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STIGMA AND LEGITIMATION IN CHRONIC FATIGUE SYNDROME: THE ROLE OF SOCIAL LOCATION

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July 1997

A Thesis Submitted to the Faculty of Graduate Studies and Research
In Partial Fulfillment of the Requirements
of the Degree of Ph.D

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PREFACE

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Candidates have the option of including, as part of the thesis, the text of a paper(s) submitted or to be submitted for publication, or the clearly-duplicated text of a published paper(s). These texts must be bound as an integral part of the thesis.

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ACKNOWLEDGEMENTS

Although this thesis represents the culmination of many years of solitary work, it would not have been possible without the participation or support and encouragement of several people. I am deeply indebted to Professor James Robbins and Professor Prudence Rains who co-directed this thesis. Discussions with Professor Robbins were instrumental in guiding me from the conceptual stage to the end of the data gathering. He taught me much about methodology and much that was invaluable in managing and coordinating a large and complex project. Professor Rains' generosity of spirit deserves special mention. She consented to become a co-director of this thesis at the writing stage. Her timely and thoughtful comments were delivered with a light touch and her encouragement sustained my motivation to continue through to completion. She taught me how to focus on one set of voices at a time in a study that explores multiple perspectives. The current presentation owes much to her suggestions and comments on drafts of all chapters. Other members of my dissertation committee, Professors James Robbins, Michael Smith and Laurence Kirmayer gave me critical comments on early drafts of specific chapters or on papers delivered at the Learned Societies and the American Sociological Association which later formed the core of chapters. Professors Robbins and Kirmayer kindly allowed me access to people with chronic fatigue syndrome (CFS) who formed a subset of their sample from a larger project on Somatic Syndromes. They also agreed that I could use a modified version of their interview schedule from that project.

My profound appreciation goes to all the respondents who agreed to be interviewed. People with chronic fatigue syndrome (CFS) made considerable efforts to accommodate me even when they were not feeling well on the day scheduled for the interviews. Several suggested other respondents, provided me with literature, personal

journals chronicling their illness experiences, medical and disability evaluations, and various position papers on CFS from organizations to which they belonged. Family members and friends, insurers, and doctors took time out of busy schedules to meet with me or to fit me in at the end of a long work day or at lunchtime. Their openness was important to drawing an accurate picture of the social impact of CFS.

My children Karen and Julie and their father Richard have supported my efforts with grace and understanding over the many years it has taken to complete this work. Special thanks go to my mother for her quiet but unfailing encouragement. My brother Roy has been a patient listener and a wise counselor during those periods when meaning and order in the data seemed frustratingly elusive. He and his wife Veronica generously gave me a home away from home for five weeks while I was conducting interviews in Toronto.

I would also like to thank Ron Gravel who provided statistical consultation on calculating the costs of CFS to insurers and who allowed me to use the sectorial classification for the occupations of claimants which he had developed for another project. Finally, this research was supported in part by the National Health Research and Development Program through a National Health Fellowship that was awarded to me (grant number 6605-3682-47).

STIGMA AND LEGITIMATION IN CHRONIC FATIGUE SYNDROME: THE ROLE OF SOCIAL LOCATION

ABSTRACT

Chronic fatigue syndrome (CFS) is an illness of unknown origin. Although its reality and nature remain in dispute, people in crucial social roles have taken positions that stigmatize or legitimize the condition. And most sufferers remain convinced that CFS is a real, physical illness. This study examined stigma and legitimation in CFS through semi-structured interviews with doctors (N=15), insurers (N=16), significant others (N=23), and sufferers (N=43). The findings confirm that CFS is stigmatized by characterizing it as a psychological disorder or a form of malingering. But they also show that the duration of the illness and associated disability are sources of stigma not previously identified with CFS. Furthermore, in the absence of biomedical findings, social judgments about sufferers' credibility became a major factor in legitimizing the illness.

By studying stigmatization and legitimation together, it became possible to identify how shifts occurred from one position to the other. By studying doctors, insurers, and significant others, it became evident that five common elements across their different social locations were influencing their views about the illness and its effect on their personal and professional lives or occupational contexts. In turn, these perspectives and effects shaped their reactions to sufferers.

Individual and social factors were found to be implicated in sufferers' illness convictions. On a personal level, persistent or recurrent severe somatic symptoms, functional deterioration, and self evaluations led sufferers to conclude they were physically sick. At a social level, these beliefs were sustained by intermittent reinforcement from sympathetic doctors, support group members, and selected medical literature. Finally this study showed the personal and social costs associated with both stigmatizing and legitimizing CFS.

LE STIGMA ET LA LÉGITIMATION DU SYNDROME DE FATIGUE CHRONIQUE: LE RÔLE DE L'ESPACE SOCIAL

RÉSUMÉ

Le syndrome de fatigue chronique (SFC) est une maladie dont les origines demeurent inconnues. Alors que la nature et même l'existence de la maladie sont disputées, des personnes occupant des rôles sociaux clés ont adopté des positions qui contribuent à stigmatiser ou à légitimer le SFC. Cependant, la majorité des personnes qui souffrent du SFC sont convaincues qu'il s'agit d'une maladie réelle et physique. Cette étude se penche sur la stigmatisation et la légitimation du SFC, par la biais d'entrevues semi-structurées menées avec des médecins (N=15), des assureurs (N=16), les souffrants de la maladie (N= 43), et leurs proches (N=23). Les résultats confirment que le SFC est stigmatisé par le fait qu'il est tantôt caracterisé comme un trouble psychique, tantôt comme un moyen de feindre une maladie. D'autre part, il est montré que la durée de la maladie ainsi que l'incapacité qui en découle, sont des sources de stigmatisation qui n'étaient pas associées avec le SFC auparavant. De plus, en l'absence de conclusions biomédicales, le jugement social porté sur la crédibilité des souffrants devient un facteur important, par rapport à la légitimation de la maladie.

En étudiant la stigmatisation et la légitimation ensemble, il a été possible d'identifier de quelle manière des glissements s'effectuent, d'une position à l'autre. L'étude des médicins, des assureurs, et des personnes proches, a démontré que leurs perceptions de la maladie et ses effets sur leurs vies privées et professionelles sont marqués par cinq éléments communs aux divers espaces sociaux. En outre, ces perspectives influencent leurs réactions vis-à-vis les souffrants.

Des facteurs individuels et sociaux se sont avérés importants pour que le souffrant se dise atteint d'une maladie. Sur le plan personnel, des symptômes somatiques graves

persistants ou récidivistes, la détérioration fonctionelle et l'auto-évaluation ont amené les souffrants à déduire qu'ils étaient physiquement malades. Sur le plan social, ces croyances ont été appuyées par des renforcements intermittents de la part de medécins sympatisants, de groupe de soutien et par la documentation médicale sélective. Enfin, cette étude a montré les coûts personnels et sociaux associées avec la stigmatisation et la légitimation du SFC.

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INTRODUCTION

The illness known as chronic fatigue syndrome (CFS) is largely invisible to the public eye, to the clinical gaze, and even to technological aids that extend the physician's vision into the interior world of the body. In fact, stereotypes of people with CFS as malingerers or psychologically disturbed are often based on the healthy appearance of many sufferers and lack of specific biomedical findings (Ware 1992). But cultural notions of how sick people should appear and the authority of objective findings alone cannot explain why different people may stigmatize or legitimize the same sufferer. By examining societal reactions to CFS and sufferers' illness experience, this study shows the role of social location in stigmatizing and legitimizing the condition.

Like many people, I first heard of CFS in the late 1980s through the media. A close friend's self diagnosis of CFS and a relative's medical diagnosis of chronic Epstein Barr virus, as the illness was then known, did little to pique my interest. They lived in distant countries. Moreover, neither gave the impression of being gravely ill. My friend, a self employed professional, continued working although at a reduced pace. My relative was granted paid sick leave. For both, daily life continued with apparently minimum alterations. My familiarity with these two people gave me no reason to believe they were not sick. As a nursing professor at the time, I had seen many sick people in tertiary care hospitals but none with a diagnosis of CFS. Beyond thinking that the illness was not serious enough to warrant hospitalization, I had formed no opinion of it.

CFS was next brought to my attention in late 1990 through a reading course on medically unexplained illnesses with Professor James Robbins who had agreed to supervise my thesis. At this time, the literature on CFS was firmly anchored in the medical domain. Although several articles briefly mentioned social difficulties that sufferers

experienced, they revealed more about medical professionals' struggles to decide on the reality, nature, and management of the illness. By then however, more textured televised reports were showing sufferers who felt that almost no aspect of their lives had been left untouched by the illness. In addition to dealing with debilitating and unexplained symptoms, many of these sufferers had encountered disbelief from doctors, insurers, family and friends. This loss of support and stigmatization from people in crucial social systems frequently led to despair and even thoughts of suicide. Under these circumstances, supportive others took on a heightened importance.

Both the medical literature and sufferers' accounts indicated that strong reactions to the illness were common. On the one hand, most sufferers insisted that they had a physical illness despite the lack of laboratory corroboration. On the other, medical opinion on the subject was divided. Doctors variously believed that CFS was organic, psychological, or psychosomatic. Some doctors could not decide while others completely dismissed the illness. My own view was that the evidence did not clearly support any of the attributions that had been put forward. This stance of suspended judgment was unproblematic for someone detached from the situation. But I could appreciate that sufferers, doctors, insurers, and families needed some kind of working hypothesis about the nature of the illness for practical, psychological, and social reasons. The question was: what were these hypotheses based on when so little was known about the illness? The illness and surrounding debates raised other questions. For example: What was it like for sufferers to live with a contested illness? What was its impact on their lives? How were doctors, insurers, and family members affected by having regular contacts with sufferers? How did they define the illness? Did their definitions of the illness and its impact on them shape their reactions to sufferers? With these questions in mind, a study began to take shape.

Two theoretical positions informed the design of the study. Freidson (1970) had suggested that studying control agencies which people move through during their illness career was both analytically fruitful and sobering: "...focus on the agents and agencies

rather than on their subjects has the virtue of continously reminding us that the process of "treatment" is a process of control that *always* rests upon a societal reaction-*always* on the imputation or diagnosis of deviance and only sometimes on "actual" deviance" (p. 243 italics in the original). A complementary stance emphasizes sufferers' illness experience, that is, the experience of living with and in spite of illness (Conrad 1987). Illness experience includes: "...the meaning of illness, the social organization of the sufferer's world, and the strategies used in adaptation...the way people feel the disease has changed them in their own and others' eyes" (Conrad 1987:5). These two positions suggested a study combining the perspectives of sufferers with that of people in relevant social systems. The resulting study was based on a total of ninety seven semi-structured interviews that included CFS sufferers, their relatives or friends, doctors, and insurers.

In early interviews, sufferers repeatedly said words to the effect: "people who knew me before I was ill, who knew the kind of person I am, could see I was ill, they believed me." But sufferers also made it clear that they were not believed by all relatives, friends, or regular doctors. Why did some people believe that sufferers were ill while others did not? What observations led others to evaluate that illness was present or absent? What was it about knowing sufferers, and knowing them in different contexts that shaped reactions? These early interviews led to a structure for organizing and analyzing the data on societal reactions according to elements in social location. Social locations shape world views and missions; histories and relations with sufferers; the nature of the illness' impact; the range of responses to manage the impact; and social locations allow differential access to observing sufferers.

The first chapter reviews the major medical issues surrounding CFS in order to understand how these issues might shape others' reactions to sufferers as well as sufferers' illness experience. An early review had confirmed the relevance of the broad questions guiding the study. These questions are presented at the end of the chapter. The review has

been updated to the end of 1996 to see whether earlier issues have been refined, resolved or remained the same.

Chapter two describes the method of data collection and analysis. I discuss the difficulties in recruiting a sample of people who have an illness that is both stigmatized and debilitating. The samples of doctors and insurers depended largely on sufferers' referrals, while the sample of family and friends required both sufferers' referrals and their permission to approach these people. Most sufferers suggested family or friends and doctors who were more or less sympathetic to them although they knew that I was looking for a range of responses. Doctors that sufferers had perceived as unsympathetic, largely declined to participate by refusing to return calls that followed a letter requesting their co-operation. As a result, there is a selection bias in the sample of doctors and close intimates, although enough of a range was obtained to suggest how CFS is stigmatized and how it is legitimized.

The three data chapters on doctors, insurers and family members follow a similar structure. I present the bases on which definitions of the problem are constructed, the impact of dealing with sufferers and ways of managing the impact. I analyze whether doctors', insurers' and family members' definitions and treatment of sufferers are stigmatizing or legitimizing, paying close attention to variables associated with social location. I begin with doctors because of their cultural role in defining what constitutes illness. I explore 1) doctors' struggles to come to a personal position on the reality and nature of the illness 2) how they deal with diagnosing an illness with shifting and unsatisfactory medical and personal definitions 3) how they explain the diagnosis to sufferers 4) the impact of giving a diagnosis they are uncertain about 5) the effect of caring for people who do not respond to treatment and 6) and how they decide to continue to treat sufferers.

Chapter four deals with insurers' reactions. They are concerned with determining vocational disability due to CFS and the associated costs. I explore the routine handling of

claims, the effectiveness of this process in dealing with CFS claims, strategy changes that have evolved with increased knowledge about the illness and rising numbers of claims. The fifth chapter presents families' or close friends' experiences and reactions. I examine the instrumental and emotional impact of being close to someone with CFS. I also explore how intimate knowledge of sufferers may be linked to stigmatization or legitimation of CFS.

Chapter six and seven detail the experiences of sufferers. Chapter six presents sufferers' accounts of their physical symptoms and disability as well as their experiences of social acceptance and rejection. Chapter seven outlines how sufferers manage the physical and social consequences of having CFS. It emphasizes their efforts to remove social stigma from the illness and its sufferers, ways to legitimize their experiences, and how they adjust to living with the illness. Taken together, these accounts show broad themes and variations in the biological and social course of an illness.

The final chapter draws together the findings and shows how different ways of legitimizing or stigmatizing CFS may be related to elements in different social locations. It also shows the costs of both stigmatizing and legitimizing CFS. I highlight the unique contributions of the study to the literature on legitimizing and stigmatizing a contested illness. These contributions are placed in context by addressing the study's limitations. Finally, I outline the research directions suggested by the study.

CHAPTER 1

NAMING AND FRAMING CFS: MEDICAL DEBATES AND SUFFERERS' ILLNESS EXPERIENCES

Despite fifteen years of extensive medical investigations, many aspects of CFS remain unknown or contested. Lane and associates' (1991) comment is still true six years after it was made: CFS has yet to meet medicine's traditional validators of a new illness- "...a defined cause, a unique clinical presentation, a known prognosis, and a predictable response to therapy" (Lane et al. 1991:342). The contested status of CFS highlights issues which Brown (1995) refers to as "naming and framing". Naming involves the processes of diagnosing and fixing a label. Framing refers to questions about the nature of an illness and its acceptance as a biomedical entity (Brown 1995). Is the illness physical or psychological, acute or chronic, minor or serious, disabling or life threatening? Framing takes into account who defines the illness, for what purposes, and with what effects (Brown 1995). This chapter shows how biomedical debates about the naming and framing of CFS bear directly on sufferers' illness experiences and societal reactions.

I use the general notions of naming and framing to organize a review of the biomedical debates about CFS. Following a brief overview of the condition and its emergence, I discuss issues that have arisen from labeling and diagnosing CFS. I then consider how etiological models and treatment frame the illness. Finally I review a much less studied aspect of CFS -sufferers' illness experience. These studies mark a beginning counterpoint to biomedicine's dominance over knowledge about CFS. The chapter ends with the specific questions derived from the review and which guided the study.

Overview and Emergence of CFS

The earliest estimates of CFS among medically treated samples showed minimum prevalence rates of 37 per 100,000 in Australia (Lloyd et al 1990) and 2.0 to 7 3 per 100,000 in the United States (Gunn et al. 1993). More recently, telephone and postal surveys of randomly chosen community samples in the United States and Britain have yielded CFS prevalence rates 0.2% and 0.56% respectively (Jason et al. 1995; Lawrie and Pelosi 1995). Most studies report a preponderance of white women in their twenties through to middle age but CFS has also been reported in children (see for example Bell et al. 1994; Pelcovitz et al. 1995; Walford et al. 1993). Ratios of females to males range from a high of 4:1 (Holmes et al. 1987; Gunn et al. 1993; Bombardier and Buchwald 1995; Schmaling et al. 1996) to lows of 1.3:1 (Lloyd et al. 1990) with many studies reporting ratios in between. A few studies have included small numbers of Blacks and Hispanics (Gold et al. 1990; Komaroff & Buchwald 1991) and the illness has been reported in Japan (Masuda et al. 1994).

Initial reports suggested that CFS afflicted people in the higher socioeconomic classes, hence the pejorative label "the yuppie flu". People in these groups may be diagnosed more frequently because they have better access to physicians, lower tolerance of disability (Cooke 1991) or the psychological and material resources to withstand repeated disbelief from doctors (Brickman and Fins 1993). Indeed, later studies have shown a wider socioeconomic distribution (Lloyd et al. 1990; Gunn et al. 1993). The gender distribution has also drawn considerable comment. Komaroff (1993), for example, has noted that some observers view women's overrepresentation as suspicious and probably an indication of psychiatric disorder. However, the high percentage of women may simply reflect the consistent finding that women seek medical care more often than men. Even if there is a true gender difference, many organic illnesses disproportionately

affect women (Komaroff 1993). The female preponderance has also been explained as an artifact of tertiary care settings in which most CFS studies have been conducted (Hickie et al. 1992). The sociodemographic data suggest that CFS affects people in their prime productive and reproductive years and impacts on major adult roles.

Chronic fatigue syndrome (CFS) is characterized by prolonged, debilitating fatigue of unknown origin. Several other symptoms and a few simple physical findings usually accompany the fatigue. Many of the symptoms are consistent with both physical and psychiatric illnesses. Laboratory tests are of little help in diagnosis or in clarifying the nature of the illness since results are either normal or non specific. As a result, CFS is diagnosed by excluding all other plausible explanations. With no known cause and few, if any, laboratory findings to explain its symptoms, CFS may be considered an "illness without identifiable disease".

When CFS came to light in the early to mid 1980s, it was believed to be a viral illness. Typically, patients reported persistent or relapsing fatigue and other non specific symptoms of varying severity following a flu-like illness. In many cases, these symptoms were attributed to recurrent or chronic activation of the Epstein-Barr virus (EBV). This virus causes most cases of acute infectious mononucleosis and is usually cleared from the body within a few weeks. But clinicians had suspected that it could be reactivated or exist in a chronic form. These suspicions were reinforced by a study of people with a prolonged illness whose laboratory results suggested persistent EBV infection although their symptoms were atypical of infectious mononucleosis (Tobi et al. 1982). Two later studies in the mid 1980s also found immunological evidence specific to the EBV among patients reporting a fatiguing illness that had lasted for a year or more (Straus et al. 1985; Jones et al. 1985).

Shortly after these results were published, commercial laboratories in the United States began to advertise tests for the EB virus and sufferers flocked to these services (Holmes et al. 1988). A similar demand for EBV testing was observed in Canada during

the years 1983 to 1989 (McLaughlin 1991). In this period, increased demands for EBV testing at a provincial government laboratory in Ontario coincided with media reports about the chronic Epstein Barr virus (CEBV). More interesting, was the fact that the percentage of significant results rose in the years 1983 to 1988, and then returned to levels seen prior to 1983. McLaughlin (1991) suggested that some event occurred in the province of Ontario between 1983 to 1988, but the data did not allow for more specific conclusions. It is possible however, that these findings reflected the gradual satisfaction of a pent-up demand for a label, as people who had been suffering from an unexplained illness became aware of CEBV.

Within a few years the EBV etiology was thrown in doubt by findings from case-control, prospective, and treatment studies. Case control studies showed: no significant difference in EBV antibody titers between sufferers and controls matched for age and sex (Buchwald et al. 1987; Gold et al. 1990); no association between changes in EBV titers and clinical status (Gold et al. 1990) and higher antibody titers among sufferers, not only to the EBV, but to a host of other viruses (Holmes et al. 1987; Youssef et al. 1988). The EBV etiology was further undermined by the findings of a prospective study in which several subjects developed a chronic fatiguing illness following infection with the Coxsackie virus (Calder et al. 1987). And a randomized double blind placebo controlled study showed that antiviral drug treatment for the EBV was no more effective than a placebo in relieving symptoms (Straus et al. 1988). Taken together, studies using different methodologies suggested that the EBV was not the primary etiological agent.

With the EBV etiology discredited, research and discussions on CFS began in earnest. Over the next ten years, the CFS literature expanded exponentially. The Medline data base which lists most studies of CFS, registered sixty eight articles between 1985 and 1989[1]. By 1996, as this study was being completed, there were almost seven hundred

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[1]This list included articles using the label chronic Epstein Barr virus because the name chronic fatigue syndrome was not coined until 1988. However, many

articles on the subject. These studies, opinions, reviews, letters, clinical articles, editorials, dissertations, and proceedings of several major conferences, examined the etiology, definition, label, course, management, epidemiology, and history of the illness. A small but growing number of studies focused on sufferers' illness experiences and the social consequences of CFS. Two striking aspects of this vast literature are the number of review articles and the number of letters from sufferers that have appeared in medical journals. To date, one hundred and fifty review articles are registered on Medline. Recent reviews are more highly specialized than the broad based overviews of the past. Review articles attest to the many efforts to synthesize and grasp the complex and rapidly increasing volume of research on CFS. Letters written by sufferers to medical journals came from both physicians with the illness and others with no obvious medical connection. But regardless of their affiliation, the voice of sufferers in medical journals is relatively uncommon and suggests political acumen as much as familiarity with the medical literature.

Naming CFS: The CDC Case Definition

The rising numbers of diagnoses in the mid 1980s were being made on poorly defined criteria. (Holmes et al. 1988). The Centers for Disease Control (CDC) in Atlanta began receiving numerous inquiries from patients diagnosed with the illness and from physicians faced with potential cases (Holmes et al. 1988:387). The CDC responded by setting up a working group of clinicians and researchers which came to a consensus case definition in March 1988 (Holmes et al. 1988:387).

The CDC case definition was expected to provide a context for interpreting past and future investigations. It was intentionally restrictive. The aim was to reduce heterogeneity of research samples and allow comparability of study results. It was not intended for

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reports of chronic Epstein Barr were cross referenced retrospectively as cases of CFS.

immediate clinical use (Schluederberg et al. 1992) and, as such, it was not a direct response to the need for diagnostic guidelines. To qualify as cases, patients had to fulfill two major criteria and eight of eleven symptom criteria or two objective and six minor symptom criteria (Holmes et al. 1988).

The two major criteria are:

1) Persistent or relapsing fatigue or easy fatigability that does not resolve with bed rest and is severe enough to reduce average daily activity by 50%
2) Other chronic conditions have been satisfactorily excluded, including pre-existing psychiatric diseases.

The eleven minor criteria which should persist or recur for 6 months are:

1) Mild fever (37.5°C-38.6°C) oral if documented by patient, or chills
2) Sore throat 3) Lymph node pain in anterior or posterior cervical or axillary chains 4) Unexplained generalized muscle weakness 5) Muscle discomfort, myalgia 6) Prolonged (24 hrs..) generalized fatigue following previously tolerable levels of exercise 7) New, generalized headaches 8) Migratory noninflammatory arthralgia
9) Neuropsychological symptoms a) photophobia b) transient visual scotomata c) forgetfulness d) excessive irritability e) confusion f) difficulty thinking g) inability to concentrate h) depression 10) Sleep disturbance 11) Patient's description of initial onset of symptoms as acute or subacute

The physical criteria should be documented by a physician, on at least two occasions, at least one month apart. They are:

1) Low grade fever (37.5°C-38.6°C oral or 37.8°C
2) Nonexudative pharyngitis
3) Palpable or tender anterior or posterior cervical or axillary lymph nodes (< 2cm in diameter)
(Holmes et al. 1988).

Debates about the case definition began almost immediately. Four months after it was published, Bell and Bell (1988) offered a close, but not identical, definition of their own for serious consideration[2]. As investigators tried to work with the CDC case

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[2] Bell & Bell (1988) offered their definition in a letter to Annals of Internal Medicine. At the time the definition did not seem to gain adherents. However, when the CDC revised its definition in 1994, some elements seem quite close to what Bell had been advocating in 1988.

definition, flaws in both its major and minor criteria became apparent. Critics found the definition conceptually inadequate and lacking in discriminatory power.

Critiques of the major criteria

The first major criterion for inclusion-*fatigue severe enough to reduce average daily activity by 50%*- raised questions of how to measure severity. Some critics charged that sufferers would have had to predict the development of CFS and estimate their premorbid level of activity, so that they could accurately determine whether they had fallen below fifty percent of this level (Barofsky & Legro 1991). Others detected a socioeconomic bias in this criterion, arguing that only high income groups could afford to reduce their activity by 50% and seek expensive medical work-ups for social dysfunction (Armon & Kurland 1991). Some tried to tackle the problem by developing new scales to measure fatigue severity (Schwartz et al. 1993; Fisk et al. 1994), while others recommended the use of existing scales (Barofsky & Legro 1991).

The nature of fatigue also had to be clarified. Fatigue is one of the most common symptoms in physical and psychological illnesses (Wessely & Powell 1989). It is both a mental and physical state. It is a major symptom in patient populations (Kroenke et al. 1988) and in British and North American community surveys (Wessely & Powell 1989). Persistent fatigue is generally attributed to central or peripheral sources which roughly means to psychological or physical illnesses. "The peripheral causes... includ[e] such illnesses as myasthenia gravis...central disorders...are assumed to include deficits of organization, integration and motivation" (Wessely & Powell 1989: 941).

To clarify the nature of fatigue Wessely and Powell (1989) developed a 13 item scale reflecting physical and mental fatigue which they administered to CFS patients and two control groups. One control group had neuromuscular disorders (peripheral fatigue), while the other had affective disorders (central fatigue). Physical fatigue was common in all

groups. However, mental fatigue was equally common in patients with CFS and affective disorders but occurred in patients with a neuromuscular condition only if they had a concurrent psychiatric disorder. The findings suggested that fatigue in CFS is of central origin and that there is considerable overlap between CFS and affective disorders (Wessely & Powell 1989).

The second major exclusion criterion *-other chronic conditions have been satisfactorily excluded, including pre-existing psychiatric diseases-* also came under fire. The consensus group had conceptualized CFS as an organic condition with psychiatric features. As a result, psychiatric disorders were part of the exclusion criteria, but neuropsychological symptoms, found in many psychiatric disorders, became part of the minor inclusion criteria. Shafran (1991) points out an unintended outcome of these inconsistencies: some investigators have invoked the second major criteria to exclude patients with major depression or other psychiatric conditions from CFS samples (Manu et al. 1988); while others have used the minor criteria to include the same types of patients in their sample (Kreusi et al. 1989). When psychiatric disorders were rigorously excluded in the study by Manu and colleagues (1988) only four percent of the sample fulfilled the criteria, which suggested that CFS is a rare condition. But in a pithy assessment, Sharpe (1992) notes that strict exclusion appears ..."to 'miss the point' clinically." (p. 207).

The question of whether psychiatric disorders should be excluded was also put on the agenda by several studies showing a high prevalence of psychiatric disorder among patients who otherwise met the criteria for CFS. Using different diagnostic tools, these studies showed prevalence rates of psychiatric disorders in the range of 45% (Hickie et al. 1990) to 75% (Kreusi et al. 1989) among CFS patients. These high rates not only raised questions about the role of psychiatric disorders in CFS, they also highlighted a major problem: CFS and several psychiatric disorders, notably depression, anxiety, and somatization share a number of symptoms in common. This overlap has prompted some investigators to advise caution in interpreting the results of scales to diagnose psychiatric

pathology among CFS patients (Millon 1989). In sum, the exclusion of psychiatric disorders has been criticized for three reasons- neuropsychological symptoms can negate the exclusion criteria and confound case finding; the low prevalence of cases when the exclusion criteria are strictly applied does not conform to clinical reality; and the high prevalence of psychiatric disorders in CFS patients suggests that it is premature to exclude disorders that may be important as causes, effects, or a part of the syndrome.

Critiques of the Minor Criteria

One of the most important questions about the minor criteria is whether they should be included on the basis of prevalence or discriminatory power. Lane and colleagues (1989; 1990) investigated the sensitivities, frequencies, and specificities of the various minor criteria. They found the specificities of myalgia, muscle weakness, sleep disorders, headaches, post exercise fatigue, and neuropsychological symptoms to be so low, that they recommended substantial revisions to the CDC criteria. The low discriminatory power of the criteria has also been affirmed by Komaroff and Gelger (1989) who found that the criteria failed to efficiently identify a subgroup of patients, who had both debilitating fatigue for at least six months and features that suggested an organic illness.

