1995: 77) as follows: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again". This basic restitution plot is overlayed with stories about visits to the doctor, the administering and interpretation of tests, as well as possible treatments and outcomes. Such narratives are based on the biomedical notion of "cure" which as the "...culturally preferred narrative...crowds out any other stories" (Frank, 1995: 83). Drawing on this culturally dominant model, then, white South African narratives about illness will typically relate a story of concern about a biological or physiological ailment, a visit to the doctor and treatment designed to cure that ailment.

4.2.1.1 The Onset of Symptoms

The narratives analysed for this research are, to a large extent, consistent with the dominant biomedical trajectory. In other words, all four narratives recount experiences of physical symptoms and visits to medical practitioners in response to those physical symptoms. Although the experience of symptoms and the response of medical practitioners does vary, the biomedical trajectory and elements of its associated restitution narrative are, nonetheless, themes evident in all four narratives.

4.2.1.1.1 *Lillian*

The narrative that initially adheres to the sickness trajectory associated with biomedicine more consistently than the others is that of Lillian. At the time of her interview, Lillian was a sixty three year old retired, unmarried matron whose physical symptoms emerged approximately two to three months after her

retirement. She lived, as she had done for most of her working life, with her retired, unmarried brother Colin. Her brother had also been diagnosed with ME just over two years prior to her diagnosis and also at about the time he had retired. Her illness narrative is, to a large extent, related in the plural, referring to both her and her brother. The following extract is an account of the onset of her symptoms and the implication that she visit a doctor.

> I came back from holiday super fit and in August it was as though my marrow had run out of my bones and then Colin said: 'Have you caught the ME? Well it's worth your while to go to the doctor'. And then it came back and I was positive Epsien Barr and coxsackie.

Although she does not expand on the "positive Epsien Barr and coxsackie" results, Lillian appears to accept these as indicative of ME. So her visit to the doctor and subsequent diagnosis comply with the dominant cultural model. She recognises, however, that the reception she received from her doctor is not necessarily the norm.

> We went [to the doctor] and said: 'Could we be infected with this flu called ME?' And he said after listening to our symptoms: 'Maybe, maybe not'. You know he's, he's one of the doctors that is willing for you to say: 'Do you think I have?' and he either says to you: 'No, no you can't have that because you haven't got this' or: 'Well let's check it up, let's do a blood test'. So, but you don't have all medical practitioners willing to do that and most will tell you: 'I'm the doctor, not you. I do the diagnosis, not you'.

Lillian clearly appreciates her doctor's attitude and, having received her diagnosis of ME, continues to relate a narrative in keeping with the dominant biomedical model. This involves embarking upon treatment which is administered by her doctor, although the suggestion to have it is made by her brother.

> Colin was on a very high dose [of penicillin] and he had that, four doses and then he actually responded extremely well. He almost, you would have said that he was about ninety percent recovered. And he stayed like that. Then I got it and he said: 'You'd better have the same

treatment', because I was going to the same doctor so he said to me: 'Have the same'. And I had identical treatment and it did absolutely nothing. It made no difference what so ever.

It is only at this point, then, that Lillian's narrative can be seen to deviate from the restitution narrative in that the "cure" is not seen to restore the body to its former state of embodiment. The other participants' points of deviation are, by comparison, reached far earlier than Lillian's. The positive reception received by Lillian from her medical practitioner is not, for example, experienced by the other participants in this study. Indeed the three remaining narratives relate stories of visits to medical practitioners that are at the outset not particularly encouraging.

4.2.1.1.2 *Colleen*

Colleen, at the time of the interview, was a fifty four year old, married woman who had suffered from ME for a period of eighteen months. Prior to the onset of symptoms, she had resigned from her job as a senior administrator at a large company based in the Eastern Cape. In the following passage, she relates her experiences of physical symptoms and the subsequent visit to the doctor.

> Well like I said on the phone I've had ME for about eighteen months. It's difficult really to say exactly when it started because it's not like having a heart attack or something that happens on such and such a day but um I started to realise something was wrong because I felt really, um just really washed out all the time. And then I started getting other symptoms. At first it was pains in my hands, um I found I couldn't hold the dogs' leads when I took them for a walk but it soon spread to all my joints and of course my throat and glands. My throat was sore all the time. And for me you know, it was out of place to feel like that, like I was feeling at the time. Actually I thought at first it must be some sort of bug that I'd picked up but um I, I just couldn't shake it off. In the beginning I was spending most of my time in bed. I would get up you know, flop down in my chair and then go back to bed. There were a few days when I felt quite good and I'd um get up and thought I was actually starting to shake the thing off but come the next day I'd be flat on my back again.

These physical symptoms described by Colleen prompt her to take action and in accordance with the dominant biomedical model and sick role trajectory, lead to the decision to visit a medical practitioner. Her initial consultation was not, however, particularly successful in legitimating the symptoms she was experiencing.

> You know I started feeling a bit guilty because Ray [her husband] was doing things, um things around the house and whatnot. So I decided to go to the doctor. But my, what a thing, you see I don't, I didn't know him <u>that</u> well. I'd been to him for other things, um sometime before this but only once or twice. But I went to see him and I told him what was wrong and all he said was: 'Oh no, not again' or: 'Not another one' or something, it was something like that. Um at first you know I didn't really take much notice because I thought he meant I had caught something that was going round. But after he'd examined me, he said he was sure this was a case of yuppie flu and there was nothing he could do for me. I still remember he just said, he just told me he had no time for it and I should go off and see another doctor. Well I tell you it took me a while to get over that.

Despite her initial experience, Colleen does decide to see another doctor and recounts this visit as having a comparably favourable outcome.

> So, but then the symptoms didn't go away and I wanted to find out you know what was wrong. So I went to another doctor and I'm really glad that I did because he was a real honey. He never made me feel like the other one that, um that he didn't have time for me and he was actually very very understanding. He did a whole lot of tests and whatnot and I think um, about a month after I went to him he told me I had ME. But even then he was nice. You know he sort of told me a bit about it and he said he could put me onto something if I wanted to but that um, he would recommend that I tried making a few adjustments to my, to things in my life first. He said I should try and take things easy you know and things like that and if it didn't help then we'd look

at things again. I think he was trying to tell me there's actually very little that can be done but he didn't send me packing like the other one.

This second visit, in response to her physical symptoms, has a far more positive outcome for Colleen and, despite him indicating that very little can be offered by way of treatment, the doctor does appear to legitimate her condition.

4.2.1.1.3 *Heather*

A similar set of occurrences is related by the youngest participant, Heather. At the time of the first interview, Heather was a twenty seven year old, married student. She had been living and working in Johannesburg at the time her ME started and six months after the onset of her symptoms, she and her husband moved to East London. Aware that something was wrong, and in accordance with the biomedical model, Heather went to see a doctor. She relates an experience that is not dissimilar to that of Colleen's.

> I think six months before we left [Johannesburg] I had started, I said to Mark [her husband]: 'There is something wrong, I shouldn't be getting so sick and feeling so tired all the time'. And um I went to a doctor and he did a whole lot of blood tests and chest x-rays and sinus and you name it he did it. And his conclusion was that I was a hypochondriac and if I had thought more positively I wouldn't be so ill. And it actually took me five years after that to pluck up the courage to go back to another doctor and say that there is <u>something</u> <u>wrong</u> with me.

Although it takes Heather much longer than it did Colleen to go back to a doctor, she does eventually decide to consult a doctor in East London.

> When I eventually did go back to a doctor, I was seeing a doctor in East London who was just a general GP and I had built up quite a relationship with him and one day I thought I would ... I wrote down on a list everything that was wrong with me. Things that I had never put together in a list that I ... you know when I've gone to the doctor about my bronchitis but I've never

thought to mention the arthritic pain in my hands, in my ankles, in my feet, in my knees and the bruising and headaches and the nausea and the list is endless. And I just decided that I couldn't take all ... and of course the tiredness and mental exhaustion and muscle fatigue, inability to concentrate and um strange things that I had, you would never put together as being part of one illness. And I went to see him and I said: 'Look this is it. This is what is wrong with me'. Um and I thank God that he took me seriously and he said to me he doesn't know what is wrong with me, but if I say something is wrong with me there's something wrong with me and he would do his best to find out what it was.

4.2.1.1.4 *Janet*

The events recounted by Heather in response to her experience of physical symptoms are similar to Colleen's as well as those of Janet who was, at the time of her interview, a forty four year old, married woman who had suffered from ME for ten years. She had trained as a nursing sister and worked in Zambia before moving with her husband and two children to South Africa. In relating her experiences, Janet implies that she consulted a number of doctors in an attempt to identify her illness.

I was devastated because they told me that there was absolutely nothing wrong with me. There was no need to um ... : 'You are a hypochondriac, don't come back again'. Or: 'Here's some pills. Take them and don't come back'. They weren't very helpful. I think it was, the main thing was that: 'You've got a full life, you need to take things easy'. Meanwhile I was having to take things easier, but I wasn't getting any answer and they didn't, you know they weren't even interested. Okay, one did take hormone levels, he took blood for heart [one, inaudible word] which were all negative anyway. So it obviously wouldn't show up. And again the general attitude was: 'Well your results are negative so you must be okay' which didn't really make me feel good because I kept on thinking: 'There's something here, but what is it?' But the doctors didn't help. And I lived like that for about four years not knowing what it was. But then I went to the UK and

the one friend we went to didn't sort of recognise me. Sort of looked at me. He didn't recognise me and said: 'What was wrong?'. [Her response to this question:] Well nothing really except I don't seem to be able to get on with my life. I used to enjoy doing things but now if I do then I have to lie in bed for two or three days. I knew there was something wrong but I've been to the doctors and said: 'I'm tired. I ache. I continually feel like sleeping'. So many symptoms and the only reaction I'd had was: 'You're depressed'.

4.2.1.2 Diagnosis

The difficulty experienced by Colleen, Heather and Janet in their contact with the medical profession indicates that the biomedical model does not easily accommodate a problematically defined and diagnosed condition such as ME. Diagnosis is, nonetheless, seen to be important as Cooper (1997: 195), in her study of ME and the medical encounter, suggests.

> "Diagnosis of an illness has been seen to be vital to the psychological and emotional well being of the patient by both medical historians (Rosenberg 1992) and medical sociologists."

In the cases of Colleen and Lillian, the diagnosis of ME was given relatively soon after their consultation with medical practitioners and the movement from a dys-embodied state to one of realignment could begin. For Heather and Janet, however, the search for a diagnosis continued.

As mentioned above, it took Heather five years to "pluck up the courage" to bring her symptoms to the attention of a doctor again. During this period, her physical symptoms are related as the cause of a great deal of psychological and emotional anguish. This anguish is relieved by the diagnosis of ME, which she describes as a "breakthrough" for her. In Heather's case, then, the affirmation of a diagnosis is, as Cooper (1997: 195) suggests, a "liberating experience".