The Oxford and Australian Definitions

In the wake of these critiques, two other case definitions were proposed by working groups in Australia (Lloyd et al. 1990) and in Britain (Sharpe et al. 1991). These definitions may be viewed as simplifying the CDC's definition as well as addressing some of its problems. Lloyd and colleagues (1990) did not exclude psychiatric disorders. However, they considered prolonged debilitating fatigue brought on by minor exertion and neuropsychological symptoms essential for inclusion. Both are optional in the CDC case

definition. By comparison, Sharpe et al. (1991) specified the psychiatric disorders that should be excluded and reduced the minor symptoms to myalgias and the neuropsychological symptoms of mood disorders. The British case definition, later known as the Oxford criteria or the Oxford case definition, also differed from the CDC in the way it measured fatigue severity. Instead of measuring fatigue severity by functioning at 50% or less of previous activity, the Oxford criteria proposed that fatigue should be present 50% of the time. The Oxford criteria were fewer, but their proposed level of specificity were likely to prove more difficult to operationalize.

As the critiques mounted, a working group at the National Institute of Health, re-evaluated the CDC criteria and recommended changes in line with the simplifications proposed by Sharpe et al. (1991) without the complex specifications (Schluederberg et al. 1992). By December 1994, a new working group at the CDC proposed a revised case definition (Fukuda et al. 1994). This group included members of the British and Australian teams that had previously proposed their own definition. The group explicitly designated the new definition as provisional and presented remaining points of dissent. The major changes included: eliminating the requirement of average daily activity below 50%, specifying exclusionary conditions that may confound diagnosis, lifting the exclusion on anxiety and depressive disorders but treating patients with these types of disorders as possibly representing subgroups of CFS, and dropping all physical signs because they had not been reliably documented. Their inclusion was therefore considered questionnable. Cooke (1991) has suggested that physical signs were probably the main features that distinguished CFS from depression. The consequences of these revisions will no doubt surface in the future.

The global consensus was timely. A few studies have underlined the problems of multiple case definitions. One study applied the three case definitions to the same sample of 805 subjects in two clinics in the United States. They found that 61% met the CDC case definition, 55% met the Oxford case definition and 56% met the Australian case definition

(Bates et al. 1994). Although these differences were not statistically significant, they could be accentuated by making small changes in definitions. For example, if the post-exertional fatigue requirement of the Australian criteria was disregarded, seventy percent of patients would meet the Australian criteria instead of fifty six percent. A more recent study in the Netherlands found that while all subjects met the Oxford criteria, only 20.5% fulfilled the CDC criteria (Swanink et al. 1995).

Labeling Chronic Fatigue Syndrome

When the original CDC case definition was published in 1988, the working group proposed the name chronic fatigue syndrome. But, several investigators have suggested that CFS is merely a new name for an old illness (Abbey & Garfinkel 1991; Wessely 1990, 1991; Greenberg 1990; Straus 1991; Salit et al. 1996). Previous protracted fatiguing illnesses have been variously called neurasthenia, chronic brucellosis, DaCosta's syndrome, chronic mononucleosis or chronic Epstein Barr virus syndrome (CEBV), post-viral fatigue, post-infectious neuromyasthenia (Straus 1991), Icelandic disease and Royal Free disease. In Britain, CFS is commonly known as acute infective encephalomyelitis, benign myalgic encephalomyelitis (BME) or simply myalgic encephalomyelitis (ME).

Several names refer to locations in which outbreaks of fatiguing illnesses were reported. For example, Royal Free disease was named after the London hospital where 292 staff members were affected (Shepherd 1989). But, it is difficult to determine whether these outbreaks should be considered cases of CFS, since past clusters of fatiguing illnesses rarely had a case definition and most lacked an accepted epidemiological or clinical definition (Levine 1994). In outbreaks where there were case definitions, few of those afflicted would meet current CFS criteria (Levine 1994).[8]

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[8] A history and discussion of epidemics of fatiguing illnesses can be found in the 1994 Clinical Infectious Diseases 18 (suppl.1): s1-59 and also by Jenkins,

Other labels such as brucellosis, chronic Epstein Barr syndrome, and myalgic encephalomyelitis implied specific etiologies. But since the cause remained unknown, the CDC group was reluctant to propose a name with etiological connotations. The name CFS was lauded as being more neutral, inclusive, and descriptive without implying simple microbial etiology (Straus 1991) and was expected to be durable (Wessely 1991: 928). But the label was hardly perceived as neutral and was attacked by both patients and physicians alike.

Sufferers' objected on two grounds. First, several believed the name gave the wrong connotation to the public and was bound to be a source of misunderstanding. One sufferer in Ware's (1992) study, stated that the name did not sound real. Another, writing to a medical journal, forcefully argued that the name reinforced the psychiatric rather than the infectious nature of the illness because it implied the condition was stress related. This woman perceived herself as someone suffering from chronic Epstein Barr virus syndrome and "protest[ed] vehemently against naming this disease 'chronic fatigue syndrome'"(Radford 1988). Another was indignant about the name which she found trivializing:

> ...the disabling weakness and exhaustion a patient with chronic fatigue syndrome experiences is so profound that *fatigue* is a euphemism at best, and probably more an insult. I have lain in bed for days, in pain because the muscles in my arms and legs were shaking from the strain of holding them still on the mattress. That is not fatigue!" (Cuozzo, 1989: 697).

The second objection was mounted primarily by British sufferers who saw the label chronic fatigue syndrome as an umbrella designation for different kinds of fatiguing illnesses. One sufferer pointed out that ME and CFS had different prevalences, symptom patterns, and responses to rehabilitation approaches using graded exercises. (Goudsmit 1994). She went on to say that people meeting the Oxford criteria were probably depressed or suffering from other psychiatric disorders. Another, made the point more vividly referring to CFS as a "dustbin" syndrome that grouped heterogeneous illnesses together

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Rachel 1991 "Introduction" Ch.1. in Post Viral Fatigue Syndrome edited by Jenkins, Rachel and James Mowbray Chichester, John Wiley and Sons.

and called upon the medical community to study fatigue syndromes separately (Anderson 1994). Critics of the separate syndromes hypothesis were scornful. One medical journalist, who had been asked to make an assessment of medical reporting on ME and post viral fatigue syndrome for the organization Action for ME and Chronic Fatigue, reported that she was attacked for '"censor[ing] the encephalomyelitically incorrect"' and accused of separating ME from a '"ragbag of chronic fatigue syndromes... to 'brand' it as the one with an organic cause"'(Read 1994).

Some professionals were also wary of the name. In a letter, one psychiatrist chided the Canadian Medical Association Journal for publishing information on a condition whose label was "vague, descriptive and unscientific" (Holland 1989). In contrast, another physician noted that the name reduces opportunities to attract serious social, political, and scientific interest (Straus 1991). The name that some professionals believed would be least likely to generate opposition, was seen by some patients and physicians to have social and political implications. The very ordinariness that the name implies, supports beliefs that patients are exaggerating their symptoms, in other words, malingering.

By 1990, a new term chronic fatigue immune and dysfunction syndrome or (CFIDS) began appearing on Medline, although it had been used since 1989 at least. Straus (1991) and Wessely (1991) suggest that many sufferers and some investigators preferred this name because they believed it incorporated immunological processes associated with the condition. The success of the Acquired Immune Deficiency Syndrome (AIDS) political lobby in bringing funding, research, fame and glory, might also have contributed to efforts to give CFS a name reminiscent of a serious illness so that it would command serious attention. Indeed, one letter to the journal Social Work suggested several parallels between CFS and AIDS. The author notes that both illnesses arose at approximately the same time, they affect similar age groups, show evidence of being acquired immune deficiencies, and are associated with viruses in the same family. He states that symptoms of CFS are similar to AIDS related complex and that, like people with AIDS, CFS sufferers are vulnerable to

cancers (Berger 1992). The references for his analysis are, to say the least, selective and controversial even for the time period in which it was written. Despite efforts like this, CFIDS has not caught on in the medical community in the same way that CFS has. Between 1990-1994, there were fifteen articles on Medline with the name CFIDS and hundreds with CFS. The label ME continues to be used in Britain and some parts of Canada. In one British sample, 56% of patients referred to their illness as ME (Wood et al. 1991). To date, no label has been universally accepted by the medical profession and sufferers.

The Impact of Naming

The naming of CFS is far from over. The case definitions were meant to be sets of criteria for selecting research samples, not diagnostic guidelines, although they soon came to be used as such. To explain why this is an inappropriate use of the case definitions an analogy may be helpful. Consider a research study of a new procedure for coronary artery disease in which the criteria for entry to the study is eighty percent blockage in three coronary arteries. To use the research criteria of eighty percent blockage in three arteries as the standard for diagnosing coronary artery disease would be clearly inaccurate. Yet such use of the CFS case definitions has been repeatedly implied. For example, an Australian physician working with medical disability claims charged that the criteria can be easily learned, intimating that people may report these symptoms to doctors to receive a diagnosis and file for compensation (Meyers 1994). Also, investigators periodically see the need to remind others that it is inappropriate to use the case definitions for diagnosing CFS in general medical settings or for medico-legal purposes (Salit et al. 1996: 540).

Current recommendations suggest the diagnosis of CFS should be made on the basis of a thorough history, physical examination, and a standard panel of laboratory tests to exclude plausible alternatives (Salit et al. 1996). Until this position is widely accepted, the socially constructed case definitions of expert groups will be seen as creating a double

standard for diagnosis-one for clinicians and another for researchers. Conceivably, this division could be used to the advantage of different groups on whom CFS has an impact. For example, insurers might attempt to invoke the CDC criteria to contest claims that were diagnosed by using less restrictive criteria. In this way, insurers might withhold medico-legal validation of CFS. On the other hand, patients and their doctors could use the less restrictive criteria to argue that an epidemic of CFS exists which requires urgent research funding.

The intent of the CDC definition was to operationalize the concept of an organic illness with psychiatric features, instead, it highlighted the psychiatric features. The multiple criteria tended to select for patients who fit a profile for psychiatric disorders (Katon & Russo 1992), because symptoms of these disorders overlap with CFS. As mentioned earlier, symptom overlap raises questions about findings of psychopathology in CFS patients using common diagnostic instruments (Millon 1989). It should be further noted that these instruments were not developed to detect psychopathology in people with organic illnesses (Brickman and Fins 1993), which CFS was thought to be. The psychiatric features were also emphasized by Wessely and Powell's (1989) study which showed that patients with CFS and depression had a qualitatively similar fatigue experience that was different from patients with an organic illness. It is likely that investigations related to the case definition contributed to framing CFS as a psychiatric disorder. The implications for sufferers being stigmatized are obvious.

The multiple criteria of the CDC definition did not make research samples more homogenous as intended (Katon and Russo 1992) and it tended to select for patients who get referred to specialty clinics (Kroenke 1991), because they are sicker or because they have the means to pursue a diagnosis (Brickman and Fins 1993; Cooke 1991). In effect, the case definition may have reinforced a socioeconomic bias in research samples.

Parallel with debates about the CDC case definition were controversies about the nature of CFS. Investigators and clinicians proposed physical, psychological, and "unifying hypotheses" to explain the illness (Kroenke 1991). As an alternative to purely biomedical models, Abbey and Garfinkel (1991) suggested that CFS might be a culturally sanctioned form of illness behavior. The strength of explanations lies in showing evidence of hypothesized factors, the link between factors and symptoms, and how factors account for the persistence of the illness. This section shows that neither empirical evidence nor force of arguments makes any position more clearly convincing than others. Despite fairly weak cases, the various ways of framing CFS may have different and profound effects on relevant actors.

The Physical Evidence

Several approaches have been used to investigate CFS as a physical illness. For example, studies have explored links between CFS and other illnesses, toxic exposure, and dysfunction in the energy producing mechanisms of the body. A sampling of such studies shows that CFS has been linked to Sjorgen's syndrome (Calabrese et al. 1994), allergies (Straus et al. 1988), and Sick Building Syndrome (Chester and Levine 1994) and possible exposure to toxic levels of organic hydrochlorides (Dunstan et al 1995). Another group of studies show impaired lung function (Payne and Sloan 1989), abnormally shaped red blood cells (Mukerjee et al. 1987), and deficiencies in muscle carnitine and acylcarnitine (Kuratsune et al. 1994; Plioplys and Plioplys, 1995) which are all important in energy production. However, these isolated studies have generated little further research so that their significance, if any, remains unclear. In contrast, studies of viruses, the immune

system, and disorders of muscle and brain have generated intense interest in lay and medical circles.

Viral activity

The high frequency of reports of flu-like symptoms and a history of CFS onset following a viral illness have undoubtedly contributed to the extensive investigation of viruses. To date, the viruses that have been studied include: Epstein Barr virus (EBV), Coxsackie B virus, herpes simplex virus, cytomegalovirus, measles virus, human herpes virus 6 (HHV-6), human T-cell leukemia virus type 2 (HTLV-2) and spumaviruses (Jones et al. 1985; Straus et al. 1985; Holmes et al. 1987; Calder et al. 1987; Straus et al. 1988; Youssef et al. 1988; Ablashi 1994; DeFreitas 1991; Levy 1994). Viruses trigger the immune system to release specific antibodies and their subtypes as well as cells which attack infectious agents directly without the mediation of antibodies. A case for a viral etiology would be strengthened by the consistency with which viral evidence is found among patients, the amount and type of antibodies to the virus found in serum, and the correlation with clinical symptoms.

Evidence of a viral etiology in CFS is weak or inconsistent. First, no single viral agent has been recovered in all cases of CFS (Farrar et al. 1995). Second, although some studies showed increases or decreases in antibody levels, the majority found normal levels of total antibodies and their subtypes in CFS patients (Lloyd 1994; Shafran 1991)). Third, no clear relationship has been demonstrated between the presence of antibodies to various viruses and symptoms of chronic fatigue. Some patients with normal antibody levels have shown symptoms while others with elevated antibodies have been asymptomatic. (Gold et al. 1990; Shafran 1991; Krupp 1991; Buchwald et al. 1987; Ablashi 1994; Gow et al. 1994). Finally, as mentioned earlier, treatment with an antiviral agent was not effective in relieving symptoms (Straus et al. 1988).

Some investigators now interpret the evidence of viral reactivation that some studies had shown as a secondary result of an immune dysfunction, rather than the cause of CFS (Kroenke 1991). Others however are not convinced that viruses play no role. Komaroff (1991) has suggested that viruses could contribute to symptoms and the continuation of illness once reactivated (Komaroff 1991). And, Levy (1994) has advanced an interesting hypothesis that implicates viruses even in cases where no evidence of an infectious agent has been recovered. He suggested that if a virus acts in a "hit and run" fashion, it could enter the host, produce immune abnormalities leading to CFS and then be eliminated (Levy 1994: s118). In this case, immune dysfunction may explain symptom persistence. Although it is not clear whether viruses have been known to act in such a manner, the story of AIDS might be an inspiration for creative hypotheses, not because the human immune deficiency virus acts in the manner suggested by Levy, but because it has generated some surprising new knowledge about viral activity.

Studies finding evidence of viral activity have been critiqued for: using invalid controls, lack of demographic data on controls, biases that favored finding higher levels of antibodies in cases than in controls (Shafran 1991), and failures to replicate findings that suggested an etiological role for specific viruses[4]. These methodological flaws together with the empirical data of case control studies, have led to the conclusion that there is no convincing evidence of a direct causal relationship between any of the viruses investigated and CFS (Shafran 1991; Farrar et al. 1995). Increasingly, investigators believe that even if viruses are implicated in CFS, no one virus is involved and viruses alone cannot account for the illness.

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[4]See for example Folks and coworkers who could not replicate results by De Freitas 1991. Folks, T. et al. 1993. "Investigation of Retroviral Involvement in Chronic Fatigue Syndrome." Pp.160-175 in Ciba Foundation Symposium 173. Chronic Fatigue Syndrome. Chichester: John Wiley& Sons. Also, Gow et al 1994 found no significant differences in cases and controls after repeating an earlier small study which had suggested that CFS patients had significantly higher levels of enteroviruses in their muscles than controls.

Immune Dysfunction

The notion that chronic immune dysfunction might explain CFS assumes that infections, or other challenges to the immune system, produce an inappropriate and prolonged response which results in symptoms (Farrar et al. 1995). Immune studies, other than those involving antibodies, show several minor abnormalities, as well as evidence of activation, suppression (Farrar et al. 1995: 9) and impaired function. Perhaps the most intriguing suggestion of immune activation in CFS comes from findings of elevated levels of cytokines. These protein products of cells are made in response to viral infections (Levy 1994) and include interferon and interleukin. Although one study has reported no interleukin activation in CFS patients (Morte et al. 1989) others have found increased levels of alpha interferon in the cerebrospinal fluid of some CFS patients (Lloyd et al. 1991). Interferon has been shown to be responsible for the fatigue, headache, muscle and joint aches associated with viral illnesses (Lumb & Doell 1992). These symptoms are also reported frequently in CFS. Other interesting evidence of immune activation in CFS involves finding cells with certain surface markers that are produced only in acute viral illness and not in depression, which is often suspected in CFS (Levy 1994)[5].

Impaired immune function and immune suppression in CFS are suggested by the incidence of allergies and decreases in natural killer (NK) cells respectively. CFS patients have shown a high frequency of allergic responses to foods and inhalants relative to the US adult population matched for age and race (Straus et al. 1988). Studies have also found decreases in natural killer cells which suggest immune suppression (e.g Caligiuri et al. 1987; Kundu et al. 1991) since NK cells mobilize to kill infected cells in the early stages of acute infections (Lloyd 1994).

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[5] See for example studies by Landay et al. 1991 "Chronic Fatigue Syndrome: Clinical Condition Associated with Immune Activation." Lancet 338 (8769):707-11. and Klimas, N et al. 1990. "Immunologic Abnormalities in Chronic Fatigue Syndrome." Journal of Clinical Microbiology 28: 1403-10.

Although several studies suggest that immunological factors may be important in the development of CFS, their clinical significance is not clear. Most patients do not show evidence of the activation, suppression, and impairment reported above (Shafran 1991; Salit et al. 1991; Lloyd 1994). Moreover, the presence and levels of these factors do not clearly correlate with symptom severity (Shafran 1991; Salit et al. 1991). These studies have also been critiqued on methodological grounds putting into question the reliability of the findings. For example, studies showing decreased natural killer cells did not make allowances for substances such as cigarette smoking or medications that can affect natural killer cell levels (Lloyd 1994). In other studies, immune assays of patients and controls were not comparable because they were not run at the same time with the same reagents (Krupp 1991). Without appropriate inter-assay controls, results cannot be interpreted properly because healthy controls may vary in some immune substances by as much as 50% on different days (Stein et al. 1991). To clarify the immune system's role in CFS, if any, data analysis of immune studies must be standardized, substances affecting immune responses controlled, and samples selected rigorously to reduce the heterogeneity of study populations (Lloyd 1994).

Muscle Disorders

Studies of muscle and brain disorders extend the central versus peripheral issue raised by Wessely and Powell (1989) in their attempts to determine the nature of fatigue in CFS. Frequent reports of fatigue following exercise, and perhaps the importance of this symptom in the Australian definition, have contributed to the search for muscle disorders. Some studies have investigated both heart and skeletal muscle function because the heart adjusts its rate and force to deliver oxygen, so that muscles may perform different levels of work. Results of heart function studies are inconsistent. One early controlled study found normal heart function at rest in CFS patients but slow acceleration relative to healthy controls during graded exercise. As a result, patients felt fatigued long before they had

reached their peak heart rate (Montague et al. 1989). However, another study found that the relationship between heart rate and work rate to be similar in patients and healthy controls. Despite this normal relationship, patients perceived that they were not tolerating the exercise and limited their endurance (Gibson et al. 1993). Skeletal muscle studies have shown a wide range of cellular abnormalities but these abnormalities have also been found in people with other painful muscle conditions and in apparently healthy controls (Edwards et al. 1993). Some studies have shown normal muscle fatigability and metabolism but impaired performance in sustained exercise (Kent-Braun et al. 1993). Findings of impaired performance may be due to the deconditioning that occurs with low activity levels. The weight of evidence in muscle studies suggest that CFS is not a primary muscle disorder and that muscle fatigue in CFS patients is centrally mediated (Edwards et al. 1993). But recent studies showing some CFS patients with deficiencies in substances known to be important in muscle energy production (Kuratsune et al. 1994; Plioplys and Plioplys, 1995) may well re-open this line of inquiry.

Brain disorders

The final type of major investigation into physical causes involves neuropsychological symptoms. These symptoms refer to mental fatigue and cognitive dysfunction such as impaired concentration and memory. They are central to the Australian case definition but also widely reported elsewhere. These symptoms are something of a battleground for deciding whether CFS is physical or psychological since they occur in both types of illness. The physical investigations have brought some of the most sophisticated and expensive medical technology into the debate about the nature of CFS. Direct investigations of neuropsychological symptoms have used measures of brain electrical activity and brain imaging techniques (scans), while indirect investigations examine performance on tests of cognitive function.

Brain scans detect abnormal structures with magnetic resonance imaging (MRI) and abnormal functioning with single photon emission computer tomography (SPECT) (Wessely 1993; Cope & David 1996). Findings of MRI studies are inconsistent. One early study showed abnormal MR results in 78% of CFS patients (Buchwald et al 1992). However, this study included subjects with symptoms suggesting neurological disorders which would disqualify them from meeting the CFS case definition (Cope and David 1996; Wessely 1993). A later study found abnormalities in only 27% of CFS patients (Natelson et al. 1993). On follow up in that study, one third of patients diagnosed with CFS showed other symptoms that suggested an alternate diagnosis. The researchers warn doctors not to attribute MR abnormalities solely to CFS in patients with this diagnoses, since they risk missing other illnesses. The significance of abnormalities in imaging studies rests on whether they can be linked to symptoms and whether they can be shown to be specific to CFS. To investigate the specificity of abnormal MR results and the relation to symptoms, Cope and David (1996) compared the scans and intellectual functioning of CFS and depressed patients. They found no significant differences between the two groups although depressed patients tended to show more abnormalities and worse functioning than CFS patients.

SPECT scans detect functional abnormalities by examining blood flow (perfusion) in the brain. Most SPECT studies of CFS patients suggest mild general reductions in blood flow (Ischise et al. 1992; Costa et al. 1995) or reduced flow in specific regions such as the hypothalamus (Costa et al. 1995). To determine whether differences in patterns of blood flow in the brain exists between patients with CFS, and others with a known viral illnesses or depression, Schwartz and coworkers (1994) compared SPECT scans of CFS, depressed and AIDS dementia patients. They found similarities in the numbers and distribution of abnormal perfusion areas in the brain between CFS and depressed patients. But CFS patients also showed a specific pattern of abnormality similar to AIDS dementia patients that was not seen in depressed patients. The authors conclude that similarities between CFS

and AIDS dementia patients may suggest a viral encephalitis in CFS. On the other hand, the similarity in numbers and distribution of abnormalities in brain perfusion between CFS and depressed patients, may account for overlapping symptoms.

The SPECT neuroimaging studies are provocative. But if any relationship exists between abnormal perfusion and the symptoms of CFS it remains to be elucidated. It is also not clear that investigators agree on the pattern of reduced blood flow in CFS patients. Like other investigations into physical cause, hypoperfusion of the brain has not been found in all CFS patients. Costa et al's. (1995) recent study is an exception. They found abnormal perfusion in the brainstems of all sixty seven CFS patients in the study sample. The high costs of these investigations are no doubt a limiting factor in replication and in attempts to use other comparison groups to determine whether CFS patients show a specific pattern of impaired blood flow on neuroimaging. The use of neuroimaging for diagnosis is not considered to be warranted at this time (Salit et al. 1996).

Some investigators have used cognitive function tests to evaluate impairments of memory, concentration, speed of information processing, planning, organizing and reasoning which are commonly reported. The most consistent finding is that CFS patients show difficulty processing information (DeLuca et al. 1993; Ray et al. 1993; Marshall et al. 1996; Scheffers et al. 1992). In contrast, some studies have shown impaired attention and concentration in CFS patients (DeLuca et al. 1993; Jones and Miller 1987) while others have found no difference between CFS patients and controls (Scheffers et al. 1992; Marshall et al. 1996; Altay et al. 1990; Schmaling et al. 1994; Krupp 1994). Results on impaired short term memory in CFS patients are also inconsistent. Riccio and colleagues (1992) and Jones and Miller (1987) reported impairments, while Scheffers and associates (1992) found none. Chronic fatigue syndrome patients frequently underrate their performance on neuropsychological tests. The discrepancy between subjective appraisals and objective performance may be due to psychological factors such as anxiety and depression (Altay et al. 1990).

On the basis of a review of twenty five studies of neuropsychological tests in CFS, Moss-Morris et al. (1996) concluded that CFS patients show "slower reaction times, poorer performances on complex attentional and memory tasks, and, less consistently, a slowness in acquiring new information" (p. 476). These impairments may all be related to difficulties with information processing. These studies, however, showed no evidence of: intellectual decline, sensory or perceptual impairment, impaired ability to focus, consistent or severe memory impairment, ability to order, organize, plan or reason. Subjective reports of performance have been found to be associated with higher levels of psychopathology. The evidence of neuropsychological studies points to associations with psychological rather than organic factors (Moss Morris et al.1996).

Despite extensive research into a number of physical factors and abnormal findings, CFS cannot be considered a purely physical illness. No particular physical factor is found in all cases, no factor consistently accounts for the onset and persistence of symptoms, and no factor satisfactorily explains all symptoms. Physical factors, such as infection, do not account very well for psychiatric disorders (discussed below) which are found in many CFS patients. In fact, studies cited as finding relationships between the two suggest that infections are more likely to be the results of psychiatric disorders rather than the cause (Kreusi et al. 1989; Cooke 1991). In addition, methodological problems put in question the reliability of some abnormal physical findings.

Psychological Evidence

The weakened case for viral etiologies, the overlap between CFS and psychiatric disorders (Ware and Kleinman 1992), and the absence of specific findings from laboratory tests and physical examination (Manu et al. 1992), contributed to the hypothesis that primary psychiatric disorders completely or substantially explain CFS. Some proponents of this position simply argued that the symptom overlap between CFS and a number of

psychiatric syndromes was so great that a new diagnostic category was unwarranted (Manu 1988). Beyond this prima facie evidence, four types of empirical approaches have been used to investigate the role of psychiatric disorders in CFS.

One approach examined rates of psychiatric disorders among CFS patients using a number of diagnostic instruments. These studies invariably showed high rates of psychiatric disorder. One study which used the Diagnostic Interview Schedule (DIS) found that 78% of CFS patients met the criteria for one or more psychiatric diagnoses of depression, somatization, and panic disorders (Lane et al. 1991). The rate of somatization disorders was thirty times the rate in population studies using the same instrument. Using different tools- the General Health Questionnaire (GHQ), the Hospital Anxiety and Depression Scale (HAD), and the Shortened Somatic Discomfort Scale, and the Schedule for Affective Disorder and Schizophrenia (SADS)- another study found that 72% of CFS patients had current psychiatric disorders. Forty seven percent could not be distinguished from patients with primary affective disorders (Wessely and Powell 1989). Lower, but still substantial rates of psychiatric disorders in CFS patients were reported in a study using the CATEGO diagnostic system (Wood et al. 1991). Forty one percent of subjects had sufficient symptoms to meet the criteria for a psychiatric disorder and a further 26% reached subcase level.

Critics questioned these rates because case definitions of CFS and psychiatric disorders overlap and because somatic symptoms included in definitions of many psychiatric disorders are also common in organic illnesses. The frequently used DIS contains nine of the thirteen symptoms in the CFS case definition. "Moreover, CFS type symptoms are enquired about twenty six times and are part of the diagnostic criteria of four psychiatric disorders" (Buchwald 1993: 35)[6]. As mentioned earlier, use of the DIS in CFS patients has also been critiqued on grounds that it was not developed to diagnose

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[6]Buchwald, D. 1993. In the discussion following the paper by Peter Manu at the CIBA symposium on Chronic Fatigue Syndrome, London, 12-14 May 1992.

psychiatric disorder in medically ill patients (Hickie et al. 1992). And, recently Farmer and associates (1996) have questioned the suitability of the GHQ for screening for psychiatric illness in CFS patients.