When that doctor told me that I was a hypochondriac and that if I thought more positively I wouldn't feel so terrible I actually believed him. I thought: 'Well, maybe I am a hypochondriac

and maybe I am looking for sympathy and for um, maybe I am, do have a psychosomatic problem'. And I actually, I mean everybody enjoys ma[de], being made a fuss of, but I kind of thought I was not normal. It was very difficult to ... I would, when I felt so very tired, when I had joint pains or whatever, I would just ignore it. I wouldn't even talk about it, I would just carry on. Um and I would often feel that I would have to apologize for not being able to do. I had to, I stopped um baking and I loathe cooking and um, the thing is it just took so much energy. I always felt I had to justify why I didn't want to do those things. Instead of being able to say: 'I'm too tired to do it' or: 'I can't', I would psychologise it and say: 'You know I hate washing dishes because my mother always made me wash dishes' or something crazy like that, when the truth of it was that I was just too tired. I just didn't have the energy to stand at the sink. It was very, very, very difficult. It still is. The breakthrough for me was when I found this doctor who said: 'If you say something is wrong with you then there is. And we'll find out what it is'. And for him to acknowledge that: 'This is what this illness is called but I don't know what to do to help you. We know it exists and we know how to identify it but we don't know what else to do'. It was a very liberating experience.

Although Heather's "liberating experience" tends to confirm the necessity to assign a diagnosis to symptoms, Janet's diagnosis of ME is met with little relief. She, like Heather, did not have her condition diagnosed immediately and, four years after the onset of her symptoms she consulted a doctor in the United Kingdom who diagnosed her condition as ME. This diagnosis is not, however, initially accepted by her.

Again I went back to the doctor for tests and everything was normal. So it was depressing because I wasn't convinced it was ME, I wasn't convinced it wasn't something else and when I eventually accepted that it could be I thought: 'Well there's no treatment anyway so I'm back to square one'.

Although despondent about her condition, Janet finally accepts her symptoms as those common to ME and like the other participants brings her search for a diagnosis to an end.

4.2.1.3 Search for an Effective Biomedical Treatment

The period following diagnosis of ME is characterised in all the narratives, as it is in the biomedical trajectory, by the search for an effective treatment. Reference is, for example, made in all the narratives to numerous treatments which are recommended by medical practitioners, other people, or found through the research efforts of the sufferer. The nature of the treatment offered by the medical profession appears to be unreliable, however, and this, in turn, feeds the perception that very little can be done for the condition.

4.3 THE MOVEMENT FROM DYS-EMBODIMENT TO BODILY RE-ALIGNMENT

Such cases of illness for which there is no treatment or imminent cure deviate, as mentioned above, from the restitution narrative. In other words, the "...tomorrow I'll be healthy again" part of the narrative does not readily apply to illnesses which are, for example, life threatening or chronic (Frank, 1995: 97, 115). Neither does it apply to illnesses such as ME that, although not life threatening, are ambiguous in nature and lack definitive tests and effective treatment. So the medical and social trajectories of illegitimate illness do not readily afford a personal trajectory of restitution. This does not mean that bodily re-alignment will not be pursued, nor that the need to attribute meaning and understanding to the illness will not persist. Conversely, the need to ascribe meaning possibly increases and that which biomedicine does not make readily available will be sought in additional and competing discourses that preside in particular social and cultural contexts.

4.3.1 Mind-Body Dualism and Illness Narratives

One discourse relevant to the experience of biomedically ambiguous conditions is identified by Garro

(1994) in her research concerning the illness narratives of people suffering from pain in the temporomandibular joint (TMJ). This discourse, which is not entirely unpredictable nor unrelated to biomedicine, is that of mind-body dualism. Within this discourse, the primary source of physical symptoms can be attributed to either the body or the mind. The dominant biomedical model places priority on the body as the legitimate source of biological illness but, failing this, will turn to the mind as a possible source of illness.

So in those illnesses that deviate from the anticipated biological course mapped by the biomedical model, an understanding based on the assumption of mind-body dualism leads sufferers and others to ask whether the condition is not in the mind. The implication of an illness being in the mind, rather than the body, is that the sufferer is responsible for the illness. Although a sufferer might not be held accountable for problems experienced in the body, problems of the mind are seen to be the individual's responsibility in that the "...mind is integral to the self" (Garro, 1994: 780). As already seen in the cases of Heather and Janet, the failure of the medical practitioners to find a physiological basis to their illness evokes an opinion of hypochondria and, hence, the illness being in the mind. This issue is not, however, confined to Heather and Janet and is indeed evident in all the narratives.

4.3.1.1 Lillian

Despite having received her diagnosis of ME, Lillian still finds it necessary to raise the issue of mind-body dualism with her doctor.

> When we, when we said to him: "The little bit we've heard about it, the little bit we've read seems to be a case of some medical practitioners are very sceptical about the condition and others sympathetic and what are your' ... I went straight out and said to him: 'What are your views? And what, is there really such a thing as yuppie flu or is it mumbo jumbo, is it all in the mind or is it a depressive type thing?'. And he said: 'No, it is a well documented thing'.

4.3.1.2 Colleen

Lillian's doctor is obviously one "sympathetic" to ME as he provides confirmation for her that her illness is not "all in the mind". Although Colleen does not raise the question with her doctor, she too casts some doubt upon the source of her illness with reference to mind-body dualism:

> I go through periods when I feel so desperate and despondent, I mean my whole life has just been turned upside down and the worst thing is that there is no real explanation. There is no real cause. I sometimes think that um this is all in my head and I'm going crazy. But you know I keep thinking, I keep thinking if I was lazy or if I enjoyed sleeping or sitting around all day I think I could understand it, I mean it would all make sense me wanting to get sick so I could spend more time in bed. But I'm not like that. I'm, I don't in fact ever have enough time to do all the things I have to. I've always got something to do, something on the go. But that's how I've always been, always on the go. So I know this can't all be in my mind or something, you know something I've invented.

4.3.1.3 Janet

Janet also appears to express some doubt about the biological status of her illness. Although she does not refer directly to the mind as a possible source of illness, it is clear that without complete biomedical legitimation the status of the illness is of concern to her.

> I feel a lot happier knowing that I've accepted that it is a problem and I think living with it makes you able to handle it far better. Living your life, living, sort of living with the disease, if it's a disease that is, who the heck knows, or living with the fatigue should I say is probably appropriate. But I, I'd love to find out, I'd dearly love to find out what actually this actually is because it really does take a lot out of you.

4.3.1.4 Heather

The doubt that Colleen and Janet express is not evident in Heather's narrative. Indeed, having received her diagnosis, Heather observes the dominant mind-body dualism with some irritation. This is particularly evident in her second interview.

> The factors that cause the illness, you know, I mean a lot of this um blame on some logic or whatever or how psychotic you are. So you know I still don't accept that because a lot of things don't change in life and yet the illness goes away. So if it's purely psychological, you know if it's only one factor then um it wouldn't.

Denying that the source of the illness is in the mind implies that it is in the body and not, therefore, the fault of the individual. This understanding is also evident in Heather's second interview.

> You know the suggestion is often made and in fact I actually heard it on a radio discussion about a month ago which infuriated me no end, the, the, that there's always this criticism of ME sufferers that these's a benefit out of it um that they gain all sorts of benefits as the side effects of being so ill. And that always frustrated me because I could see in my life certainly how I wasn't benefiting at all. So I never felt that it was my fault um definitely. And it frustrated me that other people would be so bold to use a very kind word, to say that it was all my fault. It's like asking someone if they believe it's their fault that they have got stomach cancer. It's totally ludicrous.

It is apparent that Heather understands her illness as primarily biological and, as a result, does not entertain the doubt evident in the other narratives. Despite this distinction, the narratives all illustrate the tendency to draw on mind-body dualism in the process of ascribing meaning to illness experiences. So, in identifying the cultural schemas that direct understanding of illness experience in Western capitalist societies, the dominant biomedical discourse and mind-body dualism appear to be two related and notable discourses. These are not the only two giving meaning to the experience of ME, however, and focus on

these two discourses alone neglects another powerful source of cultural knowledge and meaning which is drawn upon in the interpretation of illness.

4.3.2 Health Promotion Discourse and Illness Narratives

The third and equally significant discourse evident in the narratives is one that has recourse to the notion of health, which implies that the meanings associated with illness are not entirely separate from meanings associated with health. To the contrary, meanings associated with illness appear to be mutually inclusive of meanings associated with health and such meanings are again intimately linked to particular social and cultural contexts. Over and above the biomedical and mind-body dualism interpretations of illness experience, then, are those interpretations of illness that make reference to culturally and socially infused notions of health. And of note in this study, are those interpretations of illness associated with the health promotion discourse of the new public health movement.

Health promotion discourse provides the basis for various interpretations of illness experience. Common to all, however, is a concern about risks to health associated with "risky" lifestyles and behaviour (Lupton, 1995: 51; Bunton and Petersen, 1997: 9). The notion of a health role is also of common concern because it is from this role that one is perceived to exist in an "at risk" state. The obligations and duties that are assumed by an individual in the health role involve efforts to minimise the external and internal risks that are seen to threaten the immune system. Such risk minimisation endeavours, in turn, involve drawing and monitoring the boundary between the external and internal environment as well as maintaining a balance between bodily inputs and outputs. It is within this interpretation of embodiment that meaning is evidently sought for the illness experiences associated with ME. The section that follows, details the personal trajectories of illness experience which are evoked from the health promotion discourse evident in the four narratives collected for this study.

4.3.2.1 Lillian

4.3.2.1.1 *External and Internal Risks to Health: Toxins and "Free Radicals"*

Lillian derives her understanding of ME from an interpretation of the body that places it in a state of constant threat from the risks associated with life in industrial society. The price of living in this pathological environment is brought to bear on the body, and the immune system in particular. From this perspective, Lillian perceives the body to be a reservoir for the toxic by-products of an immune system rendered inefficient by living in "modern times". Health and illness are not, then, simply understood in physiological or psychological terms, but are, instead, linked to the bodily by-products associated with a particular social context. Lillian refers to these by-products as "free radicals" and the maintenance of health and avoidance of illness involves monitoring and eliminating these "free radicals". This particular interpretation of her illness is offered at the point in her narrative where she describes the process of completing the application forms to join the local "Fit For Life" group. This she and her brother had done on the day prior to the interview.

> When we filled in that 'Fit For Life' membership when you join you've got to fill in a form, they ask you several questions, you know, a: 'Yes' and a: 'No' and: 'Have you got?' and we did that and then they said you know: 'Do you have any illness?' any you know, they cover all the things like high blood pressure, diabetes, obesity. I mean we've got none of those sorts of things. But then they ask if you know: 'Have any other?' and we put in there we had ME. And then it said: 'Describe it' and there we just wrote that we lead normal, normal-like activities with periods of intermittent tiredness and muscular pain. And then we just said that the doctor had told us to try and see ... you see the whole thing is looking back at things, toxin related. And by walking and that, you perspire and your blood goes ro[und], you know better circulatory thing and all that. So what we are saying is basically if there are toxins and things that need to be removed, by you walking a set pace and promoting circulation etcetera your body must get rid of things that shouldn't be there.

This understanding of her illness as "toxin related" is reinforced immediately by her account of the initial consultation with her doctor and the blood tests he had carried out at the time. She mentions in this extract "the vitamin thing" which she had explained earlier as being a treatment given to her by her doctor.

> What I also want to harp back to was the blood tests where he [the doctor] said to me that it only proved to me that I'd had a bad viral infection but it was dormant at this stage. But he said that in the articles he's read, it stated that today, many people are having viral and other types of illnesses um and other bacterial *dingeses*. But it seems as though in the modern times we're living in I don't know if it's, whether they're related to stress or whatever, that your body doesn't seem to be able to clear the things that have happened in it, infections or whatever they are, be they bacterial, viral or whatever. And he said that they now talk a lot about it. The remnants that remain in your circulatory system that the immune system does not totally conquer and they refer to this as free radicals. And he said that they feel that the vitamin thing that they have given us here enhances your immune system and by the combinations that they have worked out that it seems to be able to eliminate those free radicals. So we thought that taking that plus walking, having better circulatory on a supervised ... I mean we could walk on our own, but you don't know if you're walking correctly. You, you're actually raising your pulse rate, and now that we've actually been and seen what they do, we realise that you can walk and it can be beneficial, you can have very beneficial walking. So we thought if we tried to eliminate the toxins with the vitamins plus with the walking, maybe we'll work. And we've got the time to do it. We go first thing in the morning and we do it, we do the walks.

Lillian makes sense of her illness, then, by reference to an immune system compromised by "modern" society and a body unable to cope effectively with the range of organisms and situations that threaten to

contaminate it. Efforts to realign the body and the self are centred on this understanding of her illness. In other words, she understands her illness as essentially toxin related and that toxin producing elements need to be monitored and controlled.

4.3.2.1.2 *Risk Minimisation: Diet and The Immune system*

Apart from exercise, in the form of walking, as well as the vitamins mentioned above, efforts aimed at reducing toxins in the body involve attention to diet. This is evident in the following extract from Lillian's narrative in which she recounts an earlier episode of illness in her life. The attention given to her diet following this previous episode of illness, is again adopted during her current experience of illness. It can be assumed, from this, that she attempts to make sense of both illness experiences from an understanding of the body placed at risk by the toxin producing effects of life in a pathological environment.

> About seventeen years ago I was very sick. No sorry, about ten years ago. I was very, very sick. I had surgery and I had something wrong with me to do with my liver and my pancreas. Um my blood tests were wrong. They couldn't actually say if I had an infection or what I had wrong with me. I was sent away to PE twice. I was sent to Cape Town. Um they could never prove anything other than it was an episode related to the liver and pancreas. And then I was off work for about two months. Um, um I was really very ill. I was very thin and I was very sick. I never ever really got better. I continued to have a lot of pain and colically all that type of pain. Um they tried many different kinds of medication with very little result and they just said to me towards the end said they don't have an actual diagnosis and we don't actually have treatment to give you. But somebody said to us: 'Why don't you go vegetarian? What have you got to lose? Maybe it would help'. Because I had a great intolerance to [one inaudible word]. So Colin said to me: 'Well let's do it, we've got nothing to lose and I'm willing to go vegetarian with you' because we live together and make, do all our meal preparations [together]. And we went vegetarian and I would say within about three to four months I improved dramatically. And gradually just came right and

never ever knew what kind of a problem it was. After a long time I gradually sort of slipped a little bit. We went to friends and got invited to a braai and then we sort of, I ate very little and then Colin said to me he was actually missing his meat and then we started gradually introducing meat. We introduced chicken first. We had always eaten fish and we introduced only chicken first and we were alright and then we started to add red meat. And so gradually slipped back into a pattern. And then, but I never ever had these problems again. Now we decided seeing we've been having hassles and there didn't really seem any particular set pattern, so we decided to um first of all we started taking out everything that had preservatives in it. And so now we won't eat it, we go through everything so we've eliminated from our kitchen every single thing that's got preservatives or colourants, chemicals, tartarazine, anything. We've taken every single one of those things out of our diet and we've made our diet absolutely simple. So now for about two months we've gone purely vegetarian again and we also eat fish. We don't, we've dropped chicken as well, no chicken. Purely eating veggies, fruit and a little cheese, the undyed cheese. We've taken everything out like that. We've taken margarine out, out of our diet because it's ... everything that's got hydrogenated oils and everything. We've taken every single thing out of our diet and made it completely bland, vegetarian. Protein we pick up from our beans and other things like that. And we've been doing that for about ... but we are ... definitely are improving.

The attention given to dietary inputs and the attempt to eliminate anything perceived to be "unnatural", and hence pathologizing, is consistent with health promotion discourse which places value on all that is "natural" and uncontaminated by human intervention.

The risk minimisation behaviour manifest in Lillian's attention to diet is, moreover, explicitly linked to an attempt to protect the immune system. As Lillian implies in the extract above, as well as the one immediately following, a responsibility exists to safeguard the immune system which, in turn, involves a lifestyle characterised by abstention, moderation and vigilance.

But it was stated that sugars, alcohol and I can't remember the other thing were very bad for your immune system. And if, you must avoid having anti-biotics wherever possible. When on one occasion I had a bad infection of something, some other thing, um I had a throat thing and I had to go onto an antibiotic and it absolutely wobbles you. And they say that um vitamin C and magnesium are the things that you need because they build your immune system. So, in addition to the diet we avoid having an antibiotic unless it's absolutely essential. And as far as the sugars, we take the sugars out. We possibly at the most have two spoons of sugar a day. I mean you watch those people who have five or six cups of coffee a day and we have one cup of coffee in the evening and we have besides that we might drink fruit juice or we have filtered water. We have everything to filter it, to take out those chemicals.

4.3.2.1.3 *Healthism and the Health Role*

Implicit in the extract above is the concept of "healthism" or the prescription of "...a particular way of life" (Parish, 1995: 22) wherein "(t)he pursuit of the ideals of health...occurs as a particular moral form" (Bunton, 1997: 230). In other words, the responsibility of the individual to adopt risk minimisation behaviour in the name of health requires a degree of self-control and the ability to resist immoderation (Lupton, 1995: 73). In the extract above, Lillian indicates such an ability and, in so doing, suggests that she is able to achieve a measure of health despite her illness. She does this by comparing her ascetic or "healthy" behaviour with the indulgent "unhealthy" behaviour of others (Lupton, 1995: 73-74). As such, Lillian illustrates the analogy drawn by Petersen and Lupton (1996: 15) in which the "missionaries" of health promotion discourse who are seen to impart values that are similar "...to those of the Protestant ethic that Weber (1976 [1930]) linked with the rise of capitalism; namely, that life should be lived rationally, in a profit-maximising way, with no room for such excesses as drunkenness, overeating, gambling, idleness, thriftlessness, and so on". So the values espoused by health promotion discourse are seen to amount to a new work ethic rooted in bodily control and discipline (Lupton, 1994: 31). And

Lillian and her brother are able, in their retirement, to pursue this "work" on their bodies as a visible demonstration of their worth as responsible, "clean-living" citizens.

From the position of the health role, as indicated above, health and illness are no longer understood in terms of physiological or psychological processes. They are, instead, seen to be dependent upon the behaviour of individuals which tends to obscure the lines traditionally drawn between health and illness. So it is *behaviour* that is, first and foremost, considered important in achieving a status of health. From this perspective, an all-encompassing "at risk" state replaces the conventional distinction between health and illness. It is, therefore, possible to be in a state of health and illness at the same time. Lillian, indeed, illustrates this understanding of her condition by drawing a further comparison between herself and other people.

> When we look at other people round and about you who are retired, they are doing as much as you are and are of an equivalent age. So I would say that we lead pretty normal lives and physically I would say well we started 'Walk For Life' yesterday and she had three people already started and had been there several weeks and they were also on level one and she's already going to push us tomorrow to a higher level than they are. So despite us having ME we are actually fitter than most people.

Fitness and health are inextricably linked in health promotion discourse. As Lupton (1995: 71) argues, "(t)he triplex 'exercise = fitness = health'..." dominates and directs ideas about health and what it means to be healthy. Lillian's estimation that she and her brother are "fitter than most people" could, according to health promotion discourse, be interpreted to mean that they are "healthier" than most people. So, notwithstanding the handicap that ME poses, Lillian demonstrates a commitment to adopting risk-minimisation behaviour that fulfils a moral responsibility to care for her health. In doing this, she also contributes to the health of the social body which is, in turn, dependent for its health on the responsible

behaviour of individual members (Lupton, 1995: 75). Her illness, then, which she understands as the pathological outcome of living in a modern, industrial society is dealt with by monitoring and controlling her bodily state with greater vigilance and moral commitment.

Such vigilance, as Lillian indicates, involves monitoring bodily boundaries and more specifically the inputs and outputs crossing that boundary. The reference to diet, medication and exercise is indicative of meaning being ascribed to illness experiences gleaned from health promotion discourse. So, although Lillian's illness has been legitimated by a medical practitioner, the account she gives of her illness experiences does not bear witness to the biomedical trajectory as the primary source of meaning. Instead, she attributes meaning from the health role she assumes.

4.3.2.1.4 *"Voices" of Authority*

The medical trajectory is, accordingly, not dominant in Lillian's interpretation and account of her illness. She receives her initial biomedical diagnosis, but proceeds to relate her experiences as they apply to the health role in which the medical profession are but one of many "voices" of authority. This is evident in the following extract wherein she relates decisions about treatment, and indentifies the authorities who act as sources of knowledge in arriving at those decisions.

> We also then went to a friend who used to sell these products um, what 'Golden Products' or one of the other products at home. Um then they said to us that there was this new tablet out called immuno [one inaudible word] and it was supposed to raise your immune system and put you back in peak and it had seven, yes it had seventeen different things. They were not vitamin Bs they were all the trace elements and all sorts of different things. So we went and discussed it with the pharmacist and then he told us about one of the physician's wife who had ME and she had gone onto this drug and it did wonders for her. So we went onto it and I would say we had about a twenty percent improvement. And we took it for several months. Then we, afterwards

> we sort of felt it was not really, well it made us feel a bit ... so we decided, we weren't really feeling any benefit and it sort of made us feel a bit yuk. So then we decided to stop it.

Although both the friend selling "Golden Products" and the pharmacist are seen to act as "authorities", a line is drawn between those "authorities" considered acceptable and those not. It is clear that Lillian accepts the extended, positive conceptualisation of health in health promotion discourse, but anything that is seen to stray from the perceived realm of the "scientific" is rejected. This is evident in the following extract:

> Yes I, I find most people have got the idea that if you've got it [ME] you've got it for life. And I don't see why you should. That's why they also asked me, we were in enquiring about something one day and someone sent us to a, um to chat to someone and she said: 'Oh, but don't you belong to the ME Society?' And we said: 'No' and she said: 'Why not?' So we said: 'Well we didn't really want to'. And then she said: 'Oh well, but you should go and ask so-and-so because she might be able to explain something to you'. We went to chat to this lady, um she rang her up for us and she said they could come around now if they like. And so we went there. She was a super person. In fact we were quite happy to go to her on a regular basis but she could actually give us very little help. I would say, she almost, she also came up with one of these sort of, almost sort of homeopathic, also into vitamins and all sorts of things, but it was something you got from overseas or something and by the time they told you the price of it you know, it had like run into a thousand rand story. And, and also she was one that talked about magnetic forces and you know all these sorts of things. We don't believe in that sort of stuff, so we weren't interested in homeopathy or anything like this. So we thought: 'No ways, we're not interested in that'.

Despite the aversion to homeopathy, the extract above illustrates the trend Fox (cited in Bunton, 1997: 234) refers to as "...the relativisation of medical knowledge". In accordance with this trend, biomedical

knowledge is increasingly seen to contend with knowledge from a range of sources, experts and advisers (ibid). Although biomedicine plays an important part in legitimating Lillian's illness, her interpretation and experience of it, draw on far more than biomedical knowledge and treatment. So, it is possible, too, that her attempts to re-align her body and self by eliminating "free radicals", which had not been achieved at the time of the interview, would continue to deviate from the biomedical trajectory.