To obtain more accurate rates and address the problem of confounding CFS and psychiatric disorders, investigators have tried several methodological approaches. One study which excluded the key symptom of fatigue from psychiatric diagnostic tools before screening for psychiatric disorders, still found psychiatric disorders in 72% of CFS patients (Wessely and Powell 1989). When several overlapping symptoms were excluded, 75% of CFS patients still had one or more psychiatric disorders, with major depression, simple phobia and dysthmia being most common (Kreusi et al. 1989). But, a recent study found that changing the attribution of symptoms from psychiatric to physical dramatically reduced rates of somatization disorder in a group of CFS patients (Johnson et al. 1996). Until there is some resolution to the problem of symptom overlap and attribution, CFS will continue to be associated with high rates of psychiatric disorders. Equally, those disagreeing with this finding on methodological or conceptual grounds will remain unconvinced.

A second approach to determining the role of psychiatric disorders in CFS examined the temporal sequence between the two. Results are inconclusive. Kreusi et colleagues' (1991) study, for example, found that only 7% of cases had no history of psychiatric disorder before they developed CFS. On the basis of this finding, they concluded that psychiatric disorders were more likely to be risk factors for the onset of CFS rather than a consequence of the illness. On the other hand, Hickie et al (1990) found that 76.5% had no premorbid psychiatric disorders. The 24.5% prevalence that they found is consistent with the level of psychiatric disorders in the general population. Their interpretation was that most cases of psychological disorders in CFS are consequences of a having a chronic disabling illness, not the cause.

To determine whether psychiatric disorders were a likely result of chronic disability, some studies compared rates of psychiatric disorders in CFS and other chronic illnesses. Compared to patients with diabetes, CFS patients show higher rates of depression and somatization disorder (Kreusi et al. 1989). People with diabetes may not be the most appropriate comparison group, since the disorder is often well controlled and sufferers may function normally for years without debilitating symptoms. Comparisons with more appropriate groups of people suffering from debilitating neuromuscular disorders showed contradictory results. Much higher rates of psychiatric disorders were found in patients with CFS than in patients with myasthenia gravis. This finding suggested that disablity alone could not account for the high rates of psychiatric disorder in CFS patients (Wessely & Powell 1989). But, when CFS patients were compared to patients with another neuromuscular disorder, multiple sclerosis (MS), and to patients with major depression, rates of current psychiatric disorders were similar in CFS and MS patients (Natelson et al 1995).

A third way of studying the links between CFS and psychological disorders examined sufferers' personality profiles. The underlying assumptions are that personality characteristics may predispose people to the illness or prolong its course. These studies have used the Millon Clinical Multiaxial Inventory, the Minnesota Multiphasic Personality Inventory (MMPI) and a Dutch scale (HAB) measuring 'action-proneness'. Developers of the HAB found significant positive correlations between 'action proneness' and measures of physical effort and extraversion, as well as significant negative correlations with measures of strain of daily work and reaction time (Dirken 1970 cited in van Houdenhove et al. 1995: 635). These findings suggest that while 'action proneness' may describe a personality characteristic, it does not imply a pathological personality.

In a comparative study of CFS patients, patients with chronic pain, chronic organic, and neurotic/dysthmic disorders Van Houdenhove and colleagues (1995) measured both 'action proneness', using the HAB, and depression. Chronic fatigue syndrome patients'

high scores on 'action proneness' were like those of chronic pain patients and these scores were unrelated to depression. On the basis of these results, the investigators concluded that patients' premorbid hyperactive lifestyles may be a predisposing factor to CFS.

In contrast to the HAB, the MMPI and the Millon Inventory are more concerned with personality pathology. A study of 28 CFS patients using the Millon Inventory found scores suggesting a histrionic personality in 33%, schizoid personality in 29%, avoidant, narcissistic and aggressive/sadistic personality in 25% and borderline personality in 12% (Millon et al. 1989). The MMPI studies show that CFS patients had significantly higher scores than controls on hypochondriasis, depression, hysteria and schizophrenia (Stricklin et al 1990 cited in Brickman and Fins 1993: 80; Schmaling et al. 1996). In addition, Stricklin et al (1990) found patients also had elevated scores on psychoasthenia.

Scales measuring pathological personalities are plagued with the same problems of symptom overlap with CFS as other psychiatric diagnostic instruments. For this reason, both Millon et al (1989) and Schmaling et al. (1996) have advised caution in interpreting scores on these scales in CFS patients. The MMPI does not differentiate between patients with organic and functional symptoms and "should not be used for that purpose in CFS" (Schmaling et al. 1996: 73).

A final approach to determining the role of psychiatric disorders in CFS examined whether key symptoms or patterns of symptoms in CFS were more similar to patients with known medical or known psychiatric disorders. Patients with CFS and affective disorders show similarities on indicators of physical and mental fatigue (Wessely and Powell 1989; Natelson et al. 1995). However, these similarities can be accounted for by overlapping case definitions. In contrast, patterns of psychiatric symptoms in CFS patients have been found to be closer to patients with organic illnesses than to patients with non endogenous depression (Hickie et al 1990; Natelson et al. 1995).

In summary, efforts to explain CFS as a psychiatric illness have focused on symptom similarities, frequency and timing of psychiatric illnesses in CFS patients,

comparisons between rates of psychiatric disorders in CFS and known organic illnesses, personality studies, and comparisons of symptom patterns in CFS, organic, and psychiatric disorders. However, evidence to suggest that CFS is completely or substantially explained by primary psychiatric disorders is inconclusive. A variety of diagnostic instruments show high rates of psychiatric disorders among CFS patients. But these rates may not be reliable because definitions of CFS and psychiatric disorders are confounded and psychiatric diagnostic instruments were not developed for use in patients with medical illnesses. Since it has not yet been determined whether CFS is an organic or psychiatric illness, the validity of finding psychiatric disorders cannot be claimed with confidence. It should also be remembered that even in studies finding high prevalences, some thirty to seventy percent of patients show no evidence of psychiatric disorders. Finally, there are no clear answers to questions of whether psychiatric disorders in CFS are "cause, effect, or covariate" (Abbey and Garfinkel 1991).

Unifying Hypotheses

The variability in sufferers' symptoms and histories suggested that neither physical nor psychological explanations alone could account for all the features of CFS. A few investigators have proposed unifying hypotheses to accommodate this variability and integrate the complex biological and psychological aspects of the illness. These hypotheses assume that heterogeneous stresses produce effects through common biological pathways. In everyday parlance stress is often understood as the result of psychosocial strains. But the concept of stress, originally developed by Selyé (1950), included both physical and psychosocial factors. Selyé (1950) showed that any type of stressor could produce a non specific response in the hypothalamus, pituitary, adrenal (HPA) axis. Based on findings of impaired HPA responsiveness in CFS patients, Demitrack (1994) has suggested that infection, [psychosocial] stress, pre-existing or concurrent psychological disorders may

converge in a common biological pathway to produce symptoms of CFS. Patients with CFS and depression show different profiles of impaired HPA responsiveness.

A second type of unifying hypothesis implicates the immune system as the final common pathway. According to this argument, articulated by Ware and Kleinman (1992), some research suggests a biological basis for depression. Both infection and depression are stressors that may affect the immune system, and some immune disturbances can produce symptoms of CFS. The meanings of findings of immune disturbance in depression have yet to be clarified (Stein et al. 1991) and immune findings in CFS are inconsistent as already discussed above.

The Sociocultural Argument.

Sufferers' histories of harried and hurried lifestyles formed the basis of a sociocultural explanation of CFS highlighted in an article by Abbey and Garfinkel (1991). These authors suggested that most cases of CFS were really psychiatric disorders or a form of illness behavior. However, it is culturally more acceptable to frame CFS as a physical illness and the illness is perceived as such. Thus, the diagnosis protects sufferers from the stigma of mental disorder. Their arguments, which are briefly summarized below, rested on comparisons between CFS and the nineteenth century illness known as neurasthenia.

Although neurasthenia first appeared among the wealthy classes including captains of industry, and professionals such as doctors, the majority of those afflicted were women. At first, neurasthenia was considered a medical illness and explained by a melange of then popular scientific models which included neural electrical conduction, reflex action, conservation of energy, evolution and social Darwinism. The particular version of social Darwinism that was offered, posited that the upper social classes had more highly developed nervous systems than others which rendered them more sensitive to the strains of capitalism. This explanation cast neurasthenia as a product of virtuous behavior,

removed any hint of mental illness, and accounted for the social class distribution. But it did not account for the gender distribution. Some physicians of the day explicitly linked the diagnosis to women's ambitions. In contrast, some prominent women sufferers suggested that it was not the fact of having ambitions that had made them ill, but having their ambitions thwarted. Drawing on accounts of such women and on feminist analyses, Abbey and Garfinkel (1991) suggested that neurasthenia was the product of the declining value of traditional female roles and the lack of alternative role opportunities for nineteenth century upper class women. In effect, differential social factors accounted for neurasthenia in men and women. Ironically, it was the smaller number of powerful men suffering from overwork who were credited with conferring legitimacy on the illness. Abbey and Garfinkel argue that the particular physical and social explanations of neurasthenia developed by physicians were shaped by cultural factors and served to protect the social identity of wealthy men.

With developments in psychiatry, most symptoms of neurasthenia were regrouped into psychiatric diagnoses. The remaining unexplained "non specific, functional somatic symptoms and psychological distress" (Abbey and Garfinkel 1991: 1644) are identical to CFS, except that the frequently reported painful lymph nodes of CFS were not a feature of neurasthenia. The residual symptoms of neurasthenia became increasingly unfashionable and the diagnosis largely disappeared. The authors suggest a similar fate awaits CFS.

Abbey and Garfinkel (1991) observed that like neurasthenia, CFS first appeared among the upper classes, it also arose in a context of increasing social and role stress, and disproportionately affects women. They proposed that CFS provides a legitimate reason for women suffering from role overload and role conflict to withdraw from some social responsibilities.

> Clinical experience suggests that among chronic fatigue syndrome sufferers are a number of women and men who feel conflicted about their working lives and the difficulty balancing their careers with their family obligations and personal wishes. The diagnosis of chronic fatigue syndrome provides a legitimate "medical" reason for their fatigue, emotional distress, and associated psychophysiological symptoms and allows them to withdraw from situations they find

> intolerable on the basis of illness rather than their own volition. (Abbey and Garfinkel 1991:1644).

Notwithstanding the mention of men, the quote above appeared in the context of a discussion of women's roles and gender dynamics in professional and self diagnoses of CFS.

The authors' comparison between neurasthenia and CFS further notes that CFS has been explained by prominent illness models of today, notably infection and immune dysfunction. But they conclude that evidence to support either hypothesis remains inconclusive or of uncertain clinical significance. Instead, they suggest that most cases of CFS are misdiagnoses of psychiatric conditions or a form of illness behavior. The term illness behavior refers to "...the manner in which persons monitor their bodies, define and interpret their symptoms, take remedial actions and utilize the health care system." (Mechanic 1983: 591). Illness behavior may become persistent and dysfunctional (Mechanic 1993) or abnormal (Pilowsky 1990). Its expression may be constrained by culture and group membership and may reflect cultural and socially acceptable means of coping (Mechanic 1983). It is in this latter sense that Abbey and Garfinkel suggest that CFS may be a form of illness behavior.

The article provoked a spate of decidedly negative responses. Critics took issue with three main points. First, they pointed out that it was controversial to presume that CFS was a psychiatric disorder (Saltzein et al. 1992). And they noted that finding high rates of psychiatric illness in sufferers was not convincing support for this position because of problems with psychiatric diagnostic instruments (Hickie et al. 1992). One physician accused Abbey and Garfinkel of perpetuating the outdated mind-body split (Bell 1992) while others admonished them to keep an open mind on the illness' etiology (Fallon et al. 1992). Several further suggested that by assuming most cases of CFS were psychiatric disorders, Abbey and Garfinkel had prematurely dismissed, selectively cited, or trivialized the physical evidence (Bell 1992; Goodrich 1992; Kaplan et al. 1992; Hickie et al. 1992).

Second, critics suggested that the notion of illness behavior dismissed the suffering of CFS patients (Bell 1992) and reinforced perceptions that CFS is a cover for malingering (Appelbaum 1992) or has other social value to patients (Salzstein et al. 1992). One author questioned the ethics of portraying CFS patients as malingerers (Appelbaum 1992), while others argued that the losses, estrangement, shame, and frustration over not being able to function at pre-illness levels belie the inference of secondary gains (Salzstein et al. 1992). Abbey and Garfinkel's gender explanation provided a third focus for attack. One group implied that it was not only nineteenth century physicians who were faddishly appropriating popular models to explain poorly understood illnesses. (Kaplan et al. 1992) Another labeled the role overload/role conflict explanation "Victorian " and "offensive" (Salztein et al. 1992). In more measured tones, other investigators pointed out that their research had shown that excessive female to male ratios were largely artifacts of the tertiary care settings in which most studies have been conducted (Hickie et al. 1992).

One terse but cryptic letter consisted of a single sentence.

> "Plaintiffs' attorneys seasoned by clients claiming monies for alleged industrial and similar injuries will spot familiar scenarios among the neurasthenics portrayed by Drs. Abbey and Garfinkel". (Shelley 1992: 1755).

Were the plaintiffs private and public disability compensation agencies? Or were they people making claims as sufferers? Was the doctor implying that Abbey and Garfinkel had confirmed lawyers' worst fears or jaded assumptions that they were representing people unjustifiably claiming compensation?. If so, would the article give ammunition to defendants' lawyers drawing the same conclusions?

Abbey and Garfinkel (1992) wrote a spirited reply. They asserted that the physical evidence was inconclusive and frequently unreplicated or unrelated to clinical status. Furthermore, the reliability of some of these findings was questionnable because of numerous methodological flaws. They conceded the problems of psychiatric diagnostic instruments, but reiterated that they had not entirely dismissed viral causes, as their

previous publications attested. Rather, they believed viruses accounted for a minority of cases. They insisted that various subgroups of sufferers deserved to be studied and charged some of their critics with politicizing the diagnosis so that only research emphasizing organic aspects of the illness would be supported. Presumably, these critics had a vested interest in physical hypotheses because of their subspecialties or 'pet' hypotheses.

Abbey and Garfinkel (1992) rejected the notion that the term illness behavior is equivalent to calling patients malingerers or that it negates patients' real suffering. They pointed to studies of illness behavior that have documented patients' profound distress. For good measure, they added that studying this concept in CFS might add to knowledge of somatization, that is, the expression of emotional distress in physical symptoms.

But Abbey and Garfinkel's use of the term illness behavior was problematic. At its most basic, illness behavior describes a set of processes circumscribed by personal, social, or cultural factors, which may be triggered by distress or sensations that are abormal for the individual. Illness behavior then would be expected in any illness, whether physical or psychiatric. Presumably, it can also be manifested in cases where illness will not be shown to be present, because of patients' misinterpretations or deliberate misrepresentation. However, it is one thing to describe the illness behavior of CFS patients in terms of how they think about their illness and distress and what they may do in relation to help seeking. But to call CFS a form of illness behavior as Abby and Garfinkel (1991) did, only clouds the issue because it equates behaviors that may be secondary to a problem with the problem itself. To acknowledge suffering associated with illness behavior is a poor substitute for validating illness, especially when suffering is seen as a result of not coping competently with life's vicissitudes.

A few studies have pursued the contentious "illness behavior" concept by investigating possible abnormal illness behavior in CFS patients. The concept of abnormal illness behavior and scales to measure this construct were developed by Pilowsky (1990 cited in Schweitzer et al 1994: 41) based on the sociological work of Mechanic and Parsons

(Schweitzer et al. 1994). Pilowsky defined abnormal illness behavior as: "a persistence in inappropriately perceiving, evaluating and acting in relation to one's health despite medical reassurance" (Schweitzer et al. 1994). Kirmayer and Robbins (1991) note that the original concept of illness behavior was normative and descriptive and that we do not know enough about illness behavior to decide what is abnormal. Furthermore, instruments to measure illness behavior are strong on symptoms, attitudes and mood, with very few items representing actual behavior (Kirmayer and Robbins 1991: 10).

Studies measuring CFS patients' performance on the [abnormal] Illness Behavior Questionnaire (IBQ) have found that CFS patients held strong physical illness convictions and were reluctant to accept psychological interpretations for their symptoms (Hickie et al. 1990; Schweitzer et al. 1994; Trigwell et al. 1995). In addition, CFS patients tended to regard their illness as the only problem in their lives (Hickie et al. 1990; Schweitzer et al. 1994) and scored high on general hypochondriasis (Schweitzer et al. 1994; Trigwell et al. 1995). One study found that the IBQ profiles of CFS patients was identical with those of patients with multiple sclerosis (MS), which suggested that CFS patients do not have a unique profile of illness behaviors.

Abbey and Garfinkel's thesis that CFS, like neurasthenia, legitimates social distress and protects sufferers from the stigma of mental illness is hardly tenable. The voluminous literature suggesting psychiatric disorders are strongly implicated in the development of CFS and their own conclusions that the majority of cases are really "...an identifiable psychiatric disorder, psychophysiological symptoms secondary to acute or chronic psychosocial stress or a form of illness behavior" (p. 1645) suggest otherwise. Chronic fatigue syndrome is far from being universally accepted as a medical illness. Without such a consensus, the suspicion of mental disorder continues to cast a long shadow over sufferers. Mental disorders remain stigmatized and diagnoses with a question mark about their links to such disorders are also likely to be stigmatized.

This social function explanation for CFS has not been vigorously pursued. Ware and Kleinman (1992) have drawn a parallel between neurasthenia in modern day China and CFS to argue that both may be culturally acceptable ways to legitimate emotional distress brought on by profound social and cultural changes. One recent study of CFS sufferers' personality, speculated that the illness offers a respectable retreat from unremitting strain because it cannot be dismantled by present medical knowledge (Van Houdenhove et al. 1995). In words reminiscent of Abbey and Garfinkel, the authors tentatively broach the subject of gender: "Could it be that the overambitious athlete complains about 'overtraining', the over-committed social worker about 'burnout', and the over-burdened modern woman who feels obliged to combine three 'full-time' jobs (household, professional career and educator of children)...about ME [CFS]?" (Van Houdenhove et al. 1995: 638).

The Impact of Etiological Frames

Framing CFS as a physical illness benefits sufferers most. This view of the illness validates sufferers' complaints and removes the stigma of malingering or mental disorder. If a physical basis of CFS were shown to be well founded, it might facilitate obtaining disability compensation, since physical evidence is more difficult to contest. As a result, public and private disability compensation institutions stand to lose the most from finding physical causes of CFS although they could still contest the severity of the illness.

Doctors who consider CFS a physical illness are viewed as more sympathetic to patients and, as a result, they may gain a following. On the other hand, such doctors have been accused by their professional colleagues of "lessen[ing] the burden of introspection and contribut[ing] to self defeating behavior (Holland 1989) or flogging physical causes for their own ends (Abbey & Garfinkel 1992). They also risk being seen as helping to

perpetuate disability because sufferers who are told they have a physical illness may avoid seeking help for treatable psychiatric disorders.

Viewing CFS as a psychiatric illness stigmatizes sufferers and has potential social and economic consequences. Considering the problems with the psychiatric evidence and lack of medical consensus on the matter, that is a high price to pay. One physician adviser to an ME Association in Britain has charged that editorial biases in the British Medical Journal (BMJ) have led insurers to refuse the mobility component of the disability allowance, on the grounds that BMJ considers ME as a psychological rather than a physical illness (Shepherd 1994:1300). It could be argued that even insurers who compensate psychiatric illness could contest CFS claims because the condition has no clear status either as a physical or as a psychiatric illness. The view of CFS as a form of illness behavior has a stigmatizing potential similar to psychiatric disorders regardless of whether it acknowledges suffering. If illness behavior is a culturally acceptable way of coping with psychosocial pressures, that implies that sufferers either have a psychological illness or that no illness exists.

Ware and Kleinman (1992) suggest that the social significance of unifying hypotheses lies in their potential to enable CFS patients to avoid the stigma of psychiatric diagnoses. For if depression is shown to have a biological basis, and both depression and infection may activate the immune system to produce CFS symptoms, then the presence or eventual role of depression in CFS does not preclude CFS from being recognized as a "real [physical] illness" (Ware and Kleinman 1992: 207). Increasingly, investigators view the physical- psychological debate in CFS as unproductive (Wessely 1989; Yeomans 1991; Salit et al. 1996). Many physicians suggest that a biopsychosocial model is probably a better way of explaining complex illnesses such as CFS (see for example Yeomans 1991), or they think that CFS is a heterogeneous illness with heterogeneous causes (Wessely 1989; Hickie et al. 1995). Such positions render the debate about psychological versus physical moot.

The Chronic Nature of CFS

While most efforts to elucidate the nature of CFS have focused on etiology, the illness can also be framed in terms of its duration. There is little debate about the fact that CFS is a lengthy illness. But there are questions of whether its duration and severity can be attenuated. The duration and severity of an illness are part of its natural history but they may also depend on treatment efficacy, and personal or social characteristics of individuals. These variables have guided approaches to studying whether CFS has to be the intractable illness of indefinite duration that some sufferers' reports suggest.

Little is known of the natural history of CFS, but studies such as those of Woodward (1993) and Ray et al. (1992) have made significant contributions to knowledge about the natural course of the illness. They have found that the onset may be sudden or gradual and associated with physical factors or psychosocial stresses. Woodward (1993) notes that the most severe period often occurs long after the onset. Major and minor relapses, differentiated by severity and duration, mark a course of many years (Woodward 1993). Relapses may be brought on by minor physical or mental effort within three to twenty four hours and last from days to weeks (Ray et al. 1992). Several other studies describe samples in which a few outlier subjects report having had the illness for twenty or thirty years (see for example Sharpe et al. 1992; Wilson et al. 1994). However, the mean duration of illness before sufferers entered several longitudinal studies ranged from two to nine years (Bonner et. al. 1994; Wilson et al. 1994; Sharpe et al. 1992; Bombardier et al 1995). In these follow up studies, which lasted from eighteen months to four years, 54% to 70% of patients showed improvement on a variety of measures including functional ability, symptom alleviation, emotional disorder, and immune status (Sharpe et al 1992; Wilson et al. 1994; Bonner et. al. 1994; Bombardier et al. 1995). A less optimistic result was obtained by Vercoulen and colleagues (1996), who found only 20% reported

improvement or spontaneous recovery after four years of follow up. But in general the results have led to the conclusion that while spontaneous recovery is rare, improvement is common (Bombardier et al 1995)

Several studies suggest that the outcomes of CFS are mediated by a number of personal characteristics. The most consistent finding shows that strong physical convictions, or a tendency towards such convictions, is associated with poorer outcomes (Sharpe et al 1992; Wilson et al. 1994; Bombardier et al. 1995; Vercoulen 1996; Bonner et. al. 1994). Poorer outcomes were also associated with the presence of psychological disorder at the time of entry into the study (Bonner et al. 1994; Sharpe et al. 1992) or at the time of follow up (Wilson et al. 1994) an avoidant coping style (Sharpe et al. 1992) or focusing on symptoms (Ray et al. 1993); referral to tertiary care (Wilson et al. 1994); membership in self help organizations (Sharpe et al. 1992); and change in occupation (Sharpe et al. 1992) or unemployment (Vercoulen et al 1996).

Better outcomes, on the other hand, were found to be associated with improvement following cognitive behavior treatment (discussed below) (Bonner et al. 1994), stable marital and occupational status, sense of control, shorter duration of illness, less use of mainstream or alternative health care (Vercoulen 1996) and lack of rigid beliefs in physical causes (Vercoulen 1996; Sharpe et al 1992; Wilson et al. 1994; Bombardier et al. 1995; Bonner et. al. 1994).

To date, no treatment has been found to reliably moderate the natural history of CFS. While treatments may be purely symptomatic, they may also indirectly express etiological beliefs. Increasingly, supportive therapies are recognized as the mainstay of managing CFS (Shepherd 1989; Kroenke 1991; Kranowitz et al. 1995). Such therapies consist of education about the illness, lifestyle management, and regular monitoring. Patients are oriented to the course, prognosis, and possible treatments of the illness. They are counseled about healthy nutrition, a proper balance between rest and activity within the limits of their tolerance, and stress management (Kranowitz et al. 1995). Knowing that the

illness is not fatal but may remit and relapse, may help patients to keep perspective, reduce anxiety, and maintain hope. This kind of treatment is usually used in conjunction with somatic or psychiatric treatments.

Several somatic treatments have shown either no benefit, or none greater than a placebo. These include: antiviral drugs (Straus et al. 1988); a liver extract folic acid preparation known as LEFAC (Kaslow et al. 1989) and antihistamines (Steinberg et al. 1996). Results of other somatic treatment studies have shown contradictory results. Positive outcomes were shown with essential fatty acids (Behan et al. 1990); magnesium[7]. (Cox et al. 1991); and immunoglobulins (Ganty and Holmes 1989 cited in McKluskey 1993: 285). But McCluskey (1993) could not replicate any of these findings. Claims from a physician sufferer that daily doses of liquorice dissolved in milk provided improvement for up to twenty months after treatment (Baschetti 1995) have not been replicated. But his claim has drawn both support from one colleague for its theoretical feasibility (Higgins 1995) and derision from another who stated that these claims were an example of the placebo effect or a denied psychogenic condition (Welch 1995).

In general, psychological treatments have not been shown to be much more effective than somatic therapies. Patients are often resistent to the idea, although many agree to low doses of antidepressants which seem to alleviate pain and sleep disorders if present. Mindful of patients' resistance and the fact that antidepressants have several beneficial effects beyond mood elevation, Moldofsky (1993) has questioned whether it might be better to use the chemical classification of tricyclics to refer to the drugs rather than antidepressants. After all, he reasons, penicillin is not known as an antisyphillitic drug, although it is the specific treatment for this disease (Moldofsky[8] 1993:292).

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[7] magnesium is essential for production and transfer of energy to make proteins (Krause & Mahan 1984. Food . Nutrition and Diet Therapy. Toronto. W.B. Saunders and Co. p155).

[8] Moldofsky made this suggestion in the discussion following the paper by McCluskey, David R. 1993. "Pharmacological Approaches to the Therapy of Chronic Fatigue Syndrome." Pp.280-297 in Ciba Foundation Symposium 173. Chronic Fatigue Syndrome. Chichester: John Wiley & Sons.

Researchers and clinicians are aware of the stigmatizing potential of psychiatric treatments. But many are convinced that such treatments can help to interrupt the possible influence of psychiatric disorders in prolonging CFS. One multidisciplinary treatment team has reported some success in inserting psychological evaluations and therapy in the management of CFS in ways acceptable to sufferers (Hatcher 1994). In this approach, psychological treatments are presented as only one of several management strategies.

A second psychological management approach that has gained attention uses cognitive behavior therapy (CBT). Cognitive behavior therapy rests on two assumptions. First, different factors may be responsible for the onset and continuation of symptoms. Onset may be due to infection, while cognitions and maladaptive behaviors may perpetuate the illness. Second, improvement may be effected by altering patients' cognitive model of how symptoms are prolonged and how they should be managed. Cognitive behavioral therapy acknowledges the reality of patients' symptoms and the normalcy and adaptiveness of avoiding activity early in the illness. However, physiological and psychological changes from prolonged inactivity may lead to a progressive decline in activity tolerance. Thus, a vicious cycle may be set in motion, whereby activity exacerbates symptoms leading to further avoidance. The CBT model suggests that it is the combination of physical and psychological effects of inactivity that perpetuate the symptoms, not infection, although that might have been the original cause. Patients must accept the model and are encouraged to continue activity even when there are symptoms. Typically, CBT lasts several weeks. Some CBT advocates suggest involving family to support patients' attempts to change cognitions and behaviors.

CBT studies show mixed results. An early uncontrolled trial, found that CBT benefitted patients who did not hold rigid beliefs in a physical cause of CFS (Butler 1991). A later randomized controlled trial showed CBT was associated with improved functioning in 73% of patients compared with 27% who received only standard medical care.

Moreover, the CBT group showed more change in their illness beliefs and avoidant behaviors which are associated with poor outcomes (Sharpe et al. 1996). Other studies have found CBT to be less effective with CFS patients than depressed controls (Freidberg and Krupp 1994). And, CBT alone or in combination with immune therapy was found to be no better than non specific treatments (Lloyd et al. 1993). That study has been critiqued for the length of treatment (Sharpe 1995), although it was not substantially less than other trials (Hickie et al 1995). Giving both CBT and immunotherapy together might have reinforced patients' beliefs that illness was physical and left them less open to working on social and psychological problems (Sharpe 1995).