4.3.2.2 Colleen

4.3.2.2.1 *External and Internal Risks to Health: Stress and "Disease"*

Like Lillian, the meaning that Colleen gives to her illness, does not simply rest on an understanding of the body as a biological organism. Colleen's narrative communicates an understanding of the body more in keeping with health promotion discourse which emphasises the importance of building up, and maintaining, the immune system as a defence from outside risks to health. In accounting for her illness, for example, she refers to personal biography and more specifically her experiences of a particularly stressful time at her place of work prior to her resignation. As a result of a restructuring process at the company she worked for Colleen was asked, after working part-time for eight years, to work full-time for a year while changes were undertaken. At the end of the year's full-time work she approached her new, much younger manager about the possibility of returning to part-time employment. This was, however, not agreed to and it ultimately led to her resignation and a rather traumatic period in her life. It was shortly after her resignation, that she experienced the onset of symptoms and in relating these personal biographical events, she reveals an understanding of her illness that concerns minimising risks to her health, and stress more specifically.

> What I find puzzling though um you know all the time I was working with so much stress and all the fighting and whatnot, I was as fit as a fiddle. Nothing wrong. I don't even remember getting a cold. But as soon as I've left all the stress, I come down with this. None of it really makes any sense because you know reading about the illness and speaking to different people, one of the

most important things seems to be getting rid of um or rather should I say managing stress in your life. I don't think you can get rid of stress like being completely free of it but what's important is managing it. And stress seems to be a big factor and I know even for myself if I start putting any pressure on myself now to do things, then I'm always worse off. At first I used to try and push myself but now I don't. I know I'm going to land up back where I started so I don't push myself at all. Um which I must tell you has been something new to me. I think one of the things, one of the main factors was when I started to work full-time I stopped my regular exercise. You know if it wasn't walking then it was tennis or going to the gym but um every afternoon I used to go for a walk with a friend of mine. And I'm not talking about a stroll around the block. We would virtually run our route every day. And I think when I stopped doing that, you know it was, it became too much after work when I sometimes might have to go shopping or whatever. So I stopped doing that and I think that was probably, it probably had a lot to do with me getting sick. You know at the time when I was having to work longer hours and having much more stress, I stopped walking. I was very fit and that exercise really helped. I mean you can't expect your body to cope with stress if you're not doing exercise and keeping fit. So if you can't release that stress and you're not keeping fit then your body eventually can't cope. I really felt those walks were good for me, you know my body felt strong and I suppose I didn't realise how much it was benefiting me, me being fit. And so that's really the time I should have been walking with all the pressure of, at work. So I think it's, it's probably the last thing I should have done you know stopped the walking.

Exercise then serves as a "safety valve" for the release of pressure which Colleen associates with the build up of work related, and hence externally imposed, stress. Her external environment is perceived as a danger to her health and this is confirmed by her retrospective explanation that her illness is the outcome of reducing risk minimisation practices at a time they were, to her mind, most needed. Colleen's thinking,

then, demonstrates what Greco (cited in Nettleton, 1997: 214; also Petersen, 1997: 198) refers to as "a form of irrationality" characterised by "...a failure of the self to take care of itself...". Health, according to this perspective, is based on an ability to "master" the self and failure to do so results in "disease". So, it is the *behaviour*, in this case the lack of exercise, that is perceived as the "... 'disease' prior to the actual physical complaint..." (ibid). This sentiment is particularly evident in Colleen's last statement in the extract above where she suggests that her behaviour, the "disease", preceded the onset of the physical symptoms.

4.3.2.2.2 *Risk-Minimisation: Exercise*

Colleen attempts to overcome this "form of irrationality" and, in so doing, highlights the need to take responsibility for her illness and health. Although this is perceived to be lacking initially, it is evident in the efforts that Colleen, like the other participants, goes to, to reduce risks to health. Consistent with this responsibility and Colleen's view that exercise is necessary to maintain a healthy bodily state, is her concern about the lack of exercise as a result of her ill-health.

> So now I just don't have the energy to do anything about it, I don't have the energy to get fit again. I think if I did, I would be much, much better. One of the first things I did when I felt I was up to it was get a book because, you see it's a book for people with ME which has a special exercise programme. Because some people say you shouldn't exercise when you've got ME you should just rest, but others say you should and I, but I know that my body can't cope without exercise. And I must say that I do feel a lot better if I can follow the exercises regularly but there are times when I can't. I can't do anything. I can't even lift the book up I'm so tired or sore. You know the muscle pain is very strange because it's not sort of like the normal pain you have, or should I say the pain you get when you do exercise. I used to enjoy that feeling, you know when you've done exercise. It's a good feeling. You sort of feel good and I um, I actually enjoyed it. But the muscle pain I get now is quite different. It's all over. It moves around. It's not just one spot and my skin is actually sore when you touch it like when you have a bruise. That's how it feels.

> And you know it's one thing to have pain when you're up but when it's there and you're not, you're just lying in bed um. So and I know I won't get better if I don't exercise but sometimes I just can't even get up.

4.3.2.2.3 *Risk Minimisation: "Paying Attention" to the Body*

Colleen's efforts to take responsibility for her bodily state and the attempt to reduce risks to her health are also evident in the need she expresses to "pay more attention" and respond to "what's going on in" her body:

> The thing is that I hardly ever got sick before but now with the ME, I seem to get every little flu or cold or whatever that's going around. I think I'm, the ME makes you or puts you at risk of picking up these things because the immune system is so low. So I've actually become far more aware than before about things like my lifestyle and diet. I think I've always been quite good about all that, and looking after my health and whatnot but it's only when you get really sick that you start to see how things like diet and exercise really are important. So I've tried to build up my immune system. You know because I can't do as much exercise as I want or I should do, I have to sort of compensate in other ways. I've had to take extra vitamins and calcium and things which I didn't do but I think they help. They build you up. And I've really actually become more aware of what's going on in my body. I know now like when I have a sore throat or my glands are sore I have to pay attention otherwise I'll come down with something. I have to take extra vitamins and I have to rest more. Before I probably wouldn't even have noticed. But now I do, I need to pay attention all the time. [...]

In taking responsibility for her bodily state and trying to achieve realignment, Colleen embarks upon a process of bodily surveillance and monitoring that relates to building up her immune system through exercise, dietary supplements and paying more attention to her body. At the time of her interview, Colleen

had not managed to achieve any sense of bodily realignment through these efforts and, accordingly, expressed the need to try alternative "treatments". As such, her narrative does not end in the sense that there is some point at which she can foresee her illness terminating. The course and the nature of her illness remain uncertain and the despondency expressed at times during her narrative is only balanced, to some extent, by the hope she places in a diet she had heard of, as well as the realisation that there had been some progress.

> There's been progress for sure. Absolutely. If I compare what I'm like now to what I was before I got sick it's, it's difficult to see the progress but I have to remind myself of the progress all the time. I think the first time I came down with this, I would say that was the worst time. I mean as far as the length of the attack. Since then, I still get all the symptoms and the exhaustion and pain but the periods that it lasts are not as long. So there are times when I feel better and um sometimes I feel much better but the thing is you never know when it's coming back to zap you. But really, the last eighteen months have been um well, like a nightmare for me. At the moment I'm still um trying out things to see what works for me and what doesn't. I've tried the exercises in the book and they help a bit. Also the vitamins I'm taking. I've been on a few diets, um I tried cutting out dairy and fats. Other times it's been protein or carbohydrates or sometimes you know a combination but I, I mean I haven't found anything that I can say: 'Wow, that really makes a difference'. But I know one woman was on a diet, a woman in East London with ME. I don't know her but I heard that she was on this diet and I actually heard that it cured her. So I want to try it. I know someone, actually a friend of a friend who knows this woman and now she is going to find out about it for me. So I'm going to get that and see what it does for me. But really I'm not the same person I was eighteen months ago. I try, I really try to be positive but you know sometimes it's such an effort to do something I wouldn't even think about before. You know simple things. Simple things like getting up in the morning, getting dressed and making breakfast. Those things just used to happen. I never, I don't think I ever thought about doing them. Now

sometimes, just getting up and then by the time I've dragged myself up I'm so exhausted that um the thought of getting dressed is well, it just sends me back to bed. And other things. Gardening or taking the dogs to the beach or um anything, going to church. Sometimes, I just haven't been able to do those things. I keep thinking that this is what it must be like for someone who has um, is paralysed. It makes you realize how fortunate you are. I mean I know that things are bad for me and I often lose all hope but when I think I could be paralysed or have some terrible disease, I mean at the end of the day, I'm going to get better, it um it might take time. But I will improve. I am improving.

Colleen's narrative, then, expresses an attempt to understand and overcome her illness by drawing on health promotion discourse wherein the responsibility to adapt her behaviour and lifestyle evidently overshadow efforts to embark upon biomedical treatment once the biomedical diagnosis has been received. In this way, Colleen's narrative can been seen to share similarities with that of Lillian's as it can, too, with that of Janet's.

4.3.2.3 Janet

4.3.2.3.1 *The Medical Profession and ME*

In trying to understand and interpret her illness experience Janet, like Lillian and Colleen, turns to health promotion discourse. She indicates, more directly, the rather limited role of medical doctors in dealing with ME and, in so doing, provides insight into the classification of illnesses that she views as "treatable" by the medical profession and those not. The medical profession are, according to her classification, not equipped to deal with ME.

ME isn't an easy disease to distinguish and I think until you've had it yourself, there's always that doubt. And obviously if you go and all the tests are negative, then there's nothing that the medical profession can do for you and I think this is a big criticism of ME is that there's absolutely

nothing they can do for you unless they give you large doses of penicillin and it does help some patients. Other patients it doesn't help at all. Reassurance. A doctor's not just there for reassurance and he doesn't always have the time to have that sort of, beside manners. And I would never sort of say or discount the medical profession because they haven't helped me. They do good work but obviously this one is as such that they just can't cope with it. I actually only go to the medical centre, go and see a doctor when it's absolutely necessary. I tend to rather fill myself up with vitamins, eat a healthy diet if I can and exercise and if I have a sore throat, eat garlic and even if I've got flu I, I won't. I'd rather have lemon and honey or um rather go and get something natural than go and bother a doctor. Because I do believe that too many people go just for, for viruses that you can't treat anyway and I tend to, to keep away.

In this passage, Janet separates her experience of ME from other categories of illness experience that she considers more appropriate to biomedical intervention. In so doing, she abandons to some extent the biomedical discourse in which the physical and psychological basis for understanding her illness experience is not readily available. So, in an attempt to understand, and give meaning to, her "illegitimate" illness Janet, like Lillian and Colleen, appears to employ the health promotion discourse of public health.

4.3.2.3.2 *Risks to Health: AIDS*

The first indications of this emerge in Janet's identification of the onset of her symptoms. In this account, she draws on particular biographical details and circumstances to explain the point at which symptoms were experienced.

You start to think, at the one time my immune system was very, very down and I caught everything that was going and I started to lose weight very rapidly and as a midwife working in the hospital, I started almost if it was like, it was like a phobia because I started thinking: 'Goodness, what if this is AIDS?'. And for a while there I actually was afraid to go for an AIDS

test because it, you know I seemed to have most of the, well a few of the symptoms for AIDS. But then I did pick up courage. I went and everything was okay. But it didn't prove anything you know. I still have the problem with the immune system.

The movement from embodiment to dysembodiment that accompanies her physical symptoms, prompts Janet to make sense of her illness in relation to her particular circumstances and, in this case, her work as a midwife exposed to possible HIV infection. Her fear that her physical experiences may be symptomatic of AIDS is significant because it provides insight into her interpretation of the relationship between body, self and society and acts as the broad interpretative framework for re-aligning her body and self. In other words, Janet's narrative has meaning when understood in relation to a discourse of health promotion wherein the conceptualisation of a health role, and a body at risk from a threatening external environment, play a central part. The fact that Janet had been working in a relatively high risk environment over which she had relatively little control explains her fear of possible HIV infection, but also indicates the need to exercise greater bodily surveillance, control and regulation. As Williams and Bendelow (1998: 71) argue "AIDS, in short, intensifies concerns and anxieties surrounding rationality, the maintenance of bodily boundaries, the contamination of body fluids and the robustness of one's immune system".

4.3.2.3.3 *The Health Role: Bodily Boundary, Bodily Balance and Risky Behaviour*

Janet, in accordance with this understanding, acknowledges the importance of identifying a bodily boundary. In the extract below, Janet also refers to efforts to maintain bodily balance within this boundary by monitoring the amount of work she does and ensuring it does not exceed her "limit".

You see I always feel that I don't accomplish an awful lot, but other people say to me you do. But then it's not consistent. Sometimes I do a lot of work, I get a lot done. Other times I don't. I don't think it actually has much to do with the illness. I think it's possibly just my lifestyle. But I

know that when I do a lot then I crack. If I'm not careful it'll come back so I know I have a limit and I try and keep within that limit. And if I find that I'm not, perhaps working very hard, I used to do a lot of catering and that really did put me under a lot of stress because it's a lot of hard work and I would probably sleep quite a lot after that so I knew that I was pushing my limits beyond the boundaries. I try not to do that. I've had to learn to do that because I've never ever known any boundary. Perhaps that's what's helped me. I don't know.

The notion of a bodily boundary remains central to Janet's experience of ME. She understands her illness in relation to having extended herself beyond this boundary to the point where she, indeed, interprets a diagnosis of glandular fever, which is often considered to be a precursor to ME, as secondary to the understanding of her "pushing" her body beyond its boundary:

> What I don't think I mentioned before was that during the glandular fever I didn't know I had it. I felt, I felt slightly fatigued, off-colour. But at the time I was running and I thought you can run through anything and I exercised the whole time through it and I think it was probably the worst thing I could have done. If I had sort of said: 'Okay, you know, I'm sick. Let's, let's just relax and rest through this' like one normally does with a, a flu, then I think I would, I would never have got it [ME]. But I think that's, that's why people get it. And speaking to a lot of other people they, it normally happens when you've been pushing yourself and haven't quite, quite been up to it. So it could be a good indication that you are pushing your body too much.

As in Colleen's case, Janet explains her illness from a position of the health role in which individuals have a responsibility to minimise risks to health. Although their explanations are seemingly contradictory, both Colleen and Janet identify risky behaviour as being responsible for the onset of their ME. In carrying out "irrational" and "unhealthy" choices, that is, to stop exercising in Colleen's case and to continue exercising in Janet's case, negligence towards the care of the embodied self is exposed to view. As mentioned earlier, Greco (cited in Petersen, 1997: 198; Petersen and Lupton, 1996: 16) argues that "(i)n the event that one

is unable to regulate one's own lifestyle and modify one's risky behaviour, then this is, at least in part, 'a failure of the self to take care of itself'". Janet's statement cited above in which she refers to herself in the plural, that is, "okay, you know, I'm sick. Let's, let's just relax and rest through this" (emphasis added) affirms her sense of dys-embodiment, or awareness of her body as separate to her self, during the glandular fever. She does not, however, act in response to her dys-embodied state. As she explains, it is *not* the glandular fever that acts as the precursor to her ME, but her failure to respond to her dys-embodied state by *adapting her behaviour*, and in her case to cease exercising, that accounts for her present state of illness.

According to health promotion discourse, then, the individual has an obligation towards the body to ensure that rational and healthy choices are taken in terms of lifestyle and behaviour. Janet's inability to recognise her "limits" and the admission of "pushing" her "body too much" constitute a failure to fulfil this obligation; and it is this, which is apparently held responsible for causing her ME. The flip side of this health promotion coin implies that if care is taken of the body, one does not become ill. Janet reinforces this understanding of her illness through an explanation she gives regarding her neighbour's diagnosis of ME.

> I've been, I've actually been surprised on a couple of occasions with people who have had ME or are actually suffering from it and I didn't recognise that they had it. Um on the other hand when my next door neighbour got it I just looked at her and thought: 'Oh no'. And what interested me was that she is a woman, she is a woman who used to love living in the fast lane, um as in work, work, work you know, not socialising, a socialising person is something different and then um, you know she, she was in many respects sort of going through the same, or doing the same sort of things I had done just before I got it and I actually said to her: 'Slow down. You don't know what you're doing to yourself'. And I, I didn't mention anything and then when she came back, um she was sick for about three or four weeks. She told me about it and I just shook my head and thought, and I told her then that I had gone through the same sort of thing and then

it dawned on her when I said you know: 'Take it easy, don't push yourself', that it seemed to affect, there seems to be a pattern there. It seems to be very predominant in people who don't know where their limit is.

Despite Janet's warning, then, the neighbour develops ME and the factor that they identify as being important in explaining the illness relates to pushing oneself beyond one's limit. This factor is not inconsistent with the high correlation, identified at the 1978 London Symposium entitled "'Epidemic Neuromyasthenia' 1934-1977: current approaches" (and referred to in chapter two [cf. 2.2.2.1]), between ME and physical activity. Janet's interpretation of the illness appears to agree with this finding but the emphasis placed, by Janet and her neighbour, on the *risky behaviour* of the individual is, seemingly, a key factor in determining who they perceive to be susceptible to the illness, and who not. So it is not just physical activity, as suggested at the Symposium, that increases susceptibility to ME (Dillon, 1978:730), but, importantly for Janet, it is neglecting the obligation to maintain that activity within a limit that appears to be at the heart of her understanding of ME. As such, she demonstrates a point made by Nettleton (1997: 214), who argues, citing Ogden (1995) that "(i)t is not environmental factors, or bacteria or viruses per se that cause illness; the critical factor resides in individuals, more particularly their self control...In fact, she (Ogden) points out, 'in the twentieth century the individual has become at risk from his or herself'."

4.3.2.3.4 *Risk Minimisation: Immune System Protection, "Listening to the Body" and Fitness*

To avoid illness, as suggested by Janet in the extract above, an obligation exists to undertake surveillance of the body which is seen to be vulnerable and at risk from both the external as well as internal environment. Janet, accordingly, places priority on recognising and monitoring a bodily "limit" and, related to the problem she identifies earlier with her immune system, sees the need to protect the immune system from the external environment which acts as a source of possible infection. Failure to engage in the

necessary behaviour could, from the health role, be interpreted as illogical if not irresponsible. So, in describing an episode of illness, she makes reference to changes in her personality as a result of ME, as well as her concern about interacting with others who are perceived to be a possible threat to her health.

> I think the longest, the longest that I've had I've had the symptoms and it's and haven't been intermittent has been three weeks. And I, I really thought at that time that I might have something else. But it came and it went as mysteriously as it came. But it means after that, that you're very fatigued. It took me a long time to get back on my feet and that was depressing. There's where the depression comes in after the episode. And I started to feel that I was never going to get any better. I was always going to be like this. I actually got to the stage where I thought if this is what life is going to be like, I'm not going to enjoy it very much and um obviously your personality changes. You become I think more abrupt with people, less inclined to socialise and you actually do change and I, I was worried about it at the time because I didn't like the me that was coming out of it. I'd always been a, a sort of great socialiser, loved people, always liked being with people and here I was sort of wanting to keep well away from them. And I was always scared to be with someone with a cold incase that started something off. So it affected me in that way. I didn't want to go out. I didn't want to, I just wanted to go to bed. I didn't want to go out and celebrate anything. If I did have to go somewhere, it was moans and groans and my husband got fed up with me too. His words were: 'Now come on you've got to see somebody. You know this is ridiculous. You can't go on like this'.

In the extract above, Janet expresses a desire to avoid contact with the external environment which she perceives as a risk to her health. Her statement declaring a fear "...to be with someone with a cold incase that started something off" is indicative of the threat she perceives others to be to her health and her efforts to minimise this threat amount to avoiding contact with them. This, as she suggests, brings about changes to her behaviour and personality that both she and her husband find out of place and of concern.

In addition to the external environment, efforts to reduce internal risks to health are expected of the individual in the health role. So monitoring the bodily boundary also involves maintaining a balance between "inputs" and "outputs". In similar fashion to Colleen's effort to "pay more attention" to her body and respond to what's going on in" it, Janet relates an attempt to do this by "listening" to her body. The self then, as Martin (1992: 125) suggests, loses agency to the body and it is the body that acts as the basis for action taken by the self in an effort to maintain bodily balance. This process is evident in the following extract in which Janet describes what she does on a bad day.

> I try to listen to what sort of my body is saying. If I've got a sore throat, I eat lots of garlic [laughs]. No, if I have, if I feel it's an infection then I try and decide. I take lots of vitamins, I always have done since I've had this. I don't know if it makes a difference but it certainly helps me. But mainly I just have a quiet day. I tend not to push myself too much. I put off things that I can put off, but if it's something I really can't put off, I just say: 'Okay fine, this has to be done, but something else hasn't'. So I more or less say: 'These have to be done today but that's all. The rest doesn't matter'. And it helps. I don't push myself. But in the beginning it was difficult to come to terms with this because I've always, I've never been a person of moderation. I've always tried to push myself. I think I perhaps realise now that I maybe push myself a little too much. And obviously we all have our bad days but I now accept that if it's a bad day, it's a bad day. And I think it's necessary to, for me anyway, to listen to what my body is telling me and just try and organise my day like that.

Apart from listening to her body in an attempt to maintain a balance between inputs and outputs, Janet also indicates a need to pay attention to diet and exercise. Consistent with an understanding of the health role, reference is made at various points in her narrative to exercise and her level of fitness. Both are considered important to feeling "good" and reducing the threat of risks to health. In this extract below, for example, Janet describes periods of progress and relapse and interprets her progress in relation to her

level of fitness:

> I see some progress now but I didn't and you know I would just get myself up to a fitness level where I really felt fit. I could run, I could walk without getting breathless, I could climb stairs without getting breathless and I started feeling really good about myself and well you know you start to get to that stage and all of a sudden the next day I couldn't get up again and this was the most disconcerting thing about it. Recently I've been feeling a lot better. I always do though when I start getting more exercise. I feel good, I start to feel good.

So Janet's attempts to re-align her body and self are understood in terms of being fit. Fitness is seen to be one of the ways in which risks to health may be minimised and consistent with this health promotion interpretation, is Janet's belief that fitness is a way of "building" herself up. This she implies in reflecting on her condition at the time of the interview and her ability to achieve bodily re-alignment in the future.