Chronic fatigue syndrome remains a lengthy illness with no reliable treatments. Symptomatic treatments may bring about short term relief and a substantial number of patients seem to improve over several years. Several studies suggest that psychosocial factors may mediate improvement.

Sufferers' Illness Experience

While the medical literature shows that doctors are aware of the personal and social consequences of CFS, their biomedical lens focus on its cause, course and management. In contrast, the few studies of illness experiences to date, suggest that sufferers frame the illness in terms of its impact on their lives and how they must cope with it. CFS brings uncertainty, loss of roles, functions and social identities, negative reactions from others, and constrictions in social networks.

Sufferers face uncertainty during extensive and often frustrating diagnostic investigations. Uncertainty in the diagnostic period immobilizes the coping efforts of some sufferers (Ware 1992) while it pushes others to "doctor shop" (Wheeler 1992). Being diagnosed may bring relief because it validates sufferers' beliefs that they are sick (Beaulieu 1994). But it does not remove uncertainty since the parameters of the illness cannot be

specified (Ware 1992). Sufferers do not know how long the illness will last, how severe it will be and whether it will be treatable. Symptoms remit and relapse unpredictably (Woodward 1993; Clarke and Browning 1993; Ray et al. 1992). Nevertheless, Woodward (1993) has found that the diagnosis was crucial to sufferers because it finally allowed them to organize a coherent way of coping with the illness.

The condition profoundly affects sufferers' quality of life. One study using the Sickness Impact Profile Scale[9], found that CFS patients' impairment level was surpassed only by terminally ill cancer patients and patients who had suffered a stroke (Schweitzer et al. 1995). Given this finding, it is not surprising that most sufferers' subtantially decreased the quality and quantity of both paid work and work at home as well as social activities (Schweitzer et al. 1995). Reductions in paid work or loss of work brought financial hardships to many sufferers. In some cases, these difficulties were compounded by legal costs while sufferers fought for social service or private insurance disability benefits (Clarke and Browning 1993; Woodward 1993). Reduced work in the home, often meant dependence on others, loss of freedom (Clarke and Browning 1993) and renegotiation of family roles (Schweitzer et al. 1995; Clarke and Browning 1993). But at the very time when they needed to depend on others, many sufferers experienced strained relationships with families (Woodward 1993; Schweitzer et al. 1995) although with time some families became more understanding (Schweitzer et al. 1995). In addition, as their social activity declined, sufferers found that friends drifted away (Schweitzer et al. 1995; Wheeler 1992; Ware 1992; Woodward 1993; Clarke and Browning 1993).

Severe debilitation and loss of roles threatened sufferers' views of themselves as active, competent and highly involved people (Wheeler 1992; Woodward 1993). But

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[9] The Sickness Impact Profile Scale (SIPS) is a widely used scale to measure dysfunction in twelve categories: alertness, recreation and pastimes, home management, social interaction, work, sleep and rest, ambulation, body care and movement, emotional behavior, mobility, communication and eating (Source: Schweitzer et al. (1995) "The Quality of Life in Chronic Fatigue Syndrome." Social Science and Medicine 41 (10) 1367-72).

negative reactions of others further threatened their social identities. All the studies reviewed, found that at some point in seeking help, sufferers encountered doctors who indicated their symptoms were non existent, trivial, or psychologically caused. Ware (1992) refers to this repeated assault on sufferers' perceptions, both sensorily and interpretively, as delegitimating their experiences. Delegitimation may make sufferers feel ashamed as they begin to doubt the validity of their own experiences and the accuracy of their perceptions (Ware 1992).

Some studies find that CFS sufferers lose self confidence and self esteem (Clarke and Browning 1993; Ware 1992; Woodward 1993). Other studies however have found the self esteem of most CFS sufferers to be well preserved (Powell et al. 1990). External attributions may play a part in preserving self esteem because sufferers do not blame themselves and may be protected from the stigma of a psychiatric label (Powell et al. 1990). The issue of attributions is interesting. As mentioned in the discussion of the chronic nature of CFS, physical attributions are associated with poorer outcomes. Yet. studies consistently show that most sufferers attribute their illness to physical causes when given the choice among physical and psychological or both (Woodward 1993; Wheeler 1993; Clarke and Browning 1993; Powell et al. 1990; Sharpe et al. 1992; Bonner et al. 1994). But, when given the attribution options of physical factors, factors "other than physical", or both, most sufferers choose the combination. The option "other than physical" may be interpreted as encompassing a larger scope than psychological and including behavioural, social, and emotional factors (Ray et al. 1995). Where self esteem is found to be affected, it may be more related to sufferers' loss of roles and functioning.

CFS sufferers cope with the illness in a number of ways. Although some show dominant styles of coping, most use a variety of methods. Sufferers seek information (Ware 1992; Woodward 1993; Ray et al. 1993) most frequently from doctors and support groups (Woodward 1993; Clarke and Browning 1993). They draw on faith and hope, and reframe their suffering to give it meaning. (Wheeler 1992). Some focus helplessly on their

symptoms, to the detriment of both their functioning and their emotional health (Ray et al. 1993).

Before diagnosis, many sufferers used a style of "pushing through" to cope with increasingly distressing symptoms (Woodward 1993). This style of coping is culturally reinforced (Woodward 1993; Wheeler 1993), and seems to be maintained when others do not believe sufferers are sick (Wheeler 1993). But in the long run "pushing through" might be detrimental since symptoms worsen with activity and people in a weakened state may be more susceptible to complications from injury and infection (Woodward 1993). Sufferers who maintain their activites following diagnosis, may do so to keep the diagnosis secret (Ware 1992). But while maintaining activity protects function, sufferers pay a price in high anxiety levels (Ray et al. 1993). Anxiety could presumably be related to both the strain of keeping the illness secret and the strain of trying to keep up while experiencing severe mental and physical distress.

Some sufferers withdraw and isolate themselves (Schweitzer et al. 1995; Ware 1992). This type of social disengagement allow sufferers to avoid demeaning comments, but they also preclude opportunities for much needed social support (Ware 1992). Other sufferers are more confrontational with detractors. Wheeler (1992) found that some women used what she terms a feminist approach, in which they were assertive and refused to silently accept doctors' judgmental attitudes. They insisted on a different, more respectful working relationship. In a similar vein, Ware (1992) found that some sufferers rejected a psychiatric diagnosis by pointing to the somatic nature of their symptoms, objective findings such as swollen glands or increased viral titers, and previous experiences with depression that were different from their current illness.

Finally, some sufferers accommodate to the illness. Accommodation may regulate symptom fluctuations and reduce exacerbations that often follow moderate activity (Ray et al. 1993; Wheeler 1992; Ware 1992; Woodward 1993). It involves active assessment and planning, slowing down, taking care of oneself, and gearing activity to bodily cues (Ray et

al. 1993). To make these changes in level of activity, sufferers must mourn the loss of a previous lifestyle and social identity (Clarke and Browning 1993). But accomodation may eventually help sufferers to gradually construct a new identity, to set goals that fit their new health situation, and be less driven by societal expectations (Woodward 1993; Wheeler 1992). Accommodation preserves emotional health at the expense of some function (Ray 1993).

The illness experience studies are relatively new and few in number. No doubt they will show that CFS sufferers have much in common with other chronic illness sufferers. But they also present the opportunity to delineate the unique ways in which a contested illness impacts on sufferers' lives.

Summary and General Study Questions

The preceding review shows considerable debate about and discontent with the naming and framing of CFS. Some sufferers and doctors object to the label, the case definitions and diagnostic guidelines, and casting the illness as physical or psychological. The illness experience literature describes the impact of CFS, sufferers' ways of coping, attributions, and help seeking experiences. Together, both the biomedical and illness experience literature suggest that CFS is stigmatized by characterizations of malingering or psychological disorder and legitimized when it is considered a physical illness. But the evidence does not suggest that any one position is more convincing than another. Thus, identifying the bases on which sufferers and others stake out various positions became the focus of this study.

This study differs from the existing literature in several ways. First, most of the medical literature reflects academic medicine's response to the illness with the objective of finding out its cause, pathophysiology, and effective treatments and with less emphasis on the clinician in the field. Woodward's dissertation (1993) shifts that emphasis and focuses

on why clinicians were reluctant to make and give the diagnosis. The present study also examines how CFS impacts on clinicians in the field, how they make the diagnosis, how they deal with an illness that is difficult to manage and how they decide on definitions of the illness.

Second, the literature on sufferers' illness experiences inevitably address the issues of stigmatization and legitimation. The present study covers similar grounds, but stigma and legitimation are the major focus. As well, it highlights the role of support groups in coping with CFS which, to the best of my knowledge, has not been addressed systematically elsewhere. Third, the literature is virtually silent on the impact of CFS on private disability insurance, although it is known from sufferers' accounts that disability compensation is a major issue. To date, there is only one published study on the subject. Lloyd and Pender (1992) estimated that CFS costs the Australian government $26 million per annum in health care, sickness benefits and invalid pensions. In 1990, a medical journalist covering the annual meeting of the Canadian Life and Health Insurance Association, reported that one company estimated that CFS accounted for 88 out of 20,000 or 0.42% of its group disability claims (Lechky 1990). Although this number is small, the age of claimants, indefinite duration of the illness, and high pre-disability salaries, makes CFS a potentially costly illness for insurance companies. In the present study, I explore the non financial impact of CFS on insurance companies.

Finally, through sufferers' accounts it is clear that families are sometimes deeply affected and family relations often become strained. But the family's perspective on the experience of living close to someone with CFS has not been addressed. The gaps identified in the literature and the conclusion that the evidence does not clearly support either legitimizing or stigmatizing the illness led to the following two main study questions as well as several subsidiary ones:

1) How do people in crucial social roles stake out positions that stigmatize and legitimize CFS when so much about the illness remains in dispute?

2) How do sufferers maintain their illness convictions in the face of widespread disbelief and suspicion about CFS?

How do sufferers and others define CFS?

What are the bases of these definitions?

Do the definitions of others legitimize or stigmatize the illness?

How are sufferers and others affected by CFS?

How do they manage the impact?

What is the relation between impact and stigmatization or legitimization?

CHAPTER 2

RESEARCH METHODS

Once the decision was made to examine multiple perspectives on stigmatization and legitimation of CFS, a study of four related cross sectional investigations was designed. I was interested in a range of societal reactions from people whose views and behaviors were informed by dealing regularly with sufferers, not simply by media publicity, or literature from support groups or the medical profession. The methodological challenges lay in developing sampling and recruitment strategies as well as interview schedules that would tap both common elements across groups and elements that were specifically relevant to each group. Prior to conducting the study, I had informally interviewed six sufferers, two doctors, and two insurance representatives about CFS and formally interviewed twenty one CFS subjects for a large Somatic Syndromes Project (Kirmayer, Robbins & Taillefer 1995)[1]. These interviews contributed to the development of semi-structured interview schedules for the samples of families, doctors, and insurers.

Sampling and Recruitment Strategies

Originally, the study was to be conducted in one large metropolitan area-Montreal, with the sample of sufferers drawn from the Somatic Syndromes Project. Samples of family, doctors, and insurers were to be drawn specifically for this study.

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[1]The final report to the granting agency was published in 1995. Kirmayer, Laurence J., James M. Robbins, and Suzanne S. Taillefer. 1995. Development and Validation of a Structured Diagnostic Interview for Functional Somatic Syndromes. Final Report to the Fond de la Recherche en Santé du Québec.

Since there was no way to identify the family or friends of people with CFS, they would have to be referred by sufferers. But doctors and insurers could be recruited either through sufferers' referrals or through professional and organizational listings. I chose to use sufferers' referrals.

Sufferers' referrals were more useful than organizational lists given the resources available to conduct the study and the decision to restrict doctors and insurers to those who have had experiences with CFS. Sufferers see a range of physicians which mirrors the range of their symptoms. Therefore, potential doctors that would have to be considered included general practitioners, general internists, family medicine physicians, neurologists, psychiatrists, infectious disease specialists, immunologists, and rheumatologists. Even in a single large city, lists of these doctors would be extensive. In addition, there are 150 Life and Health Insurance companies in Canada that could possibly have been involved with CFS claims. However, official lists give no advance indications of whether insurance companies or doctors have experience with CFS. Finding those who had regular contact with CFS sufferers by random mailings or telephone calls could be time consuming and inefficient. Comprehensive mailings or calls, on the other hand, would be prohibitively expensive. For these reasons, I asked sufferers to provide names of: one or more doctors they had seen, a significant other who might be willing to discuss what it was like having someone close with CFS, and their insurance company if they had ever received disability compensation. Sufferers were given the opportunity to peruse the interview schedules to be used with others if they wished to do so before providing me with names.

For ethical and practical reasons, I decided that doctors and insurers would not be asked about the specific sufferers who had referred them. Instead, they would be asked only about their general approaches to people with CFS, their views on the condition, and how the condition had impacted on their business or practice. To move

beyond a purely modal picture, doctors and insurers would also be asked about typical and atypical cases.

The decision was based on four assumptions. First, I believed that a general approach would be more acceptable to doctors and insurers as well as to sufferers on ethical grounds. The traditional relationship between sufferers and insurers and sufferers and doctors is based on the principle of confidentiality which is enshrined in professional codes of ethics. Recent privacy laws in[2] Canada have strengthened this principle by requiring individuals and organizations, that have a fiduciary relationship with the public, to obtain written consents from individuals before releasing information to third parties. Even if sufferers' consented, I believed that doctors and insurers would not agree to an interview to discuss identifiable individual cases. Second, I assumed that many sufferers would balk at consenting to have personal information, that they might be unaware of, disclosed to a third party. After all, not many people know the contents of their own medical files. Such disclosures would also put me in an untenable position if sufferers asked me about the contents of their files. I would have to withhold from them information to which they had allowed me access in the first place. But if it was clear that no personal information would be sought, sufferers might be willing to provide me with names with no expectation of obtaining reports of their files. Third, it was assumed that doctors and insurers might be less willing to participate in the study if it meant having to review specific files.

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[2] In January 1994- *the act respecting the protection of personal information in the private sector*- was passed into law. On the one hand, it aims to ensure the confidentiality of all personal information recorded in the files of private corporations in Québec and on the other, it allows individuals to have access to their files under specific conditions. The individual may have access free of charge, but transcripts require a small fee. The person may have information corrected and information not authorized by law deleted- since only personal information necessary to the purpose of a file may be recorded therein. Corporations must inform the public of where files may be accessed as well as the methods by which this may be done. (The Journal-vol 1 number 4 mar/apr 1994- supplement to L'infirmière du Québec p.4)

Finally, it was assumed that doctors' and insurers' who regularly deal with CFS sufferers and claimants do not respond in an arbitrary and ad hoc manner. Rather, they use guidelines, cues, or principles, even if vague or unarticulated. Therefore, general or patterned responses might actually reflect how doctors and insurers had behaved with any given sufferer more accurately than reconstructions of specific cases from memory or notes.

Two modifications were made to the original plan to use one large metropolitan site and to recruit subjects from the Somatic Syndromes Project. When a large enough sample of sufferers proved more difficult to obtain than had been expected, it became obvious that the size of other samples generated through sufferers was also at risk. Not all sufferers could name a significant other who they thought would be willing to be interviewed and not all sufferers were involved in disability compensation. These issues in the patient sample threatened to reduce the size of the other samples. As a result, a second large metropolitan area- Toronto was added to increase the sample of people with CFS and support groups were approached to recruit subjects. The remainder of this section describes the recruitment of the four samples and discusses issues related to the sampling technique.

Sufferers and family members were initially contacted by telephone and doctors and insurers were sent an introductory letter. The aim of the letters was to assure potential subjects that I was a bona fide student, carrying out research that had been reviewed and approved, and that would be supervised. I felt this was necessary in view of the negative publicity that both doctors and insurers have received regarding CFS. I thought my requests might be met with suspicions about who I was and what my 'real' purposes were. The letters outlined my status as a doctoral student, the purpose of the study, the nature and approximate length of the interview, assurance of anonymity, and advance notice of a follow up telephone call. Members of my thesis

committee agreed to act as appropriate contact persons, should a problem arise (See Appendix A for letters).

When sufferers and family members were first contacted by telephone, a standard approach was used to convey the information about the study that doctors and insurers had received by letter (see Appendix B for standard phone calls). All potential subjects were given the opportunity to ask questions before deciding whether to participate. These discussions lasted from a few minutes to almost an hour and covered issues such as who was funding the research, concerns about confidentiality, the reason for my choice this particular topic, the number of other participants to the time of my call, and practical payoffs of participating. The most frequent reaction from sufferers and from some insurers and family members was appreciation that someone was taking an interest in studying the condition. A date, time and meeting place was arranged with subjects who agreed to participate.

CFS sufferers

Forty four subjects were recruited from three sources. Some subjects were approached at the time that I was arranging a brief (fifteen minute) one month follow-up for the Somatic Syndromes Project and asked if they would be willing to participate in the present study immediately following that interview. These subjects were drawn from the practices of physicians. Of a possible twenty two subjects, four declined. Two others did not believe that they had CFS despite their diagnosis, and another had a chronic psychiatric disorder that might have explained some of the symptoms. These three subjects were not asked to participate in the current study. The remaining fifteen subjects agreed to participate.

Support groups became a second source of subjects. I sought permission from leaders of one urban and one suburban support group in Montreal to address a meeting

to explain the purpose and conduct of the study, answer questions, and leave written instructions for contacting me (see Appendix C). The two leaders also provided the names and telephone numbers of a few people who were not present at the meeting but who they thought would be interested in participating. Twelve subjects were recruited in this way. Leaders of associations in the two cities were a third source of subjects. They provided names of members and I contacted these people. One subject whose name had not been proposed, contacted me and asked to participate. This person would not reveal how she came to know of the study, saying only: "You can't conduct a study like this, without the grapevine hearing about it." This, in a city of some two million people! Two people could not be reached after repeated tries and two refused yielding a sample of sixteen people referred by association leaders. The forty four people who agreed to be part of the study represent 87% of those asked.

Criteria for inclusion of sufferers were held to a minimum. Sufferers had to speak English and have a diagnosis of CFS from a medical doctor. A medical diagnosis was important although the reliability of the diagnosis cannot be ascertained. As the review of medical issues showed, there is no standardized way to diagnose CFS in general medical practice. As a result, different doctors may use different criteria. In addition the problems in diagnosing the condition may increase false positive cases. However, it was assumed that a physician's diagnosis is more reliable than self diagnosis because of physicians' greater knowledge of other conditions with similar symptoms and because the process of diagnosis involves eliminating other plausible explanations for symptoms. Thus, physicians were likely to have made some attempt to exclude other conditions prior to diagnosing CFS. It may seem contradictory to insist on a physician's diagnosis while acknowledging the problems of unreliability of such diagnoses. But an important aspect of this study was to examine others' reactions to people who presumably had a legitimate diagnosis of CFS. A further important issue was to examine what sufferers' experiences were like once they had

received such a diagnosis. One person was excluded from the analysis after it became clear, well into a lengthy interview, that a physician had not confirmed his self diagnosis. The final sample consisted of forty three people who acknowledged that at least one physician had confirmed the diagnosis of CFS.

Sixty three percent of the sample were women and 37% were men. Forty four percent were married, 21% divorced, 30.2% had never been married, and 4.6% were widowed. Twenty six percent were in school or working full or part time. Sufferers' median household income fell in the $30, 000 to $39, 999 range. In general, they were well educated with 15.4 mean years of school which indicates some university training. Years of schooling ranged from 10 years to 20 or more. The earliest and latest ages at which the illness began were 15 and 58 respectively, with the mean age at onset being 34.2 years. Sufferers had been ill for an average of 7.0 years.

Significant others

Sufferers were asked for permission to contact a significant other who would be willing to discuss how they understood CFS and how they had been affected by having someone close with the condition. They were offered the opportunity to review the interview guide which would be used for family members or other significant persons. Twenty eight of the forty two sufferers suggested someone. Four family members declined and one could not be contacted before I had to leave Toronto. The remaining fourteen subjects did not suggest someone for a variety of reasons, but no refusals followed perusal of the interview schedule. Sufferers refused because they had no close family or friends in their respective cities, they did not feel comfortable offering the names of others, significant others did not know they had CFS, family members were themselves severely ill, or were minor children. Eighty two percent of the significant others who were contacted, agreed to participate. The final sample of

twenty three people included friends, parents, spouses, adult children and a sibling. Sixty nine percent of these family members and friends were working. They were generally well educated with 16.2 mean years of schooling.

Insurers

Eighteen people with CFS were receiving some form of income replacement. Two were being paid from government programs, two from professional associations and the rest from eight private insurance companies. The latter were the focus of my interest. A ninth company may have been involved, but one person declined to give the name of his insurance company even after reviewing a copy of the interview schedule that would be used with insurers. One person asked me not to contact his company and I agreed. Six of the eight companies were eventually contacted, one of whom refused. The remaining five were supplemented by six other companies, who had experience with CFS, though not with sufferers in the study. These companies were suggested by other insurance interviewees. Eleven companies, representing 84% of those asked, agreed to participate.

Although this is a small number, an internal survey conducted by the industry to determine insurers' experiences with CFS, netted interest from twenty one companies and actual data from only twelve of the one hundred and fifty Life and Health insurance companies in Canada (personal correspondence)[3]. The small participation rate may have been due to the fact that statistical data was sought. My own requests for such data revealed that many companies do not store the type of data

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[3] The company that conducted the survey refused my request for the final report citing ethical reasons. Participants had not been informed at the time of their entry into the study that results would be available to people who were not members of the Canadian Life and Health Insurance Association (CLHIA). Their written response to my request mentioned the low participation rate.

I was requesting or, if they did, it was not in easily retrievable form. Some companies, for example, stated that they did not categorize disability claims by conditions bringing on the disability.

Several insurers who agreed to participate in the present study suggested that I interview people at different organizational levels. Some companies offered the opportunity to interview more than one person since disability compensation involves a division of labor that reflects the specialized tasks of dealing with a claim. The sixteen people who were eventually interviewed included underwriters, vice presidents, medical consultants, claims or benefits supervisors, adjudicators and rehabilitation consultants. They had been working in insurance for two years to twenty years. They estimated that they had seen from two to almost three hundred CFS sufferers.

Doctors

Thirty two CFS sufferers supplied names of twenty two health professionals with whom they had dealt. Telephone calls were made approximately one week after the estimated arrival of the introductory letter. Up to two calls were made. Potential subjects were dropped if they did not respond to messages left with their offices within a three week period after the second call. Based on this criteria, five physicians were dropped. Two could not be contacted at all after repeated attempts. Perhaps they had moved or retired. Two other physicians refused. Thirteen health professionals agreed to be interviewed in person or by telephone. My own professional network referred two other physicians to the study. Fifteen health professionals participated for a response rate of 65%. They included general practitioners, mental health professionals including one who was not a physician, infectious disease specialists, immunologists and rheumatologists. There were ten males and five females. They had been in practice

from six to seventeen years and individually had seen from six to almost one hundred cases.

Disadvantages and advantages of the sampling technique

All four samples were non random, criterion-based samples. Sufferers had to have a diagnosis of CFS and others had to have had regular direct or indirect contact with CFS sufferers. The strategies for generating the samples raise two related issues. First, I was seeking a broad range of views and reactions from people who deal regularly with CFS sufferers. One method of eliciting diverse perspectives on a phenomenon is to sample for maximum variation. This type of sampling may allow the emergence of views from people representing a range of power (Fay 1987) and also surface positions that challenge the researcher's a priori or incipient hypotheses (Guba and Lincoln 1989 cited in Crabtree and Miller 1992: 37). The groups of doctors, insurers, and family members are diverse with respect to their specialties, organizational roles, and relationship to sufferers. They also stand in various power relationships to sufferers. But sufferers tended to refer doctors and family members who were more or less sympathetic to their plight, although they did refer a minority who still had doubts about the illness or had done so in the past. Also, the insurers who agreed to participate did not include anyone who completely rejected CFS, although several admitted to doing so in the past, and some remained skeptical. As a result of the referral patterns, self selection, and possible social desirability biases in responses, the sample probably does not achieve maximum variation. Rather, it underestimates negative reactions to sufferers.

A related issue concerns the use of support groups and associations as sources of the sample of sufferers. Sufferers who join support groups may share common but unknown characteristics that influence them both to join groups and to respond in

similar ways. Thus, they may provide a specific view of the phenomenon. As well, groups themselves might influence the views that sufferers eventually hold. However, the inclusion of a group of sufferers through physician referrals, increases the chances of obtaining a broad cross section of sufferers with a variety of illness experiences.

Sufferers referred by physicians were somewhat different from those referred by support groups. The physican referred group had more women (73% versus 61%). There were no differences in the percentage of sufferers who were currently married (46.6 % versus 46.2%) but the physician referred group had fewer divorced people (13% versus 19%) and more people who had never been married (40% versus 27%). This may be related to the fact that almost 75% of the physician referred group were in their early twenties to early thirties at the time of onset, while only 37% of support group sufferers were. None of the physician referred group were widowed but a small number (7.1%) of support group sufferers were. More of the physician referred group were working (27% versus 15.4%) and their median household income was much higher than that of sufferers from support groups ($50,000 to $59,999 range versus $20,000 to $29,999 range). The mean years of education was slightly higher for the physician referred group (16 versus 14.1). This group became sick at a younger age (mean age of onset was 32 versus 35.7 years) but there was no difference between the groups in the average duration of illness (7.0 versus 7.2 years).

The advantage of using support groups and associations in studying a stigmatized condition is that it greatly facilitates access to sufferers. People with stigmatized illnesses may manage information in ways ranging from total concealment to being public spokespersons. Indeed, one sufferer who lived at home could not provide me with the name of a family member because the family was unaware of the situation. Concealing illness from family members living in the same household has also been noted in people with epilepsy (Scambler 1984). In contrast, another subject has spoken out on televised documentaries of CFS. The depth of concealment that

sufferers may desire, places leaders of associations and support groups in a gatekeeping role. Individual leaders played out this role differently. In one city, the full names of potential subjects were given to me in a matter of fact manner. In the other, one leader felt strongly that only first names should be provided. Some sufferers who were suggested had expressed a general interest in participating in CFS research. But others were probably contacted specifically to ascertain whether their names could be passed on to me.

Besides the human gatekeepers, sufferers had technological gatekeepers. Most sufferers had telephone answering machines or call display which shows the number from which calls originate. In many cases, my first attempts to contact sufferers by phone were diverted to answering machines. Initially I did not leave messages. But after many unsuccessful attempts to reach people at various times of day, I began to do so. I suspect that sufferers used these machines not only to record messages when they were unavailable, but to screen and control who had access to them. I began to leave a simple message: "X (support group/association leader) gave me your name and said that you might be willing to talk to me" along with my name and number. The call was always returned. The names of support group and association leaders were probably an important entrée to sufferers, since they provided a clue to the reason for my call, without revealing information that sufferers might wish to conceal from others in their household. It is quite likely that many thought that I was a fellow sufferer seeking their support. When people were reached directly, the names of association and support group leaders probably indicated that I had already passed a first level of screening and should at least be given a hearing.

Sources of data

The main sources of data for the study came from interviews with sufferers, a family member or close friend, health professionals, and representatives from insurance companies. Support group documents supplemented interviews with sufferers. These documents provide a level of response to negative reactions that is different from the individual interviews. Two insurance companies provided small data sets that corroborated and extended the interview material.

Procedure

Ninety seven interviews spanning two large and two small cities in Canada were conducted in the period from July 1993 to October 1994. Interviews took place in people's homes, their offices, my office, or in neutral public places such as coffee shops or, in good weather, in parks. A few doctors were interviewed by telephone. These doctors were returning my follow call to an introductory letter, at times when they had fifteen minutes or so to answer questions. I took the opportunity to do the interviews by phone rather than risk losing them by insisting on face to face meetings. Differences between face to face and telephone interviews seemed to be a function of time rather than the medium. Doctors seemed to relax with time and provided more details in longer interviews.

All participants who were interviewed face to face were asked to sign written consent forms that included: the study's purpose, areas of questions to be asked, approximate length of the interview, assurance of anonymity, the option to withdraw from the study at any time, and thesis committee members to contact should there be questions or concerns about the study. A separate statement, requiring a separate signature, was added at the end of the consent form seeking agreement to tape the

interviews. Sufferers were also asked to sign a separate consent form agreeing that I could contact a significant other. (See Appendix D for the five types of consents).

Seventy eight percent of those who agreed to face to face interviews also consented to taping. These tapes were later transcribed. For telephone interviews and interviews in which people refused to be taped, notes of key words and phrases were taken. These notes were elaborated as soon as possible after the interviews.