> My attitude now is that I'm going to slowly get there and I'm kind of not going to let it ruin my life anymore. It's all fair and well saying that now, but I haven't had a really bad day for maybe a year so it's given me a more positive attitude. But on the other hand if I had a bad day tomorrow then I think my attitude would be knocked out of the window because it is depressing. Very, very depressing. And I think as long as I'm feeling that I am getting better and I am not as sick you know the symptoms are not as bad then yes I will have a positive attitude and I will continue to progress slowly and build up my energy which I'm doing now. And I'm hoping that I can perhaps get myself back to a type of fitness I was before. Maybe not the same but at least where you can function normally all the time.

Janet's illness narrative, like that of Colleen's and Lillian's, does not reach an end. Although she has experienced a relatively long period of time free from the symptoms of ME, the extract above relates her concern about possible relapses. In so doing, it illustrates the point Williams (cited in Annandale, 1998: 259) makes about bodily re-alignment, which he suggests may be "...precarious, fragile and in need of constant repair work...".

4.3.2.4 Heather

4.3.2.4.1 *External Risks to Health: The "Unnatural" Environment*

Of the four narratives, Heather's is the only one that imparts an account of successful medical treatment. This was done at the time of her first interview where she described her state at the time as follows:

> I'm much better than I was, I have found a doctor in Johannesburg who has done a lot of research and she has got a theory about this and I've been on her treatment now this month for a year and I'm much, much, much better. I'm not completely well and I'm not as well as I remember before I had this illness, but I'm much better. I'm able to go through most days without having to sleep whereas a year ago I would have slept four or five hours a day um and then have a ten hour sleep at night which didn't leave much time to do anything else. Ja.

So, apparent in Heather's narrative is a theme that follows to some extent that expected in a medical trajectory. In other words, her narrative relates the onset of symptoms, consultation with a doctor, albeit more than one doctor in her case, and the implementation of biomedical treatment. Although a prolonged version of the restitution narrative, her experience of illness nonetheless follows a biomedical account of illness experience. It does not, however, begin and end with biomedicine. Like the other participants, Heather also draws on health promotion discourse to make sense of her condition. This is evident in her account of the onset of physical symptoms which she describes in relation to biographical details.

> It's quite difficult to actually pinpoint when it started. As a child I had a lot of chest infections and that kind of thing. I had glandular fever when I was in standard eight um which a lot of people have asso[ciated], a lot of doctors have associated with this illness. Um and, but um, I in our first year of marriage, I had a foot operation and I was under anaesthetic for forty five minutes and if I think about it, it was from then that I started to go, to become more ill more often and take longer to recover and then, it was like the tiredness set in. But it was only when we moved to East London where I actually had time, because we moved in December and I started varsity in February so I had three months to just be um and I slept basically every day from ten until three

for three months and thought: 'Oh well, it's just the pressure and stress of moving and winding down after living in Johannesburg, living at the speed that everybody lives in'. Um but it didn't go away, it got worse and worse.

In the account above, Heather attempts to make sense of the onset of her physical symptoms and in so doing refers to previous illnesses, an operation, as well as her move from Johannesburg to East London. These events are, in addition, interspersed with information that has recourse to health promotion discourse. She identifies, more specifically, the "stress" and "pressure" of living a high-speed Johannesburg lifestyle as possible "risks" to her state of health. The theme of "risks" and threats to health is one that appears to supplement her biomedical understanding. In talking about her and her husband's move to East London, for example, she indicates that she was "wildly ecstatic" about "getting out of Johannesburg". The reasons she cites for this provide some insight into a lifestyle she views as pathological.

I grew up in Harare and I never quite adjusted to coming back to Johannesburg [her family had lived in Johannesburg for a short period when she was very young]. And I think living in East London was closer to the lifestyle that I had grown up with, smaller town, people are friendlier. I never got used to, I think I said earlier the speed at which people lived or live in Johannesburg. Also the crime rate. That really began to bother me. I hate being seen behind bargler burs, burglar bars. That's one of the, this thing, this illness does to you. I do that all the time. When I'm tired, I switch off, muddle words around. Anyway, ja in Johannesburg when we left you had to have double burglar bars on the windows, you had to have security gates on all your doors, um on all your exit doors. So living down here where, you have to be careful, but you don't run the risk of, of ... we've lived in this house for five years and we haven't even had a smell of a burglary. In this area one or two people have been broken into but nothing serious. I mean my car stands outside. If my car, my car was left outside one night like it is here, it would be gone. And I grew up in a country where although it was in a war it was a bush war, and we didn't even lock our doors, let alone have burglar bars and things like that. So perhaps I was the incentive for us moving to East London.

The new public health's concern with the "unnatural" external environment as a threat to health is apparent in the extract above. Indeed the threat to health posed by the pathological urban environment is intensified by Heather's reference to crime. Crime, like the fast pace of modern living, is conceptualised as an external risk to health. Heather recalls an incident during the initial part of her first interview which is indicative of this thinking. In this extract, she recounts the events that led up to the emergence of what she calls a "reactive depression" that started a year prior to her diagnosis of ME:

> Um what happened, the start of my depression was, um it was a reactive depression. I, as I told you earlier [in a conversation prior to the interview] I walk on the beach everyday and I had gone down to the beach one morning and gone walking with the two little dogs and um I was sitting on one of the sand dunes reading and I hadn't noticed that the beach had emptied of people. There are certain times that people walk um, you know you can go to the beach and there are always people. And a man, a white man, walked up to me stark naked with an erection and I thought I was going to be raped. And I, I prayed. And fortunately two old ladies that had seen him but that ... it was actually quite funny in retrospect. They didn't have their glasses on so they didn't realize that he was naked but they had seen him as they came down onto the beach and had noticed that he wasn't a regular and that he looked a bit odd, um suspicious. And fortunately they had seen him walking down the beach and they were afraid that if they walked around one of the corners that they would kind of be trapped. So they turned around together to walk back up the beach and as they were kind of equi-distance, they hadn't even seen me, equi-distant from me he just turned and sauntered up the beach. That really, really rocked my faith, my sense of security um which I suppose a lot of South Africans deal with on a day to day basis, but I've been pretty sheltered much of my life so I haven't had to deal with it. When I went to the police to report it, they were amazed that I even wanted to lay charges. We had managed to get his car um license. The police were amazed that I was even prepared to lay a charge of indecent exposure because they said: 'Would I be prepared to go to court?'. And they were surprised when I said: 'Of course

> I'll go to court'. Anyway, he was, we went to court. They got this guy. He said that he was guilty and when they asked him why he'd done it he said he was bored. Um, he was fined two hundred rand which his mother paid for him. And that, that was the start of it because that was, it rocked a very deep sense of security that I had always had. I think as a woman you can understand it, I mean that kind of situation. So I had that, I was at that point, I was depressed and had all these things. He [the doctor] put me onto Eglonol which was okay, it helped a bit. Um that was in, in second year so I just managed to get through my varsity exams. So, ja.

The healthier lifestyle offered to Heather by a more "natural" and hence risk-free environment is apparently contaminated by this incident. It impacts directly on her health by impeding her pursuit of a healthy lifestyle. She alludes to this in the following extract:

> Ja I enjoy the beach. I love the beach. That's my soul food and that was as well, to go back to the depression that also took away from me two years of freedom to go to the beach. So I suppose in a way this illness has taken a lot of my freedom. Freedom to just do whatever you are supposed to do, to be able to just do things and not have to worry about, ja so I enjoy the beach. I love walking. I love the sea. I love being outside in nature and the wild, camping, hiking.

The threat posed to Heather's safety by the incident related above is interpreted as part of the pathological environment that threatens her health more broadly. In this way, the experience of her illness is closely linked to her acute awareness of the external environmental risks to her health which, in turn, inhibit her "freedom to just do" and receive her "soul food" (which is the time that she spends on the beach and perceives to be health-giving).

4.3.2.4.2 *The Health Role: "Tuning in" to the Body and Healthism*

It is evident, given this interpretation, that her movement from dys-embodiment to re-alignment must

involve more than simply overcoming the physical symptoms associated with her illness in accordance with the biomedical trajectory. Indeed, Heather provides some indication of what might be involved in the process of realignment in the following description she gives of a healthy person:

> A, a healthy person would be someone who is in tune with themselves enough to be able to draw their own parameters around their lifestyle. And not live a life according to the dictates of, completely what other people, environment, whatever dictates. Obviously, um, ja so that is what I mean is a healthy person, someone who has worked out for themselves how to live best.

Apparent in this description is an understanding of health as a personal project that involves lifestyle choices and being able to control those choices. In other words, her understanding of health is more in keeping with health promotion than it is with biomedicine. This means that Heather's state of illness prompts her to focus more attention on her body, as well as her lifestyle and behaviour, in an attempt to bring about a greater degree of health. This, in turn, involves attention to being "in tune" with herself.

> I've never been a health fanatic, um I don't particularly, I've never been a sporty person, but I enjoy the outdoors. Um, so I've probably become a bit more aware of taking care of myself. Also because I realised that if I do get my exercise, my 'soul food' on the beach, um I think it helps my day tick by. And physically that's good for you, you know the physiological reasons for having exercise. So probably I have learnt to be more disciplined in terms of I don't, I've never been a junk food person, but I'm aware now that if I eat a lot of junk food I'm more in tune with my body, I can <u>feel</u> what it does to me, whereas I probably years ago I wouldn't even have realised that the sluggish feeling I was feeling was as a direct result of eating seventeen hamburgers in one month, kind of thing. You know it's an extreme example which I would never do. So, ja I have become more health conscious. Um I wouldn't say though that I'm becoming a fanatic in terms of not eating this or that or having my 'X' amount of exercise or whatever.

Heather's example of "eating seventeen hamburgers in one month", which is used to illustrate being "in tune" with her body, might be interpreted differently in a different socio-economic context, but her objection to such "extreme" behaviour is indicative of her adoption of the moral values and responsibilities associated with health promotion discourse. As mentioned earlier, Heather appears to understands her illness in biological and biomedical, rather than psychological, terms which suggests that she is not held responsible for her illness. At the same time, however, another system of illness classification appears to be in operation. In terms of assuming responsibility for illness, it is apparently not simply a case of sufferers of illnesses with a psychological basis being held responsible for their illness and those with a biological basis not. Heather, instead, implies a classification of illness for which one is held responsible and another for which one is not, based on one's behaviour. Depending on one's behaviour, then, one is seen to be either "innocent" or "guilty" in terms of causing one's illness. This "healthist" perspective is apparent in her haste to indicate that she would "never" eat seventeen hamburgers in one month; an "extreme" act of unhealthy behaviour. She also implies such thinking in relating the behaviour and health statuses of two relatives. In the first, she comments on the death of her mother which had occurred a few months prior to her first interview as a result of emphysema.

> Well ever since I can remember, the doctors have been telling my mother to give up smoking so I'd say she's probably had it [emphysema] for the last twenty years, ja. And she continued to smoke. She made herself progressively worse.

In the second, she comments on her mother-in-law:

> He [her husband] actually has a mother who is very ill um, in that if she doesn't watch the way she eats she's going to have a heart attack and die.

In both these examples, Heather implies that her mother and mother-in-law are "guilty" of irresponsible behaviour and that their illnesses, and death in the case of her mother, are to be expected as a result of it. So rather than simply being linked to biological or even psychological states, health and illness are

statuses being linked to behaviour and a perceived moral responsibility to care for one's health.