The four interviews are outlined below. Interviews consisted of demographic variables, questions on how people understand CFS and the impact that it has had on them. The first several interviews in each group ended with a general question asking whether from the respondent's perspective important areas had been omitted. As a result of this query, one question about views on support groups was added for insurers, and one question about sufferers' experiences with help seeking was added to the interview with family members. (For the full interview schedules see Appendices E, F, G, and H)

Patient Interviews

The interview schedule for people with CFS was modified from the Somatic Syndromes Project which consisted of a mixture of structured and semi structured questions. During interviews that I conducted for the Somatic Syndromes Project, it became clear that CFS subjects wanted to respond with finer differentiations and nuances than allowed by structured, forced choice answers on Likert type scales. Therefore, in the current study subjects were given broad latitude to elaborate on answers to any questions including those that were structured and forced choice. These questions were retained in the present study to provide gross validation of information on the same issue gathered at different points in the interview. This form of triangulation or getting the same information in different ways, is one way in which information may be compared for consistency in a cross sectional study such as this.

Questions were not repeated if sufferers had already responded to them in the process of answering an earlier question. Instead, I paraphrased my understanding of their responses, and asked for their confirmation. The interview schedule was used to assure that all areas of interest were covered. If subjects did not spontaneously address issues in response to the question asked, probes were used to elicit the information.

Interviews with sufferers focused on five main aspects: symptom experiences including onset, duration, severity and pattern of waxing and waning; the impact of the illness on roles and functioning; sufferers' beliefs about cause; attempts to manage the illness through help seeking and treatment; and reactions from health professionals and disability insurers if applicable.

Family Interviews

The interviews with family or others close to sufferers, covered three main areas: knowledge about sufferers' experiences such as when symptoms began, the duration, severity, help seeking and pattern of relapses and remissions; ideas about cause and treatments that might be helpful; and how having someone close with CFS had affected their lives.

Insurer Interviews

Insurers were asked about five main areas, the company's routine handling of claims; experience with CFS claims; responses to the challenge of CFS and views about cause and duration of the condition. Insurers were also asked about their specific roles in dealing with CFS claims. Questions about the company's experience with CFS claims included the adjudication process, changes to the process over time, the longest and shortest periods for CFS and when claims began. A question on insurers' views

of support groups was added at the suggestion of the first person who was formally interviewed.

Doctor Interviews

Doctors were asked to respond to five areas: their approach to diagnosing, explaining and treating CFS, their views on support groups and alternative therapies, whether their thinking about the illness had changed over time, impressions of typical and atypical patients and what was most challenging in dealing with sufferers.

Analytic strategy

The analytic strategy for the interviews consisted of examining the data at three levels. First, transcripts of each interview were summarized according to the broadest content areas of questions. Summaries were then pooled according to categories and read and reread for recurring themes and variations in the first gross categories. Through this process, it became obvious for example that doctors were proposing three types of causes to explain the condition, five different labels, and the same three modalities of treatment. It also became clear that doctors feel the impact of CFS as they define, diagnose, explain and treat the illness.

At this point, I developed codebooks with operationally defined codes and/or subtle exemplars. Since I did not have a second coder against whom to check the fit of data to the categories, I followed Miles and Huberman's (1994) suggestion that lone researchers recode a percentage of the data a few days after the initial coding. I recoded 20% of the data from each group. Discrepancies were matched against definitions and other examples before a final decision was made. I also reviewed the material for information that did not seem to fit the existing codes, information not previously

recognized or known, and links between categories of information. Through the latter process I realized that treatment failures affect clinicians most deeply.

In the second level of analysis, I tried to connect the findings to some larger picture of the group. Thus, doctors' reactions as they defined, diagnosed, explained and tried to treat CFS suggested that they were merely carrying out their usual functions associated with the role of physician. But the outcomes were particularly unrewarding as patients did not get well. It seemed that doctors were exercising the authority granted by society in a situation where they had little basis for being authoritative. This level of analysis connected the more obvious findings to deeper aspects of the societally mandated role of physicians.

The third level of analysis, which is presented in the final chapter, compared categories of information across the four groups searching for similarities and differences in others' reactions. One finding that emerged from these comparisons is the fact that people in different social locations have access to different information about sufferers. Some family members see sufferers on a daily basis, with all the variations in severity that occur over extended periods of months or years. Doctors see patients intermittently, even if regularly, and only for brief periods. Insurers see patients least of all. Depending on their job, some insurers work only with paper, although they receive reports from their own employees who may see claimants. The relatively more detached position of insurers provides them with a different picture of sufferers' experiences, which in turn may influence their reactions.

Ethical considerations

The overriding ethical concern during data collection and the writing of this report was the anonymity of subjects. This concern applied as much to sufferers as it did to those who react to them whether sympathetically or not. It applied within groups

and across groups. The concern was highlighted because of the small size of the samples, some participants knew each other, and in some cases, the groups represented power differentials and competing interests.

All subjects were informed that the research included interviews with people from the other groups. On a few occasions, numbering perhaps six out of the ninety seven interviews, subjects asked for identifying information on others within their group or across groups. For example, one insurer asked what other companies I had sampled. A few sufferers asked whether I had interviewed another sufferer whom they knew or what a family member had to say about them. The very rarity of these requests was a problem because it was unexpected. The issue was not that I had to absolutely guarantee the anonymity of all participants. But my response had to both guard the identities of subjects and demonstrate sensitivity to those making the requests. As well, some of these requests came at the time that I was asking prospective subjects to participate in the study. My strategy was to point out that just as I had promised them anonymity, should they agree to participate, I had also made the same promise to all other participants. No one refused to cooperate with the study following such an explanation. In fact, it might have increased their confidence that their own identities would not be disclosed.

A more difficult issue is reporting data in a way that achieves a balance between including so much context that the person may be identified by a series of small events or characteristics and decontextualizing the data and therefore distorting its intent or introducing biases. This was especially problematic when family members disclosed information that they incorrectly assumed their sick relative had already told me. Or, when they presented a view of their relationship with the sufferer that was in marked contrast with what I had been led to believe. In such cases, the information was summarized to its essence, without identifying details, and the gender of the sufferer or relative was changed in the report.

Possible physical and emotional effects of the interview on sufferers was a second concern. Before the interview began, sufferers were told that if they felt fatigued at any time they should take a break or continue the interview at a later date. In addition, at various points in the interview I offered subjects the opportunity to take a break. Only one person completed the interview over two sessions. That interview lasted some five hours. Several took short breaks during the interview because of fatigue. I also suggested breaks when strong, negative or painful feelings were obviously close to the surface. A few cried as they recalled reactions of others or the impact of the illness on their lives. At these times, I gave sufferers the option of discontinuing the interview. No one did so. I sat with them and asked what, if anything, had helped them to cope with these difficult issues. This gave them the opportunity to review how they had been able to carry on despite the effects of this illness on their lives, or in some cases to reveal the central meaning that this illness held for them. In one case, no coping strategies seemed effective and in two others, the depth of their emotions lingered through the rest of the interview. The majority, who commented, appreciated the opportunity to tell their story in its entirety. Some felt that they could no longer discuss their illness experience with friends and family who had grown tired of hearing about it.

Reliability and Validity

If the researcher is considered the instrument in qualitative studies the question of replicability may seem moot. Nonetheless, some qualitative researchers have begun to argue for better descriptions of methods and procedures that could facilitate replicability (Miles and Huberman 1994). In this account, I have provided a detailed description of the conduct of the study including all major decisions and revisions as well as the underlying assumptions or rationale.

The study relied mainly on subjects' recall in the period of a single interview. Threats to the validity or truthfulness of the data arise from this method because of recall accuracy, biases in presenting information in the best or worst possible light, and intentionally screening and withholding information because trust in the researcher may not have been established. Triangulation of methods and sources of data were the main means assuring the trustworthiness of the information. Some aspects of the internal consistency of narrative accounts could be checked by single structured questions. Family members provided the best external validation to the main elements of sufferers' accounts. But the general accounts of their doctors' and insurers' were also largely consistent with what sufferers had reported. Where discrepancies were found, the narratives provided clues to explain such findings. For example, when different sufferers reported different reactions from the same doctors or insurers, the accounts of doctors and insurers sometimes revealed that over time shifts had occurred in their ideas and approaches.

Finally, based on the work of Kuzel and Like (1991), Crabtree and Miller (1992) suggest that the validity of conclusions is strengthened by sampling strategies that search for subjects who disconfirm a priori hypotheses or emerging theories, by "thick descriptions" of settings and contexts, by connections with existing theory and by delineating the generalizability of the findings (Crabtree and Miller 1992: 86-88). The intent and limitations of the sampling strategy have already been discussed. In the empirical chapters, I contextualize the analyses with qualifiers of themes and patterns to the extent that they are known and link conclusions to the appropriate literature.

CHAPTER 3

THE CHALLENGE TO CLINICIANS: TREATING THE PATIENT NOT THE DISEASE

"Our ultimate goal is to treat, always the patient never the disease..." Crawshaw (1990)

Conflicting medical findings and opinions about CFS left the practicing clinician[1] with a fundamental problem: how to think about and manage an illness in which patients' self reports are largely uncorroborated by physical examination and laboratory findings. In such circumstances, each clinician must decide on the illness' reality and nature as well as appropriate treatments. This chapter describes fifteen clinicians' struggles with such decisions. It shows how their perspectives and reactions were shaped by the interplay of three elements of their social location: frames to assess and dispose of unconfirmed complaints, experiences with patients, and the cultural authority to define and treat illness.

The analysis of clinicians' perspectives draws mainly on Freidson's (1970) observation that personal clinical experience plays a key role in doctors' concepts of illness and on Dodier's (1994) scheme of frames which he developed through studying occupational doctors[2] in France. Freidson (1970) suggested that when doctors do not agree

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[1]Since the sample included one health professional who was not a physician, the term clinician will be used frequently throughout this chapter when speaking of the sample generally. When speaking specifically of doctors or the process of diagnosis, which involves medical laboratory examinations that only doctors may authorize, I will use the term doctors. In the medical literature, clinician, practitioner, doctor and physician are all used interchangeably to denote the practice role. Four doctors were consultants whose role was to verify the illness or to confirm there were no other causes such as infections. Normally consultants do not follow referred patients. But in this group, all except one, followed a small group of CFS sufferers.

[2]In France occupational doctors perform yearly job fitness evaluations which employers must take into account in assigning work tasks. These doctors are recognized as experts in determining eligibility for sick benefits. Employees

on the diagnosis and management of a contested illness, varying concepts of illness will be sustained by personal clinical experiences. But these experiences are further constrained by "patients' conceptions of illness [which] place limits on the number and kinds of cases the doctor will see, thereby influencing his conceptions of the components of illness...[and] whether or not an illness 'exists'"(Freidson 1970: 277).

Dodier (1994) identified occupational doctors' conceptions of illness by examining the frames they used to assess and dispose of complaints with little or no objective evidence. The different frames which he derived put varying emphases on objective findings, strategic behaviors or motives, and the medical principle of doing something to help the patient. Of interest to the present analysis are the clinical, solicitude, and psychosomatic frames. In the classical clinical frame, objective evidence is paramount. When such evidence was weak or absent, doctors who used a strictly clinical frame searched vigilantly for secondary gains and often concluded that workers were malingering. However, similar cases could be viewed through a frame of solicitude in which patients' subjective experiences superseded objective findings. Doctors who used this frame admitted that they could not be certain of what patients were experiencing. They were therefore willing to give patients the benefit of the doubt and granted them sick rights. They justified their decision by the medical principle of doing something to help the patient. A psychosomatic frame provided a third option for occupational doctors. Here, the doctor looked for underlying psychological factors, often grievances, to explain symptom complaints. They could pronounce psychiatric diagnoses and treat or refer accordingly, or they could mediate between the patient and the offending party. Doctors usually used a consistent frame to assess and dispose of complaints, but sometimes they ruptured the

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or employers may request a medical consultation at times other than the mandatory yearly examination.

assessment frame in treatment. Dodier's aim was to show that doctors' work is far more complex than the classical clinical frame, described by Foucault (1973)[3].

To appreciate clinicians' struggles in dealing with CFS, I draw mainly on Starr's (1982) analysis of medicine's authority to define and treat illness. Starr (1982) proposed that medicine's claim to both social and cultural authority rests on specialized knowledge, developed through rational inquiry and empirical evidence. This scientific base gives medicine the legitimacy that allows its definitions of health and illness and its definitions of relations with other social actors to prevail. The scientific base also casts others, especially patients, in a position of dependency. Patients must rely on doctors for access to sick benefits and for physical and psychological care that may mean the difference between restoration to function and disability or even death. I argue that in dealing with CFS, doctors enter an arena in which the state of medical knowledge undercuts their authority and that their responses to CFS, whether stigmatizing or legitimizing, can be understood in terms of severe constraints on their ability to act authoritatively.

Framing CFS: Reality and Nature

Medically defining CFS involves two debates- one about the reality of the condition the other about its nature. Two issues frame the discussion about reality. The first is whether CFS is a legitimate illness or an example of malingering. This question arises from the absence or paucity of objective findings relative to the degree of disability claimed. The second issue is not concerned with reality in the sense of whether illness exists, but with whether a new syndrome exists which deserves a separate classification. This issue arises because of observed similarities between CFS and already classified conditions, notably

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[3]See also Reiser, S. J. 1981. Medicine and the Reign of Technology. Cambridge MA: Cambridge University Press for a historical evolution of the clinical frame and various assaults on it in the early twentieth century through the mid 1970s.

depression, and because some clinicians questioned whether the disparate symptoms of CFS constituted a specific illness. In this study, clinicians were not specifically asked about their views on the reality of CFS, but several spontaneously volunteered opinions. To decide whether the illness was real, they used social judgments about patients, the medical literature, and discussions with colleagues as proxies for objective evidence.

Views on Reality

No clinician suggested that CFS patients were malingering, but some specifically underlined why they thought patients were not. Some clinicians found the sudden onset of illness and protracted recovery of otherwise well functioning young people unusual enough to believe there was "there's something there...these people are not crazy". Many saw patients who brought literature on the illness and its treatments, continued their social roles long after symptoms began, and attempted to resume activities at the first hint of remission. They evaluated these behaviors as evidence of actively seeking to resolve the problem, reluctance to enter the sick role, and eagerness to leave it. They saw no indications of secondary gains.

> When symptoms start they don't stop they run faster...they want so badly to get well that on good days they end up putting too much energy out, then they relapse...they want to prove...I am not malingering.

Other clinicians saw patients whose lives had been "ruined by this illness" as they lost their livelihoods, their valued active lifestyles, and their families. They were also hard pressed to find secondary gains from this illness.

> These are very intelligent people...they are really trying [to get better] but with modern life so complex, add this to the soup and the whole thing falls apart...Families don't want to deal with it, they don't believe in it, or they get fed up after months of the person not doing anything. Some get divorced. I know one [person] whose wife had it. They got divorced. He couldn't deal with it.

On the issue of whether CFS was a new and separate illness, some clinicians were doubtful. These clinicians were impressed by the similarities between CFS and post-viral-fatigue, neurasthenia, and asthenia. Their knowledge of these illnesses came from their own clinical practice and the medical literature since the terms neurasthenia and asthenia are rarely used today. To these clinicians, CFS was merely a new name for an old illness.

> I am not convinced that CFS is a new disease...I think it is the same as neurasthenia. The literature on that condition is almost the same. [It is a case of] different names at different times.

> I tell them [patients] that I, and many other doctors see CFS like symptoms among our patients with infectious illnesses.

What is interesting is how the symptoms of CFS led these clinicians to other poorly understood and contested illnesses.

Finally, in terms of the reality of CFS, some clinicians initially believed that CFS was a collection of unrelated symptoms rather than a discrete illness or syndrome. They had reason to rethink their position after noting striking similarities in sufferers' accounts. As they saw more patients, they became convinced that all could not be fabricating the same symptoms.

> At first I was not really convinced that it was a syndrome. I thought it was a group of different problems, this was not long ago...as I have seen more patients, I see more clearly the similarities in symptoms than I did before...[now] I think of it more as an entity than a bag of different diagnoses.

They were further persuaded that CFS was a bona fide syndrome by colleagues who had considerable clinical experience with the illness and by expert opinions in the literature.

In considering the reality of CFS, these clinicians concluded that the illness was not a guise for malingering, that it may represent a singular syndrome, but it is probably not new. They had ruled out secondary gains, evaluated patients' characteristics and sick role behaviors, and examined characteristics of the illness. They used a frame of solicitude to give patients the benefit of the doubt that illness was present: "these people are not malingering" "there's something there". This frame was not constructed from objective evidence, but from social judgments about patients' credibility. Credible patients fit social

norms of sick role behavior, statistical norms relative to age and health status, and prototypes of known illnesses. Credible patients also rendered accounts that were similar to others. One doctor's colleagues helped to neutralize his lingering doubts about whether the illness was a syndrome. Believing that CFS was real, was the first step towards legitimation.

Etiological Frames

All clinicians acknowledged that the cause of CFS is unknown. What they were willing to discuss were their own etiological hypotheses. Clinicians variously considered CFS a physical, psychosomatic, or non specific disorder, or an illness combining both physical and psychological factors. In psychosomatic illnesses, psychological suffering underlies physical complaints. In non specific or heterogeneous illnesses, either physical or psychological factors may trigger the problem. Illnesses due to combined causes require both physical and psychological factors. These four hypotheses were based on experiences with sufferers and a selective weighting of the medical literature. These hypotheses were usually reached after struggling with different causal perspectives and in some cases, they remain highly unstable. Causal hypotheses may condition explanations and treatment decisions.

Combined Etiologies

By drawing on their knowledge of sufferers' histories, clinicians who proposed combined causes identified possible risk factors and triggers for CFS. Frequently, identified risk factors were psychosocial. They included current or premorbid psychological problems, a family history of psychiatric problems, significant losses close to the onset of the illness, over commitment to work and play, and the stress of being an

under qualified woman in a demanding job situation. Triggers could be either physical or psychological insults that activated the immune system or the physiological stress response.

> When people were first getting it, I noticed that it was primarily females. I said to myself "Is there a psychosomatic component here?" I must admit that I subscribed to that at the beginning. There is a possibility that a lot of women are going out into the competitive world without the equipment. I don't know if that plays a role...even though there are these social factors [now] I wonder ...whether there is something attacking or changing...their enzymes.

> Often they have had a severe event in life such as the death of someone close, loss of a home...and then they may be exposed to a viral infection during this time. Both together may lead to the illness.

> ...a combination of a particular psychological makeup...plus a set of illnesses that the patient may have been exposed to... There is probably some kind of immune disturbance. Whether that immune disturbance is triggered by a physical ailment of some kind or whether it is triggered by the psyche is not clear.

> There is often a family history of affective disorder, substance abuse, somatic illness- some psychiatric overlay. I think family history may put them at some risk, because with this history, you may have something like a virus or accident that triggers a cascade of symptoms. The variations reflect this underlying process, but it is present in different forms.

Physical Etiologies

In contrast to the model of combined causes with risk factors and triggers, clinicians who proposed physical causes drew on a broader range of factors. These factors included: clinical experiences with other illnesses, the medical literature, positive evaluations of sufferers' mental health, and in one case, a vague "hunch". Some of these clinicians had experiences with post viral fatigue or had read about such illnesses. To bolster their views that CFS was a physical illness, some pointed to neuroimaging studies, immune findings, and findings indicating an impaired adrenal response to stress. Furthermore, several speculated about possible pathophysiological mechanisms through which physical factors may produce symptoms. For example, it was proposed that the body might not be clearing viruses as expected or, that viruses were creating subtle changes in the brain and affecting central energy control functions. But the defining characteristic of this group was that they viewed manifestations of psychological problems as the consequences of having an intractable and poorly understood illness rather than the cause.

> Initially, I met three or four CFS patients, who, no question about it, were in excellent mental health, but it is discouraging over time if you don't feel well, and your life and career are on hold. The depressed mood that you may see is not an initial cause or factor, but therapy is needed to cope with the anger the illness causes.

Psychosomatic Etiology

Only two clinicians took the position that CFS is a psychosomatic disorder. They agreed that CFS closely fits descriptions of neurasthenia/ asthenia and that evidence for a viral cause of CFS was not compelling. Their experiences with patients might have been an additional influence on their view of CFS as a psychological disorder.

> It is a disease that is diagnosed only by symptoms. The patient often looks fine but feels tired...There is often a lot of psychological substratum present...There is a feeling that it might be an infectious disease but we haven't seen any clear indication of this.

> My gut feeling is that the condition is akin to asthenia in the 1920s, that is, people are too tired for life...When some patients are ill, their attitude is that they are going to attack the problem, they are going to beat it. With the CFS patients I have seen, I don't see that. They see the problem as bigger than they are.

The defeatist attitude that one described was in marked contrast to the observations of most of the other clinicians who regarded patients as "trying to get well", "resilient" and "resourceful". The implied causal role of "psychological substratum", without reference to the need for additional physical triggers, contrasts with other clinicians who viewed psychological manifestations as consequences or risk factors, but not as sole causes. One of these clinicians was a consultant, whose experiences with sufferers was limited to the period necessary for determining whether an infection could explain patients' presenting symptoms. The other's experience was limited to following a handful of CFS patients. It is likely that both the limited numbers and types of patients with whom these clinicians had experiences influenced their concepts of CFS as psychosomatic.

Non Specific Etiology

Although clinicians who considered CFS a non specific illness also believed that it could be psychologically caused, they did not believe that these were the only causes. They had sufficiently varied experiences to be convinced that some, if not all, cases of CFS were

physically caused. Their experiences included not only the usual office visits. Some had made home visits and some knew patients socially. In their view, severe levels of impairment among some of their basically "well adjusted" patients strongly suggested a debilitating physical illness.

> The thing that struck me was the degree of impairment in young people who were otherwise quite well. These were people who, to use the words, were "struck down by an illness" ... I made home visits at the beginning. I wasn't really convinced of what was going on. And it was amazing to meet the families and the parents and grandparents and brothers and sisters and to get a feeling of the whole social aspect of this...I think that over the course of the years, I am convinced that more of the patients I am seeing have an underlying psychiatric illness than when I started out at the beginning. And maybe that's a kind of a learning curve for the physician involved.

Shifts in Etiologies

Regardless of their eventual hypotheses, several clinicians revealed that they had wrestled with a number of possibilities.

> I started off thinking about it as similar to asthenia. Then I waffled and thought it might be viral. But the more I read and heard, the less the viral etiology seemed to be borne out.

> I started off not knowing. In between I was deciding whether it is physical or psychological or a mix of both. With some patients it is obviously psychological, some fatigue seems to be more associated with a psychological cause than a "true blue" chronic fatigue syndrome.....There are two camps about the cause- one which says it is physical, the other that it is psychological. But you can't separate them like that. I think prolonged stress can weaken the immune system, so that these individuals catch bugs, bacteria, and with their weak immune system they can't get rid of them.

> Initially, I thought it was more psychological, psychiatric as opposed to a true physical illness. But my thinking has gone through a 180° turn. Now I think it is the physical illness that leads to the psychological problem that patients are dealing with.

Ideas about cause remain in flux for others.

> [My thinking] is constantly changing. I see a lot of overlap with depression, with accident compensation syndrome where ...the level of disability seems out of proportion to the documented injury. Recovery doesn't seem to occur as one would expect. I see more similarities with pain syndromes, or somatic dysfunction with the muscle aches, the way symptoms are conveyed. The apathy, the anger that is unresolved, how they affect functioning and interpersonal relationships is more like work accidents.

> I go back and forth. I think of CFS as a psychophysiological reaction to social stress. But sometimes I think , maybe they will find out it is all organic. I feel tortured about it- how I might be influencing people.

Even clinicians who believed their etiological hypotheses were stable, could waver when the illness' refractoriness to treatment challenged their identities as healers. One doctor gave some insight into how this might occur.

> I really believe that this disease is real. I don't think that this is psychosomatic. I don't think it's depression...[but] after a while when the patient keeps coming back, and they are not better, doctors don't like that, we are supposed to make people feel better. So you start to feel bad...you start to doubt yourself and think "maybe this is only depression".

Here the doctor explained how treatment failures tempted him to move to a psychological frame. He went on to say that on occasion, such shifts had occurred and had resulted in awkwardness in his relationship with the patient. He knew the patient had recognized a shift from a legitimizing to a stigmatizing construction of his or her complaints. He was clearly dismayed by the fact that a threat to his professional identity had lead to strains in the doctor-patient relationship.

This small number of clinicians offered four different types of etiological hypotheses about complaints that are supposed to represent the same illness. The range of their hypotheses shows the medical literature on the subject in microcosm. The number of hypotheses and their instability illustrate how doctors may think about an illness when the discipline of medicine is still in process of developing the foundational knowledge that gives authority to the practitioner's concepts of illness.

Etiological hypotheses or frames were unrelated to specialty. The two people who thought of CFS as psychosomatic were not mental health professionals and the three mental health professionals were divided between thinking the illness was physical or caused by a combination of physical and psychological factors. Etiological frames seemed to be related to clinicians' varied experiences with patients and to giving greater weight to literature which confirmed these experiences.

Through regular office or home visits and social connections to patients, clinicians gained varying degrees of information about the psychosocial aspects of patients' lives. Such contextual data are often relegated to the margins in doctor-patient encounters (Waitzkin 1989). But these clinicians showed the extent to which contexts were drawn in

from the periphery to frame the illness. Part of the mix on which their etiological hypotheses were founded were observations such as: "people have had a severe event...then an infection", there is a lot of "psychological substratum", sufferers were previously "well functioning" or were "women [in]... the competitive world without the necessary equipment". Clinicians who used contextual data to suggest that CFS is psychosomatic go beyond the solicitude frame by seeking underlying psychological causes for complaints that cannot be objectively verified. But in Dodier's view the psychosomatic frame is relatively benign and subjective complaints are not "radically illegitimate, as in the case of the clinical frame" (Dodier 1994: 503).

The literature that clinicians perused, allowed them to compare CFS to different prototype illnesses, integrate disparate aspects of the illness into a coherent paradigm, and assess particular findings as equivocal. I suggest their weighting of the literature was selective, because the review of the medical literature in chapter one showed that no etiological hypothesis was more compelling than another. In all likelihood, these clinicians gave more weight to those readings which confirmed what they were seeing in practice.

The Impact of CFS

The previous section showed clinicians' difficulties in arriving at abstract positions on the nature and reality of CFS. But without specific positive findings or medical consensus to lend authority to diagnosing, explaining, and treating CFS, practicing clinicians felt the impact of this illness most clearly in their dealings with sufferers. Diagnostic difficulties stemmed from the lack of clear guidelines, the fact that CFS is a diagnosis of exclusion, and sufferers' resistance to psychiatric evaluations. Once the diagnosis was made, some doctors wrestled with how to tell patients the diagnosis and how to maintain hope as they explained the illness' protracted course and lack of reliable

treatments. To continue to care for CFS patients, in spite of the difficulties they presented, clinicians had to develop strategies to deal with their own and patients' frustration.

Diagnosing CFS

Doctors saw three types of patients-those seeking a diagnosis for their distressing symptoms, self diagnosed patients, and in the case of consultants, patients referred for confirmation of the diagnosis. Many believed that a number of referrals and self diagnosed patients were misdiagnosed. They variously attributed the high numbers of self diagnosed patients to media publicity, misconceptions about the condition, and support groups. Some doctors in Britain have also blamed ME (CFS) support groups for promoting self diagnosis (Hurel et al. 1995), although this has been refuted (Shepherd 1995). Doctors in the present study were not asked how they felt about self diagnosed patients, but they gave no indication that such sufferers were particularly difficult. In fact, one doctor tried to determine whether patients suspected they had CFS if they did not spontaneously offer this information. And a psychiatrist justified accepting patients' self diagnoses as a means to an end.

> Sometimes my colleagues get mad at me for being such a wimp. I also get mad at myself and think why don't I just say its depression. But then I think, if they believe that it is CFS and I can work with them and get them back on track in ten sessions or so, its worth it

These attitudes are in contrast with a study which used vignettes to elicit doctors' reactions to self diagnosed ME (CFS) patients. That study showed that doctors believed such patients were less likely to comply with treatment, more likely to pose difficult management problems, and more likely to require excessive amounts of time. Doctors did not want to have such patients in their practice and would likely refer them to a hospital for a second opinion (Scott et al. 1995). Critics, skeptical of the prevalence of such negative attitudes, have noted that symptoms in the vignettes were more typical of depression than CFS

(Arber 1995; Shepherd 1995a). And one study has found that 90% of doctors in an area of New Zealand accept CFS as a clinically valid diagnosis (Denz-Penhey et al. 1993).

In some ways, diagnosing CFS followed the standard procedure for diagnosing any illness. Clinicians integrated information from sufferers' histories and physical examinations and developed a set of tentative diagnoses that could plausibly account for symptoms. Alternatives were then ruled out successively by laboratory tests. In many illnesses, these processes are sufficient to make the diagnosis. Diagnosing CFS introduced an additional element to the usual process, since psychiatric disorders also had to be ruled out. When sufferers came with "thick files from doctors they had seen previously", the reports of colleagues became additional data to consider in making the diagnosis. These reports were usually perused only after clinicians had heard patients' histories first hand.

A consultant's account illustrated the diagnostic process.

> I usually discard all the information that the patient comes in with and I start right from scratch...with a standard history and physical paying particular attention to the details of the progression of illness to try and get some kind of feeling for how it began and the sequence of events. Then I spend a lot of time talking about activities of daily living to get a feel for the degree of impairment. And that's where most of the time is spent, I am trying to get a feel for the physical but also the psychological or cognitive impairment which seems to be a very major part of this. And after that I usually do a functional inquiry from A to Z of symptoms to see... first of all that there are enough symptoms in there to make me comfortable giving the label or secondly enough symptoms in there that would make me uncomfortable with the diagnosis because of overlap with other conditions. Then I examine the patient and after that I will go to whatever ancillary information is available. Patients tend to come with large stacks of tests, and opinions from their physician. If that's available I will read through and then I try and make a decision as to whether I think the diagnosis is clear or not clear. I would say most of the time its not clear. Its the rarer case where the diagnosis to my mind is completely obvious. So then I try to make a diagnosis. If I can't reach a diagnosis I tell them why I can't reach a diagnosis and I invariably end up explaining the difficulties of making a diagnosis. Oftentimes, I have to go into how we establish the diagnosis of chronic fatigue so that the patient understands the difficulties in making the diagnosis...when I am struggling to make up my mind, is it or isn't it, I really look at the cognitive aspect before deciding.

The account showed the aspects of history which were salient to this doctor: symptom onset, constellation, progression, duration, and degree of impairment. Cognitive impairments received particular attention and weight, because after seeing some sixty to seventy CFS patients, experience had taught him that "cognitive decline is quite characteristic". He listened for symptoms that would either rule in or rule out CFS.

But some clinicians highlighted issues in the history other than the characteristics of the presenting symptoms. For example, a psychiatrist was the only who mentioned specifically probing for "secondary gains", although the accounts of other doctors showed that several addressed this issue. Similarly, a rheumatologist searched for evidence of "fibrosytis", a chronic pain condition that has overlapping symptoms with CFS. Other doctors focused on traumatic life events around the time of onset, antecedent viral or other physical illnesses, family histories of mental disorders, and premorbid or concurrent psychological disorders.

Continuing his account the consultant commented on laboratory testing:

> ...the longer I am doing this, the less tests I tend to order. I think there is a law of diminishing returns with ordering multiple investigations. I don't send people for weird and wonderful serology and immunology. I discourage them from pursuing complicated neurological tests- SPECT[4] scans and so on. I don't think they give patients any satisfaction in the long run.

The exotic tests which he avoided were not used by clinicians in the study. They ordered a standard battery of basic tests, with a few adding tests for specific conditions such as hypothyroidism. Some re-ordered previously done laboratory tests, perhaps because of the elapsed time since the last tests or concerns about their accuracy.

Laboratory tests were usually not helpful in pointing to a diagnosis, since they were either negative or non specific. At this point many, though not all, doctors referred patients for psychiatric evaluations. Mental health professionals made their own evaluations. The consultant was among those who insisted on a psychiatric evaluation. But he was faced with two problems. He could not always find a psychiatrist who would accept the referral and he knew that many patients react negatively to any imputation of a psychiatric disorder.

> I tell patients that I am reluctant ever to assign a label of CFS without having a psychiatric evaluation. And regardless of how they feel, I insist on a psychiatric evaluation. And then I struggle to try and get a psychiatrist to see the patient, which is not always easy.

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[4]SPECT- single photon emission computed tomography scan. SPECT has become established for the measurement of regional cerebral blood flow (rCFB). (Wessely 1993).

It is not clear why he had difficulty finding a psychiatrist to evaluate these patients and this was not explored. Perhaps there were biases within the psychiatric community against the illness or against the role of simply being a consultant.

To deal with patients' resistance to psychiatric evaluations he, and other clinicians, developed routine approaches to sell these referrals. They focused on their own discomfort rather than the patients' or invoked the authority of current medical thinking, as uncertain as it was, to justify the need for psychiatric evaluations. Routinizing discourse that deals with unpleasant information has also been noted by Taylor (1988).

> I insist on a psychiatric evaluation. The way that I do this without offending the patient is to tell them that the etiological literature shows that many doctors believe there is a large psychological component and that a psychiatric evaluation is necessary to at least make sure that that is not a problem.

> I always insist that these patients are assessed by a psychiatrist. This is not my area of specialty and it is possible that I could miss a subtle psychiatric disorder that is underlying the symptoms...I do this to get a baseline on my patients. I try to show that it is not depression at the onset. Depression later is a consequence of having an illness, not a cause.

Diagnosing CFS was a time consuming process. Several physicians saw patients three or four times before making the diagnosis, and sometimes even before ordering tests. The lengthy pre diagnostic period may be a general function of diagnoses of exclusion. But the time might have also reflected clinicians' fears of misdiagnosis. They had seen many referred patients who they believed were misdiagnosed and some suspected that they too might have made such misdiagnoses. Taking time before diagnosis was one way of reducing the probability of a misdiagnosis. But sometimes this was not enough to allay their concerns. Long after giving the diagnosis, some clinicians used follow-up not only to monitor patients' progress but also to confirm "there is nothing to make me rethink the diagnosis". But sometimes they did rethink their diagnoses:

> After two years, some suddenly start doing 15K or cross country skiing. I don't think they ever had it. Maybe at the time I did, but there were some things they never talked about. All of a sudden they are better...it is not likely that it was CFS, something else was wrong.

Besides misdiagnoses, clinicians were concerned about missing concurrent or subsequent illnesses by attributing all present and future symptoms solely to CFS.

> I tell them it [diagnosis] doesn't mean they cannot also have another illness or that they won't have other illnesses that may be more serious in the future. Therefore I feel that good monitoring is important. What I am afraid of is missing a diagnosis of something serious. It is a diagnosis of exclusion. I have to make sure that I am not missing something.

A misdiagnosis is the fear of the novice physician (Helman 1985) and a missed diagnosis the mistake dreaded by all physicians (Scheff 1966). These twin concerns of misdiagnosis and missed diagnoses shadowed the seasoned physicians in the present study as they diagnosed CFS.

The CDC criteria

In this climate of uncertainty, some doctors thought the CDC case definition might be the answer to their diagnostic difficulties. A few tried to apply the CDC criteria, but became disillusioned about its usefulness when they saw patients who they were convinced had the illness but who did not meet all the criteria.

> I think that interpreting the criteria too strictly is doing a disservice to some patients who I think have variations in the syndrome, to the point where I am pretty confident that the diagnosis is there, even though not all the criteria are fulfilled. The criteria were developed for research purposes. It was to show that those who fit the criteria did have the disease, but in terms of clinical application, I think that the criteria may at times be too exclusive.

> If I would use the hard and fast CDC it would exclude a lot of patients.

> I would say that some people fit the CDC criteria. But about half manifest many of the symptoms but are missing some to meet the definition. But in my mind, these people do have CFS.

Their experience underscores the fact that the CDC criteria were not meant for use in general clinical practice (Schluederberg et al. 1992; Salit et al. 1996). It also shows the temptation to use restrictive criteria for diagnosis, perhaps because these criteria at least furnished some standard guidelines which doctors hoped would reduce the uncertainty in diagnosing CFS.

In sum, a major difficulty in diagnosing CFS stemmed from the fact that it is a diagnosis of exclusion. And in trying to exclude psychiatric disorders, clinicians were concerned that patients would construe referrals for psychiatric evaluations as an imputation of mental disorder. Thus clinicians had to develop strategies to make such referrals

acceptable. The requirement to exclude psychiatric disorders might also have had an unintended effect. Since the rigor of psychiatric evaluations varied and clinicians highlighted different elements of history, it is possible that different clinicians were giving different diagnoses to patients with similar symptoms.

Moreover, in the matter of diagnosing CFS clinicians may trust neither their colleagues' nor their own judgments. Since they thought many referred patients were misdiagnosed, it was not unreasonable for them to re-order tests in some cases or to review their colleagues' reports only after hearing patients' histories for themselves. In making the diagnosis themselves, clinicians were concerned with missed diagnoses and misdiagnosis. They managed these concerns by being vigilant about these possibilities in follow-up visits. Arguably, clearer diagnostic guidelines and a consensus definition that could serve not only the CFS researcher but also the practitioner would have reduced some of the difficulties in diagnosis.

Explaining the condition

Explanations of CFS usually covered the diagnosis, hypotheses about cause, course and treatment. Treatment will be discussed in the following section. The tone of explanations was cautious and tentative. The content reflected clinicians' attempts to preserve patients' morale and avoid stigmatizing explanations on the one hand, while maintaining their own credibility on the other. Finding this balance was neither easy nor straightforward.

Some physicians withheld a diagnosis. The two physicians who believed that CFS was modern day neurasthenia or asthenia did not use these labels with patients. Instead, they told patients they did not know what was wrong. One justified the decision by saying that labels were not helpful. By strongly maintaining this position, this doctor avoided the issue of etiology.

> They may have been told they have it [CFS] or think they have it. I try not to argue with the label and instead work with their symptoms...I do not think that the label is helpful. I tell them I do not know what is going on.

The other physician, *if asked about CFS*, would explain that the label existed, the illness was chronic but not life threatening, and while an infectious etiology was hypothesized, it was not clearly supported. By not faithfully reproducing their ideas in explanations and omitting psychiatric labels, these physicians avoided overtly stigmatizing patients.

Other doctors downplayed the diagnosis or gave it as a last resort. Their stated reason was to protect patients from a demoralizing diagnosis.

> I don't like to present it as a possible label because of the overlay of ideas of it as going on forever and as an extremely severe post viral type of syndrome that slowly passes into CFS and goes on and on. I don't like bringing it up. I put that nomenclature on as a last resort

> I try to say that the diagnosis is not too important, because many of them have read a lot about it and they give a name to it. But the words seem very depressing, its a bad diagnosis to have.

Invoking negative effects on patients as a reason for withholding a diagnosis, has been found in previous studies of CFS (Woodward 1993) and a life threatening illness (Taylor 1988). These stated reasons may hide doctors concerns about a controversial diagnosis (Woodward 1993) or their discomfort with 'telling bad news' (Taylor 1988; Waitzkin & Stoekle 1972). The latter explanation seems closer to clinicians' expressions in the present study.

Kirmayer (1994) brings a more nuanced perspective to the issue. He argues that withholding a diagnosis is not necessarily negative. Diagnosis brings a certain authority to illnesses that are not well understood. And while authoritative meanings may provide a structure from which other meanings may be negotiated, they may also block both patients and doctors from improvising interpretations and treatments that may be of value. In a similar vein, Crawshaw (1990) argues that when a diagnosis becomes the only way to give meaning to symptoms, doctors faced with unidentified suffering may simply dismiss patients.

Doctors who gave a diagnosis used the labels CFS, myalgic encephalomyelitis (ME), post viral fatigue, or descriptive diagnoses such as "fatigue with possible depressive

etiology", or if pain was a prominent complaint, "regional pain syndrome". One doctor discovered the extent to which CFS is recognized as the official label. When he was asked: "What name do you use for the condition?" he replied laughing: "I use CFS. I tried using ME on the government forms[5] and they rejected it. They sent it back". Regardless of the chosen label, their language was cautious: "everything points to CFS" or "other doctors would probably say the same thing."

In discussing etiology, some clinicians shared their own views of cause and possible mechanisms, as well as the range of hypotheses found in the medical literature. They underlined the fact that neither their own views nor those in the literature have firm empirical support. They qualified their explanations with phrases such as: "It is probably due to an infection", "it appears to be related to a virus" or "no one understands the cause but...". They were sensitive to sufferers resistance to psychological causes. If they believed in non specific or combined causes in which psychological factors are hypothesized to play a role, they presented these views in the context of current medical thinking about stressful lifestyles, for example. In this way, they may have mitigated the impact of their personal views on patients that they might continue to treat. Concerns about patients' reactions to any suggestion of psychological factors could reach the point where clinicians hesitated even to discuss concurrent affective disorders that they detected.

> I may tell them about any concurrent affective disorder that I detect, but I try to downplay the depressive terminology because some patients think that means they are seen to have a psychiatric illness and may begin using somatic defenses.

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[5] The government forms referred to are applications for income replacement due to disability through the Canada or Quebec Pension Plan. Some people qualify for a disability pension from these sources only. Other patients have private insurance coverage. But under a cost sharing agreement between governments and many private insurance companies, patients with private coverage must often apply both to the government and their insurance companies. Patients applying for disability must have an initial and subsequent reports from their regular doctor. Disabilty forms can take a significant amount of time for doctors. This will be discussed in the next chapter.

Doctors were also careful when to do otherwise would have put their credibility in doubt. Thus, in discussing the course of the illness which is variable and unknown, they emphasized improvement but suggested average time lines and stressed individual differences. They drew on their experiences with other CFS sufferers to prepare patients for remissions and relapses. They believed it was important to discuss the course of CFS in order to reassure patients that the illness was not fatal and that they would improve. Their intent was to keep alive hope and optimism, while presenting the reality of the situation.

> I tell them that when it gets better is very individual and variable. I don't say it never gets better, that's devastating for someone to hear. And, I don't tell them it will be better in three months because they would come back and when they are not better, it makes you look like an idiot.

The undercurrents running through clinicians' explanations were perceptions of CFS as an illness that could ruin lives and perceptions of sufferers as resistant to any suggestion of a psychological disorder. As a result, regardless of privately held ideas, they tried to avoid clearly stigmatizing explanations. Some avoided a label and discussions of etiology. But in so doing they may have left an ambiguous impression. Others introduced psychological factors as one of several hypotheses in current medical thinking about CFS. They may have softened impressions of devaluation. Those who suggested the illness is physical, unequivocally legitimized patients' complaints.

The uncertainties associated with the illness made clinicians insecure about the accuracy of their information, hence the cautious and uneasy tone of their explanations. If they did not contextualize and qualify their explanations and were proven wrong in the future, their credibility was at stake. At the heart of their explanations may have been attempts to do what Kirmayer (1994) suggests is necessary in such situations- reducing uncertainty enough to carry on with treatment.

Treating the Patient, Not the Disease

Although no treatment has been shown to cure or reliably alleviate CFS symptoms, doctors were loathe to give the impression that nothing could be done. This may be seen in part as a bid to retain their authority to treat, in part as a reassertion of the solicitude frame. They offered symptomatic treatments, lifestyle counseling, and supportive therapy.

> No one likes to be told there is nothing you can do for them. If they have fibrositis they may benefit from anti-inflammatories, and I may give them an antidepressant at bedtime to help them sleep. When it is pure fatigue, I tell them it is not necessary to take medications. I try not to say I have nothing, I say you do not need specific medications...I tell them not to drink alcohol, recommend healthy living and setting reasonable expectations for themselves. I say that it is better to spend one hour during the day, doing something that you want to, and maybe gradually work up to two hours, than trying to accomplish everything that you did before.

A few suggested psychotherapy or tried alternative treatments. The most common symptomatic treatments included analgesics, anti-inflammatory drugs, sedative- hypnotics for sleep or anxiety, and antidepressants for sleep problems and pain. All clinicians made a point of stating that antidepressant dosages were well below the recommended levels for clinical depression. At patients' requests, some clinicians agreed to prescribe drugs not normally associated with the presenting symptoms. A few added acupuncture and one had tried " a few remedies from the health food stores [with] no effect".

Lifestyle counseling was aimed at maintaining function, gradual improvement, and a better quality of life. It included information on nutrition, rest and activity patterns, stress management, and social integration. Some clinicians advised alcohol abstention. They encouraged patients to be kinder to themselves and to find a source of pleasure in each day.

> I tell them to keep good habits, keep active intellectually and physically. I encourage them to do volunteer work, if they can't work at their regular job, to feel useful. They may be prone to staying home and not being active because of the fatigue.

Sometimes their advice was met with resistance by patients who felt they were not understood.

> Often they will say that they cannot exercise, it's hard to convince them to do something, because when I try to, they feel that I don't understand. I explain that I don't want them to get worse. Even if there are no clear treatments, and it is time that will cure them, they must protect and maintain what they do have.

Most clinicians provided supportive therapy. They believed it was essential to deal with discouragement and depression brought on by the prolonged course of the illness, the feeling that life was on hold, and the loss of social roles. They scheduled regular follow up to "reassure [patients] that they are not crazy, they are not alone", to keep hope alive and to help patients put their situation in perspective. One supported patients by intervening with family members who did not believe in CFS.

But despite thinking that support was important, many clinicians did not find it a satisfying form of treatment. One observed: "there is no treatment except support, there is no concrete action from yourself to the patient", and another felt that closer follow-up would be worthwhile "if there was something one could do, if one could see a rationale for visits- but it's only being supportive." Supportive therapy could be undervalued to the point where it was hardly recognized as a form of treatment. One doctor stated that there was no treatment for CFS and that he offered none. Nevertheless, he commented:

> [The biggest challenge]...as a physician a patient comes in and tells you that he is miserable and you have nothing physical to offer them. You have to give them a little hope. Encourage them to fight and not give in. Encourage them to do more and more very gradually.

The mental health professionals offered psychotherapy for a subsample of their patients who were open to this form of treatment. A few other doctors advised some form of psychotherapy when it seemed that anger and depression might become chronic problems. In offering treatment, clinicians hoped they would help patients to carry on and have "some semblance of a life".

Views on Alternative Therapies and Support Groups

Clinicians were asked their opinions of alternative therapies and support groups since their patients were likely to seek out these adjuncts to medical treatment. Most knew or suspected that many of their patients had either considered or tried alternative therapies. Their opinions of these therapies ranged from being dismissive, to indifferent, or

conditionally open. The consensus was that, with the possible exception of acupuncture, patients had not been helped by alternative therapies. Some clinicians were clearly against these treatments as unproven and unstandardized. Others neither encouraged nor discouraged patients from trying alternative treatments. Some were open to the idea under certain conditions and for pragmatic reasons. They conceded that regardless of what they had to say, many of their patients would consider or try these treatments. They also acknowledged that conventional medicine had little to offer CFS patients and that it has no cornerstone on what is helpful. But they preferred their patients to use them as a sounding board to evaluate the harmlessness or potential dangers of these therapies.

> I try to make sure that there are no objections to treatments, that they are not doing something that is potentially dangerous...I get concerned about restrictive diets....that are deficient in nutrients...I say if they are going to try it, do so for a short time. If they lose 7-10 lbs. in this time, stop. I ask them to let me know, and at least let me have a say before they take the treatment. They often approach it by saying 'A friend of mine wondered if it would help me to go and see__' And I say ' let's talk'. I am not sure if 100% of patients try alternative therapies, but probably 90%. And the rest may be trying but not telling me.

A few had explicit criteria for approving patients' trials of these remedies: the patient finds them helpful, they are not harmful, and the cost is not exorbitant.

> If they feel that taking three cold showers a day helps them, I say 'go for it'

> If I can't do anything for them, as long as its not 400 a day of something, I don't know if these therapies are doing any good. If after two months they still have the same problem, they are probably not benefiting, then I think its time to stop....If it's very expensive, I would ask them 'Do you want to spend the money?'

Clinicians could afford to be magnanimous because in their experience, most patients did not continue alternative therapies for very long. Notwithstanding the limited effectiveness of their own treatments, their role in treating patients was in no danger from alternative therapists.

Their reactions to support groups varied over a narrower range- from cautious to leery. Most would hesitate to recommend support groups because they had little knowledge of these groups. Others hedged because they believed support groups could be harmful or helpful, depending on their approaches and depending on individual patients. For these clinicians, the problem was that they had no way of determining how a given patient would

be affected. One recounted patients being devastated after being exposed to the worst scenarios in support groups and believing such fates were inevitable. Others surmised that support groups could contribute to chronic disability because they "medicalize patients' distress", "reinforce illness behaviors", "institutionalize illness" and "possibly encourage dependency". One wondered whether patients didn't "pick up symptoms" from such groups. Another gave a cautious nod to groups who were "more or less involved with the mainstream" of medical thinking.

Support groups have been blamed for promoting self diagnoses, dangerous treatments such as colonics and anti-yeast diets, (Hurel et al. 1995; Scott et al. 1995) and reinforcing disability by encouraging sufferers to apply for invalid pensions (Miller 1991) or by reporting poor prognoses (Lawrie and Pelosi 1994). But at least one group of authors (Hurel et al. 1995) have retracted their charges following refutations (Shepherd 1995a, 1995b; Arber 1995) and more careful verification of the facts.

When physicians treat with prescription drugs, they exercise authority reserved for the medical profession. When they attempt to vet alternative therapies, they are also asserting their cultural authority to treat illness. But supportive therapy, lifestyle counseling, and even some forms of psychotherapy are not solely within physicians' purview. These forms of treatment are not even confined to the larger domain of other mainstream health professionals. They do not qualify as esoteric knowledge which professionals claim as a warrant for their advice and action (Hughes 1971). Thus, physicians may have been dissatisfied with these treatments not only because of their limited effectiveness but because of their diffuse ownership. At the same time, clinicians were operating from a frame of solicitude. They wanted to help CFS patients. Thus supportive treatments and lifestyle counseling became the mainstays of management. The most convincing evidence of the solicitude frame is the fact that clinicians did not abandon their CFS patients. It was far from easy to deal with these patients. And there were no monetary incentives to keep patients who "take a lot of time" since physicians' incomes are

volume driven in the Canadian system. But to continue caring for CFS patients, clinicians had to learn how to mitigate the impact on themselves.

Mitigating the Impact, Continuing Care

The limited success of treatments left clinicians feeling profoundly frustrated, angry, sad, insecure and resigned. They felt that as health professionals they should be "helping people", they were supposed "to make people better", they wanted to "see improvement". They envisioned helping through concrete action, preferably through physical treatments. Instead they found "the things you know don't apply", "you can't hurry them along to get better". They found it "frustrating to see them [patients] and not develop something constructive", not to have "anything physical offer". Frustration resulted from not being able to meet their own or patients' expectations. These doctors wanted to do something for patients based on medical knowledge.

> ...It is much harder to do nothing than to do something when patients so desperately want you to do something. You have to resist not trying a little bit of this, or a little bit of that. I am not against trying things, but it has to be sensible and academic. I don't want to be trying things just for the sake of trying and end up making the patient sicker.
>
> They tell me about the studies using supplements, drugs...they bring articles and lots of questions that make you think they are looking for a miracle, when inside you know that there is no miracle, at least, not so soon, or maybe there won't be. I feel sad about that. about how desperately they are seeking a solution. This is especially true if they are also neglecting some things that may be helpful to them.
>
> These are not happy patients. They lose their optimism and sometimes they look at me and say "Do something". I am not God. It makes me feel very insecure not having something to offer them.

Undoubtedly, clinicians deal with other untreatable illnesses that may engender similar frustrations. But CFS may be particularly frustrating because it remains so nebulous. There is no defined cause to instigate the search for a magic bullet. There is no elucidation of a pathophysiological mechanism that might be regulated, if not fixed. In many ways, the illness seems so ordinary that everyone can relate to its elements, even if not all at once, or on a chronic basis. Yet the condition remains so resistant to treatment.

The emotions engendered by treatment failures could have been powerful incentives to dismiss patients from their practice, dump them by referrals, devalue their condition by labeling it psychological, or discredit them as malingerers. Clinicians knew colleagues who had done just that.

> They [CFS patients] are probably marginalized more by the medical profession than the general society. Many doctors don't want to see them. These are not acute patients that improve. They are long term.

> Unfortunately they 'doctor shop' and we dismiss them. We should be focusing on helping these patients, they are people who are trying to get better, Instead we get frustrated. We don't know how to help them. They make a lot of demands on us. Doctors who used to see a lot of these patients, don't see them anymore. They don't have anything to offer them.

But in many ways these fifteen clinicians represent the most sympathetic doctors that CFS sufferers are likely to meet. They had grappled with the questions about the reality and nature of CFS. They had seen the same extensive help seeking patterns and felt the lack of satisfaction in dealing with patients who did not improve or recover as expected. They too could have chosen to discredit patients who made them face their limited effectiveness and in so doing aroused strong negative emotions. Instead, they were able to continue caring for these patients by treating the patient and not the disease. They learned to plan for patient demands, deal with their own emotional reactions, and carry on in spite of skeptical colleagues.

The demands of treating sufferers were managed by being prepared, empathizing with sufferers, or limiting their numbers. Over time clinicians learned to plan for the predictable demands of caring for people with CFS. They knew that more frequent support would be necessary periodically because of the illness' relapsing course. As a result, they built in extra support during exacerbations as part of the treatment plan. They also knew that some encounters would be time consuming and intense. The impact of such encounters could be contained by empathizing with patients.

> They can be very obsessive about every aspect of the disease...but I don't know that I wouldn't be as well. So you have to sort of catch yourself and say, wait a minute if I was in their shoes, maybe I would be asking the same questions and doing exactly the same things

> A few were a little bizarre perhaps. But sometimes I wonder if with this illness you don't become bizarre. You are just suspended, nobody knows about this illness, patients, and doctors too, feel very insecure. It is a diagnosis of exclusion, there is no treatment...

The impact of CFS could also be mitigated by limiting the numbers of CFS patients in one's practice. Consultants were in the best position to do this without creating ill feelings. They did not have to follow patients once they had made their pronouncements. However, only one of the four operated in this manner. The others followed some CFS patients but limited the number in their practice.

Clinicians managed their emotional reactions by identifying the sources, placing reactions in perspective, and finding value in what they could do. They recognized that their emotional reactions were as much a function of what they expected of themselves as helping professionals, as it was a result of patients' not recovering. Some accepted that, contrary to their early expectations, they could not make a difference. Self blame and guilt were therefore inappropriate. These perspectives helped them to control feelings of frustration and personal limitations.

> There is also the frustration in caring for them. I started out feeling that I was going to make a difference. I was going to help them to get well. I don't think that anymore. I now see it as chronic, that I am not going to have much impact.

A few actively tried to recognize and keep in check the temptation to shift the blame to patients when treatment did not lead to recovery.

> When they are not changing, not going back to the way they were, I have to make sure that I don't get mad at them for this and that I don't burden myself with feeling guilty for not being able to help them.

One clinician reminded herself to be patient when feeling exasperated with the slow rate of improvement.

But clinicians also had to find some measure of satisfaction in what they were doing. They acknowledged that while their efforts did not produce the optimum outcome, it was still important to provide symptomatic treatments, hope and encouragement, education about balanced lifestyles, and to create a climate of openness and sensitivity in which patients could discuss issues such as alternative treatments.

> The challenge is to be open, to listen, to act as a sounding board. But it is worthwhile to talk to them about wacky treatments, for example, that they want to discuss with you. That is helpful for them to hear from my point of view, from my training and background, integrated with whatever else makes me come to these conclusions.

They could find value in symptomatic treatments and counseling about alternative therapies which drew on their biomedical knowledge. Even if they did not find satisfaction in lifestyle counseling and supportive treatments, they could see that patients might find them helpful.

To justify why they continued to care for CFS patients in a context of skeptical colleagues, these clinicians reframed patients' behaviors, invoked professional duty- to do something to help these patients, and underlined the role of experience in colleagues' reactions. Instead of viewing patients' extensive help seeking as "doctor shopping", some clinicians interpreted it as trying to get well. Viewing patients' behaviors in this light would likely make it easier to continue working with them despite difficulties encountered. Some considered it their professional duty to see these marginalized patients saying: "someone has to see them medically". One doctor put his colleagues' reactions in perspective by recognizing the role of personal experience in shaping physicians' reactions.

> I can remember bringing a patient into hospital...and having multiple consultant services see the patient. The debate raged...even within those consulting services and depended entirely on the personal experiences of the consultant. I remember very vividly the neurology service seeing the patient ...who had subjective signs of muscle weakness, The consultant came by and said this person is depressed or malingering. And the next week a new consultant took over who happened to have a [relative] who was diagnosed with CFS in_____, and he just looked at this and said, "why, he's got chronic fatigue". And it just brought home to me the whole issue of how we as a profession have to be open to various diagnoses and we have to be ready to accept things that are vague and do the best with the resources at hand.