4.3.2.4.3 *The Health Role: An Economy Of Energy*

To return to the discussion of being "in tune" with her body, Heather recognises her body as a system best characterised as an "economy of energy". In the second interview, for example, she reflects on her earlier experiences of her illness as follows:

> I think because of being forced into making choices about, in terms of energy, what I wanted to use my energy for, um I think I began to realise that there were certain things or habits in my lifestyle that drained my energy and were fruitless. And so, for example, I used to be a perfectionist, I still swing that way, but um I would want to have a perfect environment and want to be perfectly turned out and perfectly everything. Um and that meant using a lot of energy on what I now have to see as unnecessary things you know. I can pick that jacket up and put it away now or I can leave it there and read my book. So I'd rather read my book than pick up the jacket, whereas before it would bother me um so that was, in terms of um, from a psychological perspective I think the kind of thing that would drain my energy would be that. Often my, the example I often give is that on a bad day I would have a choice between cleaning the toilet or sitting outside in the sun and reading a book. Well, the toilet would need to wait. Those are the things that when you've got a little bit of energy you have to do.

Her illness, then, forces her into making choices about how to "spend" the limited amount of energy that she has most effectively. This understanding of embodiment and her condition within it, is also evident in a comment she makes regarding diet:

> Whether you've got ME or not there's enough research to indicate that if you eat, if your diet is largely made up of unprocessed food your body functions more effectively. And that's what you're looking for. You're trying to get optimum functioning out of very little.

Within this economy of energy, Heather's illness means "trying to get optimum functioning out of very little". This understanding is also apparent in her assessment of her symptoms which are measured in relation to her ability to function or not:

> The severity of my symptoms was in relation to things I couldn't do, but also in relation to things that I could do and how long it would take me to do those things. Um cause I think ja, I mean there are certain things that you can't do but there are a lot of things that you have to do or want to do and it just takes longer and so on a bad day it would take me two hours to do um something and on a very good day it would take twenty minutes. And also the success rate. For example, a pathetic example like baking a cake. On a really bad day I'd often, you know I don't bake often, but would be like knowing, reading add three eggs, but taking two out, reading add three eggs and still putting two in and that kind of thing. It's like I'd say the neurons aren't firing, the connections aren't quite being made so also not being that successful.

In relating the symptoms she experienced on a really bad day, Heather uses metaphors that again suggest an understanding of her embodied state as one lacking energy. This lack of energy is not only experienced mentally in the form of "neurons not firing" as already mentioned above, but her physical condition is also described in terms of an enervated body weighed down and exhausted:

> Um, it's quite hard explaining the symptoms to healthy people who've never had anything more than a cold because they really can't understand, they really have no idea. But I'd say on a really bad day, I'd wake up in the morning and I would feel like my head, my whole head was stuffed with cotton wool, but with the weight of lead. And that, so it's almost like the neurons weren't even firing, they would kind of fire and miss. And I'd feel, my body would feel like I had, you know if you have x-rays, and they put that, that lead apron on? That's how I felt. So, just a simple move, arm lifting like that [she demonstrates by lifting her arm slightly], you can imagine having that lead weight. That's what it felt like to move, to lift.

The lethargy that dominates this description of her symptoms on a bad day is consistent with her experience of an embodied state characterised by a depleted economy of energy. Her illness involves a process of learning to balance as efficiently as possible, the energy she spends in relation to the energy that she has and her attempts at bodily re-alignment are in accordance with this understanding. She expands on this process of learning to balance bodily output with input in the following extract:

> This illness impacts so severely on every single aspect of one's life, it's not possible to isolate an area in my life, where it hasn't touched. It influences relationships, ability to work, to produce to perform, to feel um comfortable at the end of the day, to feel that at the end of the day I have done something of value, whatever it was, even if it was just to paint a square block on the wall. Um, to have to come to terms with um ... I love hiking. I haven't been on a hike for five years because it's just physically an impossibility, I just do not, I cannot, do not have the stamina anymore. But the exhaustion that comes from doing too much exercise takes so much out, it's not worth the sacrifice. Um so having this illness means that I've had to opt out of many many things that have always been part of the way I live, um, and being able to and having to learn that I have to set my limit at way below what I know I am able to do because if I go beyond that point I put too much pressure or stress on myself and then I'll wipe out for days at a time, so it's always having to say 'no' more than having to say, being able to say 'yes'. And that, that is depressing. I'm not a couch potato by nature um but one is almost forced to be that. So in the one sense this illness has taken a lot from me, but in another sense it's, it's forced me to actually look at how I live my life. Um it's forced me to not have to do, because I have been unable to do. Um and I have been forced, instead of working for hours and hours and hours at a stretch without taking a break I have been forced to make my day into small um pieces of work that I would reward myself. Initially I used to reward myself for working for an hour at a time by sleeping for an hour. Um, but now I don't need to do that.

Although expressed in slightly different terms, this account of Heather's illness is similar to that of Janet's wherein she describes learning to avoid pushing her limits beyond her new found boundary. And like Janet, Heather's attempts to balance bodily inputs and outputs are central to her experience of ME and her efforts to reach a re-aligned state. So it would appear that Heather's efforts to overcome her illness, like those of all the participants, are more expressive of health promotion discourse than they are of biomedicine. Her conceptualisation of her body, far from being simply physical and psychological, is, furthermore, understood in terms of an economy of energy which during her illness is experienced as constraint ("...it's forced me to not have to do, because I have been unable to do") as well as capacity ("...it's forced me to actually look at how I live my life").

4.3.2.4.4 *Bodily Re-alignment*

This departure from biomedicine is also evident in Heather's account of bodily re-alignment, or the point at which she overcomes her illness. Unlike the other participants, Heather is the only one to relate this final stage of illness wherein the body and self are seen to achieve a degree of embodiment akin to their pre-illness state. Although this account of re-alignment does not follow the biomedical trajectory, it is also not in keeping with the discourse of health promotion. Instead, Heather explains her re-alignment in religious terms. This she recounts in the following extract which responds to a question asked during her second interview. The question sough information about her condition which had, up until that point, been understood to be one of progress through a gradual process of improvement.

> No, no there was a definite day where I was better. Um, so I mean I, I mentioned earlier that I did this treatment through this doctor in Johannesburg, and I really believed that that treatment which was very difficult treatment to do, um I did that for eighteen months and that definitely helped to um decrease the intensity of the symptoms and the, the um period between sort of bad times and, but I also believe God, I believe God helped me in a con[ference] ... we went overseas. We went to a conference of the Church that we go to and um I really believe that they just said

if anyone had a chronic illness that they had been suffering with, stick your hands up and together ask God to heal you. And I believe God healed me, um he said to me: 'It's finished'. And we back-packed for three months, um caught seventeen flights and what we did was absolutely difficult, and in that three months, um I had two days where I just couldn't function. It was actually while we were at Disney World and that's pretty much what most people feel after they've been, but it was that, that experience in Disney World is the last time that I felt that absolute weight and stuffy feeling I spoke about. Um so for me there was a definite end to the illness. Um the remarkable difference in me.

The movement in Heather's "illegitimate" illness experience from dys-embodiment to bodily re-alignment is terminated by what might also be viewed as "illegitimate" means. Although credit is given to biomedical treatment for improving her condition, the final movement through her illness experience is brought to a relatively abrupt close by the healing experience she describes above. So, the termination of her illness, like her efforts to understand and overcome it, are understood in ways that are seen to digress from the standard biomedical trajectory.

4.4 CONCLUSION

The illness narratives discussed in this chapter all relate endeavours, on the part of ME sufferers, to make sense of their illness experiences. In so doing, they serve as uniquely experienced accounts of bodily disruption that detail the profound impact an illness such as ME has on the lives of sufferers. The stories, which recount efforts to make sense of and minimise this impact, expose to view the personal and individual nature of the illness. The minutiae of these personal trajectories append, moreover, to epiphanies or pivotal points in the lives of the narrators which serve to individualize further these accounts of illness experience.

At the same time, illness narratives from particular social contexts draw on dominant cultural schemas

which, in the case of white South Africans tends, in the first instance, to be biomedicine wherein the medical profession reside as the authority over illness. The dominance of the biomedical discourse exists to the point where stories of illness following the biomedical trajectory might, indeed, be forecast. So, despite the individual nature of illness narratives, shared knowledge and understandings are to be anticipated and all four narratives discussed in this chapter bear witness to this dominant model of medicine in which the expectation to consult a medical practitioner in response to a biological or physiological ailment prevails. The "illegitimate" status that ME holds in relation to biomedicine does not, however, easily afford stories of illness experience that follow the restitution plot. Chronic illnesses, and especially those associated with relatively little biomedical consensus concerning aetiology, diagnosis and treatment, remain problematic in respect of medical, social and personal trajectories. The meaning and interpretations of experiences associated with such illnesses are, therefore, sought in alternative discourses. If illness cannot, for example, be located in the physical body, biomedical explanations of illness resort to the mind as the site and source of illness, as is evident in the re-constructed illness narratives discussed above. Although the certainty with which the illness is understood as a problem of the body rather than the mind varies, mind-body dualism as a frame of reference for understanding ME remains influential.

In addition to these two alternative although related explanations of illness, is a third competing discourse, namely, the health promotion discourse associated with the new public health movement. Although it might be argued that all emerge from the same "scientific" source, health promotion discourse involves a wide range of social agencies and institutions and is not, as a result, held under the reserved authority of biomedicine. This diminishing authority is reflected in the findings of this narrative analysis which suggests that biomedicine might not be the dominant frame of reference for understanding the embodied experiences of "illegitimate" illnesses such as ME. Accompanying the physical realities of the illness that exemplify the biomedical model, are explanations concerning possible causes and restorative action that have recourse to *individual behaviour* as opposed to physiological or psychological processes and

biomedical intervention. The emphasis placed on behaviour is suggestive of an interpretation that places risky lifestyles at the centre of illness explanations. The themes that subsequently emerge from the narratives relate to the health role's concerns about safeguarding the body's boundary from internal and external risks to health which are, furthermore, subject to the adoption of a lifestyle marked by bodily surveillance and risk minimisation behaviour. Such narratives are, therefore, indicative of a far more penetrating and understated, yet potent, form of power associated with the new public health movement's endeavour to regulate and control the social body.

CONCLUSION

This thesis has employed a sociological theory of embodiment in an attempt to interpret the illness experiences of four individuals suffering from the condition known as ME. Such an approach, which considers the body to be a socially constructed phenomenon, calls attention to important links that exist between the body and society. As such, it represents a fundamental departure from dominant biomedical and behavioural approaches to ME which explain and understand the condition as one imbedded in the body or mind of individual bodies respectively. In contrast to this position, it has been argued that a theory of embodiment directs attention to an emotional and meaningful state of ***being ill*** in which personal, subjective accounts of illness experience, are not only preferable to those accounts imposed on the sufferer's condition externally, but also reveal the meaningful interpretations given by the sufferer to their embodied state. In the process of assigning meaning to this embodied state, individuals draw on socially and culturally shared knowledge which, in turn, discloses valuable insight into the relationship between body, self and society.

Chapter one developed a theoretical frame of reference for understanding the body as a socially constructed phenomenon. In so doing, it provided an overview of the dominant naturalistic approach to the body which informs medical, behavioural and sociological interpretations of pain and illness. Based on an understanding of the body as a natural, pre-social entity and illness as a diseased biological state, it was shown that sociological studies adopting a medicalised view of the body are associated with what is referred to as an "outsider" perspective. Meaning from this "outsider" perspective is imposed on states of ill-health externally and in isolation from subjective, embodied experiences. As such, it was argued that the "outsider" perspective, underpinned by a medicalised view of the body, is considered inappropriate to understanding personal or "insider" accounts of illness experience.

So, in developing a framework that advances an understanding of pain and illness as embodied experiences, chapter one introduced a second, alternative approach to the body. It was indicated that in contrast to the naturalistic approach, this social constructionist approach does not accept the body as a biologically determined and constant entity. Instead, Bryan Turner's eclectic theoretical approach was used to develop an argument for a socially constructed body and, hence, socially and historically changeable phenomenon. Drawing on Foucault, it was shown that this socially constructed body absorbs and reflects its meaning from discourses or modes of knowing about, and controlling, the body. In addition, Turner's attempt to overcome dominant notions of mind-body dualism by emphasising the body's construction as embodied consciousness, provided the basis for the introduction of a phenomenological element. It was shown that this element points to the actual experience of embodiment, wherein the rational mind and the physical body are bridged by attention to bodily intention, control and action. So, in this way, it was argued that Turner's theory of the body provides a radical alternative to the dominant naturalistic approach and, in so doing, paves the way for an understanding of pain and illness as socially constructed phenomena that are, at the same time, individually experienced embodied states.

Chapter one, having identified Turner's theory of embodiment as a theoretical point of departure for the thesis's focus on the meaning and experience of pain-as-illness, turned to a second point of departure regarding the scope of focus. In keeping with an understanding of illness and health as mutually inclusive terms, it was argued that sociological attention directed towards the embodied experience of illness, necessitates attention to its "positive" opposite, health. In other words, the meanings associated with illness experience are intimately linked to meanings associated with health and, for this reason, an argument was made for an expansion of focus to incorporate dominant discourses of health in accounting for illness experiences. And identified as particularly relevant in this regard was the new public health movement's health promotion discourse.

Chapter two focussed on the condition myalgic encephalomyelitis or ME. It highlighted the "illegitimate" biomedical status held by ME which has provided fertile ground for the debate concerning its aetiology, diagnosis and treatment. It was noted, that the scientific evidence linking the condition to a causative agent or agents, which is a prerequisite for the biomedical stamp of approval as a "legitimate" condition, remains in the case of ME, elusive. This, it was indicated, serves to fuel the debate surrounding ME which is founded on the dominant naturalistic or medicalized view of the body and provides, as a result, two competing interpretations of ME. On the one hand, it was shown that ME, although lacking a precise causative agent, is associated with a number of viral infections and is consequently perceived to be an organically-based condition. On the other, and in keeping with the dominant conceptualisation of mind-body dualism, it was shown that the condition is explained as psychologically-based, or a case of it being "all in the mind". Owing to the contention and constituencies surrounding ME, the thesis opted for an understanding of "ME sufferers" as those, not suffering from ME, but suffering from the bodily experiences currently identified and named ME.

A further point of clarification regarding terminology was made concerning "pain". It was noted that the more traditional biomedical understanding of pain, as a symptom of illness, has been challenged in recent decades with reference to chronic pain (or pain that is experienced over a long period of time). This challenge has initiated a conceptualisation of pain-as-illness, rather than pain as a symptom of illness. So, in this way, it was argued that an understanding of pain-as-illness was to be employed in assessing the meaning and experience of pain in ME sufferers.

The chapter moved on to argue that the experience of pain-as-illness creates an awareness of embodiment that usually remains marginal to conscious awareness. This awareness creates, in turn, a state of dys-embodiment wherein the body is alienated from the conscious, emotional self. In this way, the division between self and body was shown to move beyond the simple mind-body duality inherent to the naturalistic

approach to the body through its acknowledgment that pain-as-illness, apart from being a physiological or psychological state, is also an emotional state. This, it was indicated, means that the state of dys-embodiment is charged with meaning; meaning that is moreover sought from shifting social, cultural and historical contexts. And this search for meaning, it was suggested, occasions a sociological interpretation of pain and illness as embodied states.

An argument was made, in closing chapter two, for the utilization of narrative accounts of illness experience as a research method, which then formed the topic for chapter three. It was indicated, more specifically, that this research method provided a suitable means of fulfilling the thesis's research aspirations since narratives hold the potential to elicit "insider" personal trajectories of illness experience, that are unattainable using the "outsider" approaches typified by medical and social trajectories of illness. In adopting the descriptive narrative research method, in particular, it was explained that the aim of the research would be to *describe* the interpretive schemas used by individuals in attempting to understand and make sense of their illness experiences. It was indicated that this descriptive narrative research method differs from the explanatory narrative research method, which aims to *explain why* illness events have occurred. In adopting the descriptive method, it was noted that the process of narrative analysis and interpretation would involve identifying aspects that were distinctive to each of the four illness narratives collected for the study, as well as aspects that could be detected as common to some of, or all, the narratives. And the aim, in short would be to report and describe what were found to be shared cultural schemas used by the participants to express and symbolise their experiences of dys-embodiment and direct their actions towards bodily re-alignment.

As a qualitative research method it was, furthermore, noted in chapter three that the findings of the descriptive narrative research undertaken for this thesis were, amongst other evaluative criteria, not intended for generalisation to a broader population. Instead, qualitative research findings are seen to have

credit in terms of "transferability", which was shown to mean the extent to which findings could be recognised by other researchers and in other situations, as accurate. It was for this reason that the presentation of the findings in chapter four remained heedful of the "thick description" advocated in the reporting of narrative analyses.

Chapter four presented the findings of the descriptive narrative research analysis. It was noted that the narratives collected and analysed represent unique and individual accounts of illness experience. As such, these personal trajectories of ME were shown to be inlayed with intimate biographical details that told first-hand stories of attempts to identify, understand, and overcome a bodily state that remains, to a large extent, illegitimate in the eyes of the medical profession and the public at large. At the same time, however, these personal trajectories were shown to represent multiple accounts of the bodily state currently named ME. As such, all four narratives were seen to testify to attempts at making sense of bodily experiences by drawing on dominant cultural schemas. It was shown, with reference to the experience of dys-embodiment, that the dominant biomedical discourse acts as a model for the response to, and diagnosis and treatment of, the experience of dys-embodiment which is to be expected amongst white middle-class South Africans. The narratives presented in chapter four suggested that even in those cases of illegitimate illnesses, such as ME, where organically based explanations and treatments were ambiguous, the biomedical model persists initially as the dominant discourse giving meaning, and direction, to the state of dys-embodiment. It was shown that, in the case of "illegitimate" illness, attempts to make sense of ME revert to, or at least make mention of, psychological explanations in keeping with the understanding of mind-body dualism inherent to biomedicine.

Apart from biomedicine and mind-body duality, additional themes were shown to be evident in analysing the illness narratives. Lillian's illness narrative, for example, related stories of efforts to monitor and eliminate toxins or "free radicals" from the body that accumulate as a result of an immune system rendered

ineffective by life in modern society. This perceived impact of society on the body prompted Lillian to assume responsibility for ridding her body of "free radicals" which involved vigilant attention to diet and exercise, a lifestyle marked by abstention and moderation, as well as accepting advice from a range of "authorities" over and above that given by medical professionals. Colleen, in turn, identified risky behaviour, which involved ceasing her regular exercise at a point in her life marked by externally imposed stress, as the "disease" that ultimately caused the onset of ME. Her efforts to overcome her dys-embodied state included exercise and "paying attention" to her body. In so doing, she illustrated a re-positioning of the self within a body bounded by an immune system. The self, from this perspective, embarks upon behaviour aimed at protecting and "building-up" the immune system, but ultimately does so in response to an all-knowing body. Janet's narrative related similar themes in which the need to "listen to her body" played a major role in her attempts to re-align body with self. In her case, efforts were also made initially to identify her bodily boundary in response to the external threat posed by AIDS in her place of work. Efforts were then made to maintain a balance between bodily inputs and outputs within that "limit". Risk minimisation behaviour aimed at reducing external and internal threats to her health included attention to fitness and avoiding contact with those individuals perceived to be a threat to her vulnerable immune system. Heather's illness narrative, in similar fashion, introduced themes that suggested an understanding of her illness unrelated to those available through biomedical and mind-body dualism discourses. Her understanding that a perceived "natural" environment is benign and preferable to an "unnatural" environment, led her to identify the fast pace of contemporary urban life and crime as external risks to her embodied state. The health role she adopted in response to her experience of ME afforded her a view of her body as an economy of energy which required constant monitoring, "tuning-in" to her body, and behaviour aimed at protecting and reserving the little energy at her disposal.

So, in the process of giving meaning to, and overcoming, the embodied experiences associated with ME, the illness narratives documented in chapter four were all seen to bear witness to the employment of a

further discourse. In contrast to Arthur Frank's (1995: 83) argument that the biomedically based restitution narrative "...crowds out other stories" of illness, then, the findings of this thesis have indicated that stories about ME as an illness were, without exception, inclusive of stories about health; and feeding the understanding of health evident above, was health promotion discourse. Despite the dominance of biomedicine, then, it was suggested that health promotion discourse provides an equally influential frame of reference for the interpretation of illness as an embodied experience. And, according to this discourse, it was shown that individual ***behaviour***, as opposed to physiological or psychological processes, is the key factor used to explain and understand illness experiences.

The analysis of all four illness narratives, then, has pointed to a concern about the social environment which is perceived to be an external threat to the embodied self. The impact of life in "modern" society where stress, crime, AIDS and an array of "unnatural" contaminants are seen to threaten the body was fundamental to the telling of the illness narratives described in chapter four. As such, the understanding of illness portrayed in them extended beyond the biological, physiological and psychological explanations associated with biomedical discourse. Efforts to re-align the self with the body also moved beyond the dominant biomedical discourse as was evident in the participants' acceptance of responsibility, which involved modifying and changing "risky" ***behaviour***, as opposed to following a biomedically prescribed treatment.

So, what is being implied from the findings above is that, apart from being lodged in individual bodies, these stories of illness have made an important link between illness and the social context in which it was experienced. All four participants were seen to express, in similar themes and varying degrees, anxiety about protecting the body from external as well as internal threats to their bodies. In adopting the health role as a moral responsibility and modifying their behaviour in response to the experience of ME it would appear, then, as Seidman (cited in Lupton, 1995: 75) observes, that the threatening social environment

"...can be controlled by individuals imposing upon themselves regimes of discipline and healthful living".

It is possible to surmise that similar accounts of illness experience, wherein anxiety about the external environment was expressed, might have been collected from those individuals suffering from earlier outbreaks of ME (cf. 2.2.2.1); particularly those young female nurses and military personnel working in what might be perceived as "threatening" social environments over which they exercised little control. Without evidence, however, this remains simply a matter of conjecture. At the same time, it is possible to surmise that similar fears about a social environment perceived to be threatening might be identified as a theme in narratives collected from individuals suffering from other illnesses as well as from individuals perceived to be "healthy". This possibility could be expected given the intensified effort of public health programmes in Western capitalist societies since the 1970s to educate the public about risks to health. This intensified effort has, at the same time, extended surveillance medicine as a form of "empowerment and subjugation" (Gastaldo, 1997: 130). And, in contributing to the regulation and control of the individual as well as social body, surveillance medicine can be seen to act as a subtle and diffuse, yet forceful, form of power. Without an understanding of the body as a socially constructed phenomenon, with the capacity to absorb and reflect meaning, such insight and its investigation would, however, remain imperceptible.

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