Summary and Conclusions

Fifteen clinicians showed how their perspectives on CFS and reactions to sufferers were shaped by clinical experiences, viewing the illness from a frame of solicitude, and by their authority to diagnose and treat. These clinicians agreed that sufferers had a real illness, although some were not convinced that it was a new syndrome. These stances contributed

to disparate etiological views ranging through physical, psychosomatic, non specific, and combined causes. In general, these clinicians were highly sympathetic to sufferers. But they found it difficult to diagnose, treat, and explain the illness. These difficulties were compounded by sufferers' resistance to imputations of a role for psychological factors, clinicians' concerns for their own credibility, and the challenge that CFS posed to their identities as healers. Although they could not entirely overcome these difficulties, they were able to continue treating CFS patients by planning for predictable demands, managing their own frustrations, and putting colleagues' skepticism in perspective.

When rational scientific inquiry reliably establishes a body of medical knowledge, it is the discipline of medicine that authoritatively pronounces on the reality and nature of an illness and points the direction for treatment. When such inquiry has not yet yielded clear directions, as in the case of CFS, it is the individual practitioner who must determine whether the illness exists, its nature, its presence or absence in specific patients, and how it should be managed. To decide on the reality of CFS, these clinicians made social judgments about sufferers' credibility by drawing on clinical and social experiences with them. They were persuaded that sufferers were credible by similarities in their accounts and by evaluating these accounts against clinical and social norms. But social judgments are not the basis of medical authority. And their stigmatizing or legitimizing imputations may be challenged by professional colleagues and by sufferers. By deciding that illness was present in spite of little or no objective evidence, these clinicians may be said to be using a frame of solicitude in evaluating sufferers' self reports. In this frame, subjective experiences take precedence over objective evidence and the principle of doing something to help the patient directs doctors responses to "illness without identifiable disease" (Dodier 1994).

The lack of knowledge about the etiology of CFS limited treatment options but kept the solicitude frame in full view. Clinicians continued to care for CFS patients, despite numerous frustrations and despite their colleagues' dismissal of these cases. Since CFS

patients were time consuming and in the Canadian health care system physicians' incomes are volume driven, there was no monetary incentive to see these patients. If anything, long term care came at a price of having their identities as healers challenged. In a study of therapists' views of difficult patients, Robbins and colleagues (1988) suggest that patients who do not get well may deny the therapists' special competence and authority to treat illness (Robbins et al. 1988). The clinicians in the present study were able to deal with the this challenge by exercising their authority to the extent possible, while recognizing its limitations in CFS.

Clinicians exercised their authority as they diagnosed, explained and treated CFS with prescribed drugs or vetted alternative therapies. But they were dogged by persistent concerns about the legitimacy of their advice and actions. Long after they had tentatively pronounced the diagnosis, many vigilantly continued to monitor for signs of misdiagnosis and missed diagnoses. Arguably, if clinicians had had a base of knowledge from which to operate authoritatively, they would not have been so hesitant and uneasy.

By accepting CFS as a real illness and withholding stigmatizing psychiatric explanations, these clinicians at least partly legitimized sufferers' complaints. By not abandoning patients, they signaled that sufferers were worthy of ongoing attention. They had learnt to treat the patient, not the disease. Dodier (1994) suggests that medical experts' positions on individual complaints is both cognitive and ethical. "Cognitive because they trace the categories and reasoning on which doctors rely to form a judgment, ethical because they commit the physician to a manner of conceiving his or her place in an apparatus of social justice" (p.490). In CFS, both the consultant expert and patients' regular doctors have a place in the scheme of social justice meted out by government programs and private insurers. The next chapter elaborates the work of insurers in CFS and in so doing, revisits the role that doctors play.

CHAPTER 4

INSURERS' DILEMMA: COMPENSATING DISABILITY IN AN ILLNESS WITHOUT IDENTIFIABLE DISEASE

Chronic fatigue syndrome (CFS) is of significant interest to insurers because most sufferers claim they are unable to work. The trickle of CFS disability claims in the early 1980s gave insurers little cause for concern. Some routinely dismissed these claims on grounds of paltry or missing objective evidence, while others paid benefits assuming that these strange claims would be both uncommon and short lived. By 1990 however, the medical officers of life and health insurance companies across Canada came to their annual meeting, amid rumors of an alleged epidemic of CFS (Lechky 1990). The rumors were especially disquieting because CFS had the potential to open doors to a flood of fraudulent claims. As an "illness without identifiable disease", CFS presented insurers with two major problems: how to determine disability and how to contain attendant costs. Their initial and more recent attempts to solve these problems highlight structural factors, inside and outside the industry, that have both guided and limited insurers' abilities to respond satisfactorily to CFS claims.

This chapter traces the evolution of insurers' responses to CFS disability claims. It is based mainly on the accounts of sixteen insurance representatives from eleven private companies. The chapter is divided into three sections. The first section describes the context in which CFS claims came to the attention of insurers. This backdrop of goals, world views, definitions, and routine operations shapes the industry's reactions to disability claims in general. It helps to explain why insurers responded to CFS claims as they did, and why their responses fell short in dealing with the problem. The second section highlights the issues that CFS presents to insurers and the difficulties of addressing

these issues with traditional measures. The final section presents changes that insurers have made as they recognized limitations in their usual operations.

The Context of Disability Determination

Insurance companies are profit making institutions. They expect to pay some claims and price their products accordingly. They estimate that 15- 20% of clients will file a claim at some time during the life of their policy. Their avowed aims are: to pay benefits to legitimate claimants and, to the extent that it is possible, "return people to work so that they are not lost to the system."

> We have a mission statement and we want to pay our claims quickly, efficiently which is what the clients are paying for. We are very conscious of the importance of disability insurance because of salary replacement. So it's very important that someone is not left without benefits because we're afraid of paying something, and they are in line for social welfare. When they are insured with us, we certainly would not want that to happen...We also have an obligation towards our policy holder, who is paying the premiums, who is offering the benefits and we want to identify those that are malingering...We have ways. In extreme cases, we will pay under condition, it's a conditional payment, if the medical comes in we will ask for a refund of what we've paid.

They have no wish to support malingerers, unemployed or unemployable casualties of tough economic times, or employees in intolerable job situations who regard disability compensation as the most acceptable income alternative. Nor are they prepared to subsidize the social welfare system. While protection of profit is a transparent goal, several insurers also assert that it is personally gratifying to see people recover and return to their usual roles.

In addition to these goals, insurers hold several beliefs about factors that may contribute to questionable claims. First, they believe that having insurance may be a disincentive to prudent behavior, thereby increasing the risk for claims; and that disability compensation may remove motivation to return to work.

> I would be interested to see, of the doctors that you talk to that have a number of patients ...what their statistics are for people who return to work that do not have disability coverage, as opposed to those who do. That would be a very interesting focus of a study...

Taken together these beliefs suggest that in some cases, the possibility of receiving compensation provides additional or independent motivation to file disability claims. Insurers use the term *moral hazard* to refer to the aggregate (but unknown) risk for disability that is attributable to insurance programs discouraging preventive and rehabilitative activities (Aarts and deJong 1992)[1].

Second, it is a truism among insurers that claims for illnesses without objective evidence increase during recessions; not because there is a rise in sickness, but because of rational self interest on the part of claimants. With decreased job mobility, fewer part time work opportunities for those with mild disabilities, or impending job losses, disability income becomes an attractive alternative to the stigma of social welfare.

> The past few years has been devastating for the insurance industry for disability claims. Because if you [are in real estate and] suddenly can't sell houses anymore then "Gosh! Have I got a pain in my back! Oh! Oh! do I feel sick and tired, depressed!" I bet you feel sick and tired and depressed not earning any money. So we have gotten a lot of claims from people in these past few years that I don't think we get in normal, non recessionary times.

Third, insurers assume that a number of personal factors, unrelated to illness, determine whether and how long people will be disabled: "disability depends to some extent on how people will react to illness. Some people who are sick try to work, while others don't". Mechanic and Volkart (1961) were the first to analyze non clinical factors that may account for differences in functioning among people with ailments of similar severity.

Insurers also hold assumptions about other actors who are implicated in disability claims; chief among them are claimants' attending physicians. In their view, attending

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[1] Aarts, Leo J. M. and Philip R. deJong 1992. Economic Aspects of Disability Behavior. Amsterdam: Elsevier Science Publishers B.V. These authors studied the Dutch social service disability system and proposed a micro economic analysis of disability insurance based on the utility maximization model. In this context, the model considers people's preference for labor force participation and optimal supply of working hours. The model introduces a number of discretionary behaviors in applying for and remaining on disability. These behaviors are based on a clearly rational economic calculus. Aarts and deJong posit that if people calculate that they are better off overall on disability, and if they prefer leisure to work, they will choose disability income over re-employment, even if the disability income is lower.

physicians are strongly motivated to write reports for claims in order to satisfy and retain patients.

> ..the doctor who has a patient who has been a patient of his for several years, he wants to keep that patient. He wants to keep that patient happy. They [patients] come and they say: "Oh, I am so tired! I feel bad and blah, blah, blah." And the doctor has lots of other things and other patients on his mind and says: "Maybe you've got CFS"
>
> "Oh, tell me what that's all about? Oh yeah, that's what I've got"
>
> And the next thing you know, that's what they do have according to everything. ....Many of them [doctors], I think are doing it with all the best of intentions, but they can hype up their patients to thinking that they really have something bad, because everybody else in the office has something bad. So we have trouble knowing that what we are reading is really representing what is there.

Another group which insurers may regard suspiciously are employers. They suggest that some employers try to get rid of problem workers by foisting them to the disability insurance system:

> We get lots of claims from employers who are trying to get rid of someone and shift them into the kind of disability mode and then expect us to support this person that they don't want to keep, or having got them on disability claims they abandon all hope of ever taking them back again. And, at the end as the person starts to recover, you have someone who doesn't have a job to go back to, so they keep wanting to stay on their disability payments. Well we're not the welfare agency, we're somebody who is paying so that you can avoid a financial loss due to being disabled, not to being fired.

In sum, long before insurers ever received a claim for CFS, they believed that a number of non clinical factors contribute to questionable if not outright fraudulent claims. These factors include: moral hazard, recessions, individual factors such as coping and motivation, as well as physicians' wish to satisfy their patients, and employers' strategies to shift problem employees to other institutions. This set of world views and insurers' goals are operationalized in the day to day work of underwriting, adjudication, and rehabilitation.

Underwriting: Risk Appraisal and Client Selection

Underwriting minimizes costs by estimating risks, selecting clients, spreading risk exposure, and setting policy terms that reflect the level of risk. The process depends heavily on information and assumptions about prospective clients. To evaluate the risk

associated with an individual, insurers gather information from his or her medical, financial, occupational and avocational histories. These data may reveal risky lifestyles, occupational hazards, and present or past medical conditions that may recur or predispose affected individuals to costly illnesses later. Certain information in work and health histories act as early warning signals of "claim[s] waiting to happen":

> ...people who have funny backgrounds that suggest this is a person who has missed a lot of work, has had a lot of strange illness, who has had several periods of depression, lots of medication,...you get leery about offering those people disability insurance because it is a claim waiting to happen. And if we can avoid those we do...because many of those are claims that I think are unjustified. Those people are not well...people who need that much support...are always going to end up being difficult claims that you never know how to handle.

To estimate the risk for an employee group, underwriters collect comparatively less information because they assume that: working people are healthy, the group's health will tend toward the mean, and no substantial financial impact will accrue from a few undetected risks. These assumptions allow new group policies to cover all people who are actively working on the day the contract comes into effect. That includes people who are legitimately absent, for example, those on vacation. However, insurers have the right to ask new members who join an existing group plan about pre-existing conditions which may disqualify them from coverage. Insurers define a pre-existing condition as one from which the client has suffered in the past, or one which manifests within a year of receiving coverage. Different medical conditions and lifestyles are associated with different levels of risks. Levels are standardized and scored by risk assessment experts who are usually reinsurers. Standardizing penalizes some people since different people deal with the same risk differently. Risk appraisals help insurers to screen out applicants and to set policy terms and premiums that reflect the level of risk of those accepted.

Despite efforts to evaluate risks for claims, underwriting is plagued by imperfect information (Rea 1981). Insurers do not know the extent to which moral hazard, personal characteristics, or larger socioeconomic pressures, will influence a given prospective client to claim disability. Flawed information reduces the accuracy of distinguishing risk levels among clients (Rea 1981). As a result, insurers will inadvertently accept some clients at

high risk for claims-an outcome known as *adverse selection.* Some insurers attribute lack of information to privacy law restrictions and clients' and attending physicians' decisions to withhold information. But Rea (1981) contends that insurers lack information largely because of the expense of collecting data. Whatever the reason, insurers know that flawed information may be costly.

Underwriters use several strategies to offset threats to profit margins from adverse selection. They may set policy terms to include compensation contingency clauses, exclusions, and time-limited coverage. They may also spread the risk by expanding the client base to constitute a population assumed to be heterogeneous for risk (Aarts & deJong 1992; Rea 1981) or by transferring a part of the risk to other insurers and reinsurers. In addition to these measures, insurers protect profits by fixing premiums of new policies on the basis of risk levels, the estimated number of claims for each level, clients' incomes, and exclusions. And they adjust premiums for renewed policies in light of claims during the previous policy. In theory, the threat of higher renewal premiums should motivate employers who offer group insurance benefits to keep down the numbers and length of claims. In reality, the competitive nature of the industry neutralizes such incentives. Employers can "shop around and rip off another company for a couple of years. But word gets around."

At the time of underwriting, insurers must not only build in controls over future costs, they must also assure that the estimated costs can be met. Legally, they must reserve against claims when a policy is sold. The amount of reserves is based on the estimated percentage of claims against all policies that are in force. When a claim is made, a special reserve has to be satisfied in accordance with the law and terms of the policy. Reserves may be invested but they cannot be used for operating expenses.

> Each time a claim is approved, there has to be an amount set aside...so that this person is sure to be covered... and this is usually until age 65. We do not stop that reserve at the change of definition on that claim. Government rules make it impossible for us to act otherwise and it would be foolhardy for us, we could not do it.

> When you sell a policy, you have to reserve against a claim. But you can base that on the fact that of the policies you sell, x percent will have a claim, therefore x percent of the policies you have in force have to be reserved against. If someone gets sick, you have to satisfy the special reserve. In a lot of instances you reserve until age 65 or whatever the term of the policy is. What it does, is it takes money out of the operating company and puts it in a box where you can't use it...Reserves may be invested...

Depending on the investment vehicle, reserves may be vulnerable to the vagaries of the market. During the recession of the early 1990s, non performing commercial real estate investments posed a serious risk to the reserves of many companies. The results were felt in the ensuing years as some companies' credit ratings were downgraded, some were bought by more robust rivals, and others collapsed. As a method of cost containment, underwriting is only as good as the accuracy of the information collected, the accuracy of underlying assumptions, and knowledge of risk factors.

Adjudication: From Client to Claimant

The receipt of a claim sets in motion a process to determine its legitimacy. It also signals a change in the status of the insured person from client to claimant. The disposition of the claim and the status of the insured person depend on decisions about vocational disability. This section presents insurers' ideas about vocational disability and the process of adjudication by which it is determined.

Vocational Disability

Insurers' notions of disability are based on a framework that is most appropriate for physical problems. In this framework, disability is conceptualized as a limitation in an individual's capacities and level of functioning due to an impairment, that is, a physiological or anatomical loss or abnormality. Usually, but not always, active pathology (injury or disease) accounts for the impairment (Nagi 1969b: Pp. 10-17)[2]. Both active

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[2]In 1969, Nagi believed that mental and emotional disorders were outside of the scope of his framwork. n 1991, he updated his to include impairments of a mental or emotional nature. However he reiterated the belief that his conceptualizations were most appropriate for physical disorders, especially with respect to rehabilitation which is closely aligned to disability. Nagi, Saad

pathology and impairment represent deviations from normal, and insurers generally expect objective evidence of these deviations in claims of limitations in the ability to work.

The expectation of objective evidence is not absolute. Insurers acknowledge that mental and emotional impairments may also limit the ability to work. However, they are reluctant to deal with these claims. First, they may have relatively limited experiences in dealing with claims for psychological disorders, since these conditions were excluded from coverage until recently.

> Until recently, many policies were sold with mental and nervous disorders excluded, which I don't think is really fair. You know, if somebody is practicing medicine and becomes psychotic, you can't allow him to continue practicing medicine...because his decision process is irrational, he may do some harm. So those exclusions were really not fair. Mostly, they've been dropped.

Second, these claims are regarded as among the most difficult to adjudicate. A claim for depression for example, may be describing anything "from unhappiness to the pain of agitated depression" and requires extensive evaluation (Brodsky 1991: 389). Third, it is difficult to judge the limitations of depression, since different people react differently: "People get depressed about things, it doesn't stop them from working. How do you measure that?"

Fourth, claims for nervous and mental disorders raise concerns about significant economic costs. Insurers fully expect claims for these conditions to rise in the next several years. Nervous and mental disorders are frequently stress related, and stress is ubiquitous in today's society. In fact, according to some insurers, health care data show that the incidence of these conditions has been rising steadily since 1985. Cost concerns also arise because insurers believe that people in high paying occupations are the most vulnerable to stress. Typically, these people have extended insurance coverage with high monthly benefits. In comparison with claimants for other illnesses, claimants with nervous and mental disorders are younger, their claims last longer, and they are associated with more

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(1991) "Disability Concepts Revisted: Implications for Prevention." Pp. 309-327. in Disability in America. Toward a National Agenda for Prevention edited by A. M. Pope and A. R. Tarlov. Washington, D. C.: National Academy Press.

fraud and litigation. While these disorders are sometimes treatable, some show patterns of relapse which means more time on benefits. Insurers may contain costs through the terms of new policies, but they can do little about existing policies, many of which had lifted the exclusion on these disorders. As a result of these concerns, the last thing insurers want is another illness under the rubric of nervous and mental disorders. Although they often spoke of these disorders in discussing CFS, they were careful not to place it explicitly in that category.

The focus of insurers' interest is of course work related disability. They define vocational disability as the inability to perform the essential duties of one's own occupation because of sickness or accident. Some insurers try to quantify 'essential' as 60-70% of the claimant's own job, but then they have to define what 60-70% entails. Many insurers have also interpreted 'own occupation' in narrow or broad terms. The narrow interpretation equates 'own occupation' with one's 'own job'. This definition gives policy holders temporary shelter from the hardships of retraining, accepting jobs they do not like or for which they are unsuited, and applying for social welfare. As one representative explained: "a dentist who becomes blind, might well be able to work, but he cannot work as a dentist". But the narrow interpretation means that companies must compensate without acknowledging residual marketable abilities of individuals who are unable to work in their own jobs. In contrast, broader interpretations consider the total training of individuals, their transferable skills, and the fact that most occupations can be practiced in different geographic locations. In effect, these interpretations increase the job pool that insurers regard as commensurate with both training and any remaining abilities. Broad interpretations may benefit companies but disadvantage claimants who may have to work in other than their preferred jobs or preferred locations.

The definition of vocational disability as the inability to carry out the tasks of one's 'own occupation' was introduced by companies as a competitive strategy. Increasingly, most companies and the courts have interpreted the 'own occupation' clause as the inability

to do one's 'own job'. Unless companies specify otherwise in their contracts, they run the risk having the courts interpret 'own occupation' as 'own job' in contested claims.

Disability for one's 'own occupation' is usually limited to a specific period of time. Professionals' 'own occupation' period generally runs until age sixty five. Typically, this category of claimant is covered by an individual policy or a professional association policy which usually pays high monthly benefits. Early reports indicated that CFS sufferers belonged precisely to this category. Non professionals' 'own occupation' period usually lasts from one to five years. Close to the time of expiry, claimants who have not returned to gainful employment are usually reassessed for their ability to work in 'any occupation' commensurate with their education, training and experience. Reassessments are usually waived for claimants who are near retirement, or for those who have terminal or progressively debilitating illnesses. On reassessment, if the claimant is found unable to work at any occupation, a *definitional change* in his or her status is said to have occurred. In recent years, the courts have limited 'any occupation' to those of similar status to the predisability occupation and paying at least 75% of the predisability remuneration. In other words, "you cannot return a vice president to a clerical job." Blue collar workers may find there is no 'own occupation' period, rather the 'any occupation' clause is triggered as soon as they file a claim:

> "Professionals have to age 65 for [their] 'own occupation'. Others in the blue collar market find they have to be totally disabled for 'any occupation' as of day one. Contracts can be as restricted as 'any occupation' or as liberal as to age sixty five. Most are for two years [own occupation]"

The elasticity in interpreting the 'own occupation' clause, the shifting definitions of disability from being unable to work in one's own occupation to being unable to work in any occupation, and the class based differences in definitions show that disability is not a fixed concept. Rather, from an insurance perspective, disability is an administrative category (Stone 1984) that different companies can and do construct in different ways for different people. Membership in the category confers certain rights and privileges (Stone 1984).

Processing Claims

Insurers begin to process a claim soon after it arrives. The claim must satisfy both administrative and medical requirements. To meet preliminary administrative requirements, an application for benefits must include the claimant's statement of disability, his or her employer's signature to validate the coverage, and an attending physician's report. The employer's signature may precede or follow the doctor's report. Some insurers believe that claimants' rights to privacy are violated when employers sign after the medical report is attached. They are especially concerned about psychiatric conditions or those that have a psychiatric component.

A benefits representative or equivalent person reviews the application to ensure that the policy is registered and that the claim falls within the contractual terms. For example, clients cannot usually claim for a pre-existing condition. Typically, contracts also require that claimants are under the care of a physician and trying to mitigate their circumstances. In many instances, continuing to work invalidates a claim. If all preliminary requirements are met, the claim proceeds to the adjudicators. They examine the claim for the fit among claimants' self assessed disability, medical evidence, and job requirements. Their task is to determine vocational disability.

Examining the Medical Evidence: Looking for Impairment

Consistent with their conceptualization of disability, insurers examine the medical report for objective evidence of impairment from a bona fide medical condition. The most useful medical reports provide a detailed history of claimants' objective and subjective symptoms, including their numbers, type and severity; laboratory and other test results suggesting physical and mental impairments; dates of examinations; treatments; an explanation of why the claimant is considered disabled; and the estimated time of return to work. If the initial medical information is insufficient, or suspected of bias, adjudicators may request further information from the attending physician, specialists, or hospitals to

which the claimant was referred. Companies with in-house medical consultants may seek their advice on the need for further information. Alternatively, they may request that claimants see an independent medical examiner (IME.)

Independent medical examiners are not employees of insurance companies. They are consulted ad hoc and paid for their expertise which often includes academic credentials. They provide detailed assessments and are willing to go to court if necessary. But they are also touted as free of the vested interest of attending physicians, who are believed to frame reports to optimize their patients receiving benefits.

> We tend to go with people with some academic affiliation, meaning they have done research themselves or are involved with it in an academic critically thinking way, in keeping with the standards of medicine. We would tend to go with somebody with those credentials, who is independent and impartial.

> Sometimes we approach them directly because we happen to know this person is in that city, ...who knows something about the disease that the client claims to have. Sometimes they are found for us by paramedical companies who say "this guy is good, this surgeon, infectious disease person" or whatever...We write them a letter and ask them to see this patient to give us their opinion on a bunch of questions related to whatever their claim is about, particularly what's the matter with them, are they really sick, are they not really sick? When do you expect them to go back to work? whether anything is going to contribute or inhibit this process. And usually you get, instead of a one page letter that's pretty common for most doctors, you get a big, long letter of 6 or 8 pages...which lists all the history and the findings, all the lab tests that have been done, everything else that you can think of. Those are very valuable. These people are not employees of the company. We pay them for doing this of course...they are not biased in their opinion. They are just saying "this is what it is". And they don't work on our side or the patient's side either, they just say. Sometimes they are undecided. CFS is one [case].

> These doctors [are] agreeable to doing an independent medical evaluation and will agree to go to court if needs be...[they] will deal with the claimant and ask specific questions or do specific testing that we would like the claimant to go through.

Claims of IME impartiality have raised questions of whether these physicians do not feel that they must find more often in favor of companies who pay them, even if no such suggestions are made (Nagi 1969b). Companies may be especially vulnerable to criticism when they have a long standing relationship with IMEs. Those who use associations that provide IMEs from a pool of experts, may have fewer long term relationships with particular doctors, since the same doctors may not always assess clients of a given company.

Medical reports demonstrating objective evidence of impairment go a considerable way to determining disability. But two other elements are necessary before claimants are deemed vocationally disabled. The impairment must be shown to restrict or limit functioning and these limitations must prevent the person from being able to work at their own occupation or own job. An important issue is how to measure limitations.

Looking for Limitations: The Issue of Measurement

Limitations are commonly assessed by two methods- self reports and observer ratings of functioning. Self reports typically ask about physical function and social disability, that is, the degree of difficulty or the assistance needed to perform basic activities of daily living, instrumental activities of daily living, and major activities, in this case -work (Verbrugge 1990). Self reports may be biased towards supporting claims as strongly as possible, especially when there is no objective corroboration.

Observer ratings are used to determine physical, and cognitive or psychological function. Tests of physical function aim to measure intrinsic abilities to do tasks rather than actual performance. Thus, they are designed around basic physical movements requiring strength, endurance, balance and coordination (Verbrugge 1990; Turk 1988). Cognitive or psychological evaluations are usually performed by psychologists or psychiatrists. Companies have the legal right to insist on cognitive or psychological evaluations administered by professionals of their own choosing. Insurers may also 'measure' claimants' limitations by ad hoc surveillance of suspected malingerers.

Some insurers noted that not all physicians perform observer ratings with the same degree of thoroughness. Some had observed physicians who made educated guesses because they did not have the equipment to test specific degrees of strength accurately. This type of variation raises issues of validity and reliability. Nonetheless, insurers defer to doctors, whether attending physicians or IMEs, to establish impairment and assess limitations. But companies differ as to who takes the final step of matching limitations to

job descriptions. Some companies accept doctors' opinions of vocational disability while others reserve this decision as an in-house responsibility. Insurers in the latter category may have more control over granting disability.

Accepted and Rejected Claims

Once a claim is accepted, payment is contingent on the terms of the contract. Contracts may or may not cover the initial period, also known as the elimination period. For example, some employers may choose government unemployment insurance (UI) disability to cover the first seventeen weeks, with private insurance contracts taking effect after this period, if necessary. In other cases, the weekly indemnity (WI) short program, offered by private companies, pays for an elimination period that may range from 26-52 weeks. Employers who choose this option register their (WI) insured programs with the government and receive a discount on the amount of unemployment insurance remitted. The third alternative offers an elimination period of two years. These contracts immediately base disability payments on the popular two year "own occupation" contract. Employers may choose different companies for short and longer term disability coverage.

Some contracts pay only for total disability and disallow benefits for claimants who work. In contrast, other contracts adjust benefits if someone on total disability attempts a gradual return to work. Should a relapse occur within six months of return to work, benefits are reinstated as a continuation of the original claim. Relapse after six months of returning to work is considered a new claim and must satisfy all the requirements described above. Other contracts will pay for partial disability allowing claimants to continue working for fewer hours or at fewer tasks. Partial payments are regarded as a means of creating goodwill by decreasing the perception of an adversarial relationship and increasing the perception that companies are trying to help. Payments are usually based on income at the time of disability. Generally, contracts pay from 50-100% of salary with most in the 66 2/3 to 80% range. Cost of living adjustments are not standard but may be purchased.

In some respects, accepted claims create an open ended adjudication process. Claimants must be prepared to continue to prove that they deserve to be paid. Proof of continued disability is generally required at the transition from disability for one's 'own occupation' to 'any occupation'. But insurers may institute surveillance, request independent medical assessments, or updated information from the attending physician at any time during the period of the claim. They are interested not only in changes in the claimant's status with respect to the original claim, but also in the emergence of new disabling conditions. The weight of the original medical evidence is critical in determining the frequency with which proof of disability will be required.

The most common reasons for rejecting claims are failure to satisfy the terms of the contract or deficiencies in the medical evidence. Thus claims for excluded conditions or claims in which the medical evidence does not show sufficiently severe impairment or limitations are likely to be rejected. Benefits may also be denied if claimants are not under close medical supervision or not receiving proper treatment. Rejected claimants have the right to appeal in writing within sixty days. Appeals are handled by ad hoc committees of five or six people which may include supervisors, adjudicators and in-house medical consultants. Insurers do not believe that they reject claims lightly. Therefore claimants who appeal a rejection bear the burden of proof. The appeals process may continue until one party, usually the claimant, gives in or the claim goes to litigation.

Rehabilitation: Transition from Claimant Back to Client

During the period of receiving compensation, claimants may be required or encouraged to participate in rehabilitation programs. The aim is to return people to work thereby reducing their time on disability benefits. Companies may retain their own rehabilitation personnel or contract out this service. Rehabilitation personnel are usually educated in a health discipline. They include nurses, occupational therapists, physiotherapists, psychologists, social workers, and psychometricians. But good social

skills are also necessary because rehabilitation personnel play a liaison role between insurance companies and claimants, attending physicians, and employers. They must often offset negative perceptions of insurance companies before they can gain the cooperation of others.

> I hope you can do something to inform them [doctors] that we are not working against them. You say "insurance" and they don't want to see you. I had one of them throw me out of his office....I don't know what's their problem, whether it's the forms, or getting paid, or if they feel threatened for some reason. Usually, once you get in, they are okay. But, it's getting in.

> I try to appreciate claimants There is always a ten or fifteen minute period, before I get into the nitty gritty of the interview... either assessing the decoration of their home, the geographic location or something which will make them feel that possibly I am not the ogre which the insurance company has sent to their home. This is what I try very hard to do...I'ts really important

Unlike other insurance personnel who may deal only with papers documenting the claim and its progress through the system, much of the work of the rehabilitation personnel involves face to face contact with others. In dealing with attending physicians, they focus on getting required forms completed and more recently on gaining their cooperation to motivate claimants to return to work. Their work with employers involves negotiating job modifications for returning employees and setting realistic expectations for job performance after a prolonged disability. Their contact with claimants covers the widest range. They may assess motivation and rehabilitation potential; develop rehabilitation programs; inform claimants of available resources; provide general emotional support; and explain terms of contracts. A commonly used rehabilitation approach is known as work hardening. These are programs designed to allow a gradual phase-in to claimants' previous jobs or new work.

Traditionally, rehabilitation programs follow medical treatment. The most developed programs are for conditions in which much is known about the limitation, for example blindness and amputation, and residual abilities are stable (Nagi 1969b). Success in these programs depends in part on claimant's rehabilitation potential which rests on both physical condition and motivation. Rehabilitation potential is closely related to disability both conceptually and operationally (Nagi 1969b). Disability highlights limitations while

rehabilitation potential focuses on remaining abilities (Nagi 1969b) The conflict of interest that ensues when a worker has to demonstrate disability to receive immediate income replacement, but harness abilities to assure an optimum future, has not gone unnoticed (Lewis 1962 in Nagi 1969b:170).

The foregoing account describes the goals, world views and operations that formed the context in which CFS claims were received. The next section highlights the issues that CFS brought to the fore in the decade of the 1980s and early 1990s.

Issues in CFS Disability Claims

Insurers received early CFS claims in the context of a mindset about the doubtful validity of subjective claims in times of recession and a perspective on disability that favored clearcut physical illnesses with objective indicators. By the mid to late 1980s, that context was expanded by media reports, the medical literature and the status of early claims. Media reports repeatedly indicated that CFS sufferers were young professionals in the higher socio-economic classes- the kind of people whose claims would be costly. Medical debates about the existence and nature of the condition had begun and insurers were beginning to worry about early claims that showed no signs of ending. In addition, to these troubling aspects about the condition, some companies were experiencing financial woes that were widely reported in the business media. It was hardly surprising that insurers wanted to know: Is CFS a disabling illness? Does this claimant have it? How much of it can we expect? And, what is it going to cost?

CFS and Vocational Disability: Impairment vs. Limitation

Insurers' early responses highlight two different emphases in determining disability. Most companies stressed the need to show impairment with supporting objective

evidence. In their view, CFS did not convincingly meet this criteria since objective evidence was often absent and when present, it was not specific to the condition

> It does not fit the criteria commonly known for disability. Until they have objective evidence they will find a problem justifying claims. It is unfortunate but that's the way it is. There is a part of the population trying to abuse the claims. You cannot tell which part is bona fide.
>
> You can have a disease, no matter what the disease is, but if an impairment isn't there, you are not disabled.
>
> When I look at the first case in 1982 I didn't believe that it was possible to be tired all the time without any specific reason. I have been very doubtful about these cases for a very long time

Without objective evidence of an impairment, the index of suspicion about malingering and nervous and mental disorders rose. Indeed, from the beginning this group of insurers believed that both malingering and mental disorders had to be ruled out in CFS claims. Moreover, they knew that the medical community was divided over whether CFS was a bona fide medical condition. By taking a hard line on objective evidence and trading on medical disputes, these insurers initially dismissed CFS claims.

A second group of companies believed that it was more important to show limitations that prevent claimants from working, rather than the specific medical condition or impairment responsible for these limitations.

> We are less concerned with establishing CFS than we are with establishing disability. That is the bottom line.
>
> I have gone to seminars on CFS and doctors were offering their services as consultants for us because they were concerned that the diagnosis was not correct, and that thirty percent are wrongly diagnosed. We don't need that because we don't care. If the person is disabled, the person is disabled. If I have enough symptoms and enough medical [evidence] substantiating that the person cannot perform, I don't care if it's CFS or depression

The effect of these differing emphases in the definition of disability on rates of accepting CFS claims is not known. Some companies were sufficiently unconcerned about specific underlying conditions that they kept no statistics on acceptance and rejection of claims by category of illness.

Later, pragmatic considerations and medical influences would modify the initial reactions of both groups. Those who were initially dismissive became more accepting of CFS claims as legitimate on the advice of their medical consultants, the CDC's imprimatur,

and the fact that the number of claims was not diminishing. The second group began to keep statistics in response to actuarial needs for the information. As the length of claims became evident, most companies also realized that it was in their interest to distinguish between CFS and treatable psychological disorders. The difference in time on benefits could be significant.

Problems of Measuring Limitations in CFS

Claims that were not immediately rejected for lack of objective evidence or questionable labels, were processed further to determine the extent of limitations and the impact on claimants' jobs. At this stage, insurers discovered that CFS claims accentuated flaws in common methods of evaluating limitations. On the one hand, self reports could be expected to be even more heavily biased than self interest would predict, since these claimants have no other way to prove disability. On the other hand, observer ratings by health professionals or surveillants brought other problems to the fore. First, these ratings usually measure general abilities rather than the specific abilities that claimants need to perform their jobs. Second, health professionals' ratings constitute point data on a condition marked by fluctuating symptoms of fatigue. This leads to questions of the validity of these measures since fatigue would be expected to affect abilities. This problem has been recognized by people with the chronic pain condition known as repetition strain injury, when they were evaluated during periods in which symptoms had abated. They reported feeling forced to exaggerate the pain that they were actually experiencing in order to be believed (Reid et al. 1991). The problem of fluctuating symptoms has also been recognized recently by a working group that evaluated the 1988 CDC case definition. They recommended that illness severity, which bears on disability, must be assessed by measures of fatigue severity and functional ability that are sensitive to changes in patients' status over time (Schluederberg 1992). A third problem is that point data may be an inappropriate measure of the endurance that most jobs require. The fact that claimants may

be able to lift 5 Kg in a physician's office does not mean that they can lift 5 Kg over several hours, if that is what their work entails.

Insurers could argue that the longer observations of surveillance address the criticisms of using point data to measure fluctuating abilities and endurance. But surveillance has its drawbacks in this regard because it is usually confined to detecting whether or not a claimant is at home and to observing claimants in exterior spaces. Observing that a claimant is homebound is open to interpretation. The person could be prostrate in bed or be performing paid work for several hours at a stretch or when symptoms allow. Such data about endurance and fluctuating symptoms are generally unavailable to the surveillant.

Observations of claimants in public places are also problematic. Typical surveillance findings that question claimants' limitations show them freely roaming shopping malls, attending support group activities, or engaging in heavy physical activities. But surveillants cannot know if several hours or days of rest preceded and followed these activities as many claimants report. In addition, the claimant seen engaging in physical activity may not be able to perform a job that primarily requires concerted mental effort. Unless surveillance documented a claimant engaging in sustained activities daily, over several days or weeks, and these activities required capacities similar to those needed for the claimant's job, it would not necessarily indicate that the person was capable of working in his or her own occupation.

> A person was observed for about a week continuously. The comment was "she shopped me out", in other words she was out shopping, busy, doing things. So here is a person who was on claim for this, who was very very active and busy and doing these things, yet claiming not to be able to do this. If you put someone under surveillance for a couple of days, then "oh you caught me on my good days, I was wiped out the rest of the three days and in bed" and that is what is recorded. It's probably one of the toughest challenges for the insurance industry.

> We use surveillance- hire investigators to confirm disability. From the medical standpoint it is hard, even Dr. ___ feels that with CFS patients, he cannot really say "yea" or "nay". It is not based on objective evidence but his knowledge of the condition. Sometimes people will tell us that they had to sleep all day because they are tired. Then you put them under surveillance and discover that they were out shopping all day, two or three days in a row. Then you have to question the condition. Are they really that disabled? Is degree of disability really what they meant, what they have volunteered?.... We have to make sure we are not dealing with psychiatric cases that can be treated, that we are not dealing with malingerers.

In short, no matter how much insurers might suspect that resort to the illness' features are convenient excuses, they cannot interpret observed discrepancies between claimants accounts and their activities with confidence. Insurers cannot know whether observed activity patterns reflect normal fluctuations of the illness, or whether knowledge of fluctuations provides malingerers with ready explanations of their activities.

Regardless of their emphasis in defining disability, or misgivings about measuring limitations, by the end of the decade insurers answered the question of whether CFS is really a disabling illness with a qualified yes. They concluded that CFS may cause vocational disability, but only in a very small number of people.

> We believe that the real percentage of people who have CFS is very low. There are studies that have shown this....Of this low percentage, [with CFS] there should be an even lower percentage that are disabled. But people use reading to know that there are minimal requests from insurers. Also there is no treatment so that there is decreased pressure to submit information. I think that there are real cases, but it is a very strange illness.

The Validity of Claims: Credibility and the CDC Criteria

Definitions of disability based on physical evidence were not very useful in CFS claims. Less stringent criteria of limitations were not likely to be widely adopted in light of concerns about increases in nervous and mental disorders and the data emerging on CFS claims. Moreover, traditional measures of limitations could be made to seem invalid because they do not take into account characteristics of the illness. With the appropriateness of traditional measures in doubt, the validity of each new CFS claim had to determined very carefully. New claims elicited ambivalent reactions.

> I think that for better or worse, unfortunately every time you get a new CFS claim you cannot help but think "oh boy, this again". We feel very sorry for the person and you must respect the fact that there is empathy but there is also the fact that we know this is going to cost us big bucks and recovery if at all is just so sometimes so short lived.

For assistance with determining disability, many insurers referred CFS cases to IMEs. But as insurers gained more experience, they began to discriminate more among IMEs.

> Now we do not send them to people that think they are chronic fatigue specialists. because I have a problem with most of those people. Most of them are into some sort of pseudo-quackery...[there are] some really whackos out there..

A few companies did not use IME services to establish CFS claims since they did not believe that true expertise exists for this condition.

> There is nothing out there to say one side or the other is right. It always comes down to the person's credibility. If we are dealing with someone who is not credible, that is, a lot of absenteeism. We have to build these cases, that is why it is very difficult.

In the end, claimants' credibility became central to determining whether claims were true cases of CFS related disability. To judge credibility, insurers combined information on claimants' appearance, behaviors, experiences and psychosocial circumstances. From their comments I have constructed a composite of how credible claimants present themselves. First, such claimants show small, if any, discrepancies between their reports and their conduct. They may or may not look sick, but their level and type of activities are consistent with common notions of disabilities in acute illness. They are not the claimants who are "outshopping" the surveillants. They do not spend inordinate amounts of time in support group activities, or selectively expend energy on leisure activities while claiming they are unable to work. If they report cognitive dysfunction, their accounts support that.

> I am impressed with the details about what they can and can't do. One person was telling me about driving and not noticing the stop lights and I said, she can't be making that up, she has to have experienced that to talk about it, she must have the problem [CFS].

In the quote above, not noticing the stop light becomes possible evidence of cognitive dysfunction. It also has a ring of authenticity that leads the insurer to think the person cannot be fabricating the account.

Second, credible claimants conform to the obligations of the sick role to: seek competent help and attempt to end occupancy in the role. Their attending physicians are not among the self styled CFS experts who promote the illness as purely physical or who offer unproven therapies. Such physicians have little credibility with insurers. Instead, they are regarded as complicit in sufferers' misguided attempts to find physical remedies to prove they have a physical illness.

> The other thing is the methods of treatment used, the naturopathic treatments, the anti yeast treatments and some people with some physicians' theories. You have to question this when there is no valid proof that any of this works, where they have been trying, such as the yeast. I have not seen a paper to show that that is good proof.

> A hundred years ago, patent medicine men went around and sold bottles of alcohol in funny colors and told people it was good for everything under the sun you know. It made a lot of people better because there is a very strong placebo effect in many things and it may be perfectly valid for someone who can acquire the presence to go to a patient who says they have CFS and say now you take this and this and do it at eight o'clock every morning and at twelve noon and at 4:30 in the afternoon not 5 , 4:30 and you do it everyday for 8 weeks and you will begin to feel better, Some of them will. Because anybody who can be that sick for that long has a huge psychological overlay problem that makes it last a helluva lot longer so maybe there is some value. It has nothing to do with the biology of this disease, whatever that is. But they [these doctors] will confuse you all to hell if you talk with them.

Credible claimants do not prolong sick role occupancy by accepting the rhetoric of some support groups that promote severe protracted disability as the inevitable lot of CFS sufferers. One insurer indicated that an internal study had found that CFS claimants in support groups almost never return to work. Finally, credible claimants do not remain in the sick role for secondary gains. If anything their losses clearly outweigh any gains from claiming disability.

> There is a dramatic change in their lifestyle. If they are not depressed, what would they be getting out of claiming illness?

> These people's lives are on hold. You can carry on like this for a while, but after years and years, it is difficult to think that they are pretending. In these cases even surveillance may not show anything

> ...actually they do have a very, very low coping rate overall. The emotional impact ,if it is not a symptom itself initially, it certainly becomes a very, very marked entity as the disability progresses because nobody likes being [disabled], especially someone who has a thriving career. And you have to attach a degree of credibility to all this, because these were all people who were just high achievers...so that it is that much more damming to them when they reach that low ebb. And without any kind of knowledge of when they are going to feel better..

The final quote shows that the magnitude of loss may be a pivotal element in believing claimants. This raises the question of whether people in lower socioeconomic classes are seen as less credible because they may be losing relatively less.

In contrast, claimants who are not credible show obvious inconsistencies between their accounts and their conduct. They may "look the picture of health". They seem to have no trouble camping, shopping or walking the dog on a regular basis. Despite claims of cognitive dysfunction, they defend themselves ably if their claims are denied or if benefits

are terminated. Some women even go on to have children while on CFS disability, which leaves insurers wondering where they find the energy. The problem for insurers is that these claimants seem to have the energy necessary for a life that is normal in every other way except participating in the labor force. These claimants seem to be enjoying the sick role's benefits rather than wanting to leave it.

It is not wholly rational for insurers to suspect CFS claimants of malingering simply because they look well. People with many chronic illnesses such as heart disease, diabetes, or cancer may not "look sick" much of the time, yet they are not met with doubts about being ill. The difference between these illnesses and CFS is that objective evidence of these conditions can be produced if necessary. The fact that appearance is an issue only with CFS claimants, suggests that it is really the lack of objective evidence that is implicitly at work in judgments of credibility.

The CDC Criteria: An End to the Reliance on Credibility?

With the publication of the CDC criteria in 1988, insurers hoped they could use more than personal credibility to determine the validity of each CFS claim. Prior to 1988, discriminating among misdiagnoses, malingering and CFS was complicated by an array of labels and by a variety of diagnostic processes used to confirm CFS. Early claims listed chronic Epstein Barr virus (CEBV) or chronic mononucleosis as the underlying impairment causing disability. In the next dozen years insurers would see the labels: myalgic encephalomyelitis (ME) fibromyalgia (FM), fibromyositis, Coxsackie virus, fatigue, stress, depression, CFS and most recently chronic fatigue immune dysfunction syndrome (CFIDS). Several mentioned the popular labels "yuppie flu or yuppie disease". A few knew that CFS had been linked to neurasthenia, asthenia and Royal Free disease. Many also knew that the label CEBV has been discredited and that some members of the medical community consider the label ME misleading.

> ...We do recall a few as having a diagnosis of quote "yuppie flu and a lot of Epstein Barr virus with antibodies". We now know that's garbage. The Epstein Barr virus has nothing to do with

> CFS. Myalgic encephalomyelitis is a current term and CFIDS is another current term. To me...."itis" at the end of a word implies inflammation and there is no inflammation demonstrated.

By the time of these interviews in the late summer of 1993 to early Spring in 1994, insurers were familiar with several of these labels. They now believe that the plethora of labels refer to the same condition.

To compound the problem of whether a claimant had CFS, unstandardized diagnostic practices were as common as unstandardized labels. Insurers believed that a lack of uniform diagnosing contributed to misdiagnoses. They hoped that the CDC case definition would solve the problem of misdiagnosis by distinguishing cases from non cases and thus reduce the numbers of CFS claims. Their hopes rested on the second major criterion which excludes a diagnosis of CFS on the basis of past or co-occurring psychiatric disorder. This criterion was meant to discriminate between cases of CFS and psychiatric disorders. If CFS could be separated from psychiatric disorders, valid cases could be evaluated for limitations. Moreover, some detected psychiatric disorders might be successfully treated and thus reduce the time on benefits for those claimants. At first glance, the CDC case definition looked as though it was an answer to insurers' difficulties.

But instead of benefiting insurers, the CDC case definition taken as a whole confounded the issue. As pointed out in chapter one, by interpreting the exclusion of psychiatric disorder and the inclusion of neuropsychiatric symptoms in different ways, widely different prevalences could be produced. Strict application of the exclusion criterion would probably have drastically reduced the numbers diagnosed with the condition, and therefore the costs of CFS claims. In support of this position, one study had shown that when psychiatric disorders were rigorously excluded, only 4% of patients presenting to a fatigue clinic fulfilled the criteria (Manu et al 1988a). The fact that the CDC case definition included a few objective physical symptoms, which insurers weight so heavily, also made it attractive.

Perhaps the promise of the case definition was too much to resist. Some insurers began to insist that claimants meet the criteria. Several continue to insist on this requirement even while acknowledging the shortcomings of the CDC criteria.

> We look for the CDC criteria. Mostly they have to meet those criteria at least....There are no objective findings that you can 'so call' hang your hat on and say, yes, there is this finding or no there is not. Even the criteria that has been established are all, with the exception of the minor physical ones, are all by a subjective interview of the patient Do you have this ,do you have this, and of course, as we said, that is all such public knowledge now that it's impossible to determine one from the other

No insurer however, acknowledged that the CDC criteria were not intended for immediate clinical use (Schluederberg et al 1992) but to reduce heterogeneity in research samples and allow comparability of results (Krupp et al. 1991).

Insurers found that attending physicians were using far more variable and more lenient criteria to make the diagnosis. They believed many doctors were unaware of the CDC criteria. Some claimants, caught between the looser clinical diagnosis of their attending physicians and the new, more rigorous research diagnosis that insurance companies were requiring, became the casualties of this conflict. By insisting on the CDC criteria, and rejecting claims that did not meet the overall case definition, insurers were going well beyond the use for which the case definition was intended. In so doing, they might have increased the number of rejections in companies that had previously accepted less stringent criteria, while increasing acceptance in those companies that had routinely dismissed these claims.

The answer to the question of whether a particular claimant is a legitimate CFS case remains elusive. Insurers had hoped the CDC case definition would obviate the need to depend on claimants' credibility to establish the validity of claims. In the process, they hoped to reduce costs. But as the case definition came under attack, many insurers realized that it did not fulfill the promise they had imagined. Still, many continue to use it. The revised case definition published at the end of 1994 has removed the physical symptom criteria. This excision undercuts a major argument that claimants have used to counter assertions that the condition is psychological: psychological disorders could not produce

some of the physical symptoms. Without the physical criteria, CFS resembles psychological disorders even more. It remains to be seen whether insurers will abandon the criteria or use the new criteria to classify CFS as a psychological disorder. But given the concerns about claims for psychological disorders, this move seems doubtful.

The Size of the Problem: Malingering and Misdiagnosis

Undoubtedly, insurers wanted to believe the study indicating that the true prevalence of CFS was low. In that case, the number disabled by the illness would have been lower still. But from the late 1980s through the early 1990s applications for benefits continued to increase. Sensitized to opportunities for fraudulent claims in recessionary times, insurers attributed part of the rise to malingering. They believed that tendencies to malinger were exacerbated with CFS, because claimants had virtual handbooks of symptom presentation through sustained, high profile, media coverage and support group publications.

> The print media. I mean there are support groups, there are newsletters, articles in the weekly paper that tell you exactly what symptoms you should have, which doctors are supportive, lawyers are even mentioned in the literature and that sort of thing. It goes back to the basis of the condition, it is so subjective to begin with it just adds to the difficulty from an insurance perspective of determining what is a legitimate CF claim.
>
> Also, a lot has been written about chronic fatigue syndrome in books, the newspapers and people take advantage of this information. So there are good cases and bad cases.....But people use reading to know that there are minimal requests from insurers. Also, there is no treatment so that there is decreased pressure to submit information.
>
> The Nightingale Society...[a CFS Association] I receive their publications, giving specific information on how to go about having your claim for disability honored and giving instructions on what to say and what to report, what information is required and so forth. That's fair, people should be informed as to how to get a disability claim. But with such a subjective disease, it makes it doubly difficult because it's even more difficult to adjudicate it, impartially and fairly.

The belief that media attention to CFS has been both ongoing and extensive is supported by study of CFS coverage in British medical journals, professional trade papers, national newspapers, and women's magazines. That study found 171 articles on CFS in the national newspapers and women's magazines since 1980 (MacLean and Wessely 1994).

With media coverage encouraging self diagnosis, insurers expected misdiagnoses from attending physicians because of the drive to keep satisfied patients. Their experiences with claims suggested that many physicians had poor knowledge of the condition in general and of the CDC case definition in particular. In their view, these factors made misdiagnosis a significant contributor, along with malingering, to the number of CFS claims. They estimate that as much as 30% of CFS claims are misdiagnoses of other conditions, most often depression. They suggest that claimants wishing to avoid the stigma of mental disorders present themselves as suffering from CFS, which is ironic, since CFS itself is associated with mental disorders in the minds of many (Holland 1989; Shorter 1993; Manu et al.1992).

> Insurers and doctors believe that some cases are disguised depression. But the social impact of having depression is not something that the person can cope with and may not want to admit depression.

> There is the view of the social historian in Toronto whose name is Shorter[3] who I listened to and I must say that I don't think that his view can be discounted altogether. He believes that CFS is not only due to social stresses of the 20th century but that it is more acceptable than say in the 19th century, a rather strong comparison, hysteria of women. But CFS is more socially acceptable, people can say to their friends, their family, I have this illness and it is more accepted.

Although insurers accept that some CFS claims are misdiagnoses of mental disorders, they are not sure whether they should think of CFS as an organic or a mental illness.

> There is even debate in the medical field about whether its an organic illness or whether its a psychiatric illness or what the case may be. So it spills over into the insurance field as well. If it really exists where do we categorize it? what sort of criteria do we use?

As mentioned earlier, there are good reasons why they may not want to see CFS classified as one of the nervous and mental disorders.

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[3] Edward Shorter is a social historian whose views are anathema to many people with CFS interviewed for this study. Shorter has written a book on the history of fatigue and articles outlining his views on CFS. The essence of his argument presented at the CIBA foundation conference on CFS in 1993 is that medicine should be cautious in attributing the symptoms of CFS to an organic cause. He is concerned that doctors may be legitimizing somatization as disease. Somatization is the expression of psychological distress through physical symptoms. People with CFS take exception when someone "who has never seen a patient with CFS" garners legitimacy for his views, while they have not yet received similar legitimacy for their experience.

A small data set (N=289) from two insurance companies covering the period from 1980 to 1993, will be used to illustrate a number of points in the rest of this subsection and the next. Table I shows that the number of accepted CFS claims increased in the late 1980s, peaked in 1992 and declined in 1993.

Table I CFS claims accepted by two insurance companies from 1980-1993

Year	Company A	Company B
1980		1
1981		-
1982		1
1983		1
1984		2
1985		2
1986	1	2
1987	4	9
1988	5	16
1989	10	18
1990	11	34
1991	11	49
1992	32	60
1993	16	14
N=289	90	199

Claims doubled in 1989 for company A and in 1988 for company B, the year that the CDC case definition was published. This increase may have been due to the wide dissemination of the criteria, and ironically to insurers' insistence that claimants meet the criteria. Once

they had accepted the criteria as a valid indicator of illness, they could only contest the issue of limitations in claimants who met them.

The table also shows a decline in accepted claims, in the last year for which data is available. Although it is not possible to say whether this represents an anomaly or the beginning of a trend, this finding requires some comment. First, a decline in the number of accepted claims may reflect a real decline in the incidence of the condition, consistent with the natural history of many infectious epidemics. But as shown in chapter one, CFS has not been established as an infectious disease. Furthermore, without Canadian epidemiological studies of CFS incidence and prevalence, there is no way to determine whether a real decline has occurred.

Second, it is possible that CFS is being diagnosed less frequently. In 1991, Abbey and Garfinkel predicted that CFS would be diagnosed less frequently as clinicians recognize many self diagnosed sufferers as somatizers, that is, people who express emotional distress through physical symptoms. A third possibility is that the decline reflects larger numbers of rejections due to more rigorous adjudication of CFS claims. This issue will be addressed later. Insurers' answer to the question of how many CFS claims they should expect, was: far less than the number of claims being filed.

The Cost of Claims: Claimants' Profiles and Illness Course

By the late 1980s three patterns emerged that fueled concerns about costs. The number of claims were increasing, early claimants were still collecting benefits and the profile of claimants showed that many were indeed young, highly paid professionals-the so called "yuppies". By 1993, the occupational spectrum had broadened although many claimants still fit the original profile.

> There is a common perception that it's the higher educated, semi and professional people who are more at risk. I would agree that yes, we do see claims in that social strata, economic strata, but that isn't to say that they are not there in what you might call blue collar workers. But we

> just don't identify them as such. We don't see too many from the blue collar class of worker. We do see more in the educated class of worker. I don't have an explanation for that
>
> When I was [first] exposed to it, it was the "yuppie disease" or whatever you want to call it, where it was you upper class doctor or lawyer type of occupation. And now that it has become more widespread as far as knowledge, it seems to have filtered down.
>
> Originally the description we saw was the typical "yuppie" working 60 hours a week. That is not the case anymore. What you will find is that often people have children. A woman will have children and work outside the home and she just cannot continue.
>
> The typical person described in the studies are not what I have seen. They come from a range of occupations, age and so on. They don't meet the pattern.

Only one company (N=199) provided data on occupations. These data support the observation that CFS cuts across many occupational strata. However, in several cases occupational titles in this data set were too vague and there were no other data on socio-economic status to classify claimants according to such established measures as the Blishen or Hollingshead indices. Instead claimants occupations were categorized by sectors. Table II shows the frequency of CFS claimants' occupations using a sectorial classification.

Table II Frequency of CFS Claims by Occupations (N=199)

Sector	Frequency of claims in percent
Education	27.2
Administration/Support	21.0
Technical/ Operator/Laboratory	15.4
Administration/Management	11.3
Health and Social Services	10.3
Marketing, Sales, Purchasing	7.7
Engineering/Computing	4.6
Media/Reporters/Publishers	2.6

Job titles were not the only indication that CFS affects people in a range of occupations. Monthly benefits varied between $248 to $5,086 (combined group). When one considers that benefits generally represent from 65% to 80% of predisablility salary, it is clear that CFS is distributed over of a wide range of occupations. However, the mean monthly payments of $1,926 suggest that claimants were relatively highly paid individuals before becoming sick.

Unlike the trickling down of CFS from high to lower status occupations, the gender distribution of claimants remained consistent. By far, the majority of claimants were women in their mid twenties to mid forties at the time of filing their claims.

> ...as far as social characteristics they are above average in intelligence and education. There are more women than men, most in their 20s and 30s no one over 50, over 45 even. Nationally, [there are] more English than French.

Insurers had no explanation for the gender distribution. But, a few observed that many women had developed the illness in the context of changing social roles and strains associated with these changes.

> It is mainly women mainly in their 30s. Mainly 34, 35, 36 that age. One thing that I have seen in many of these people is that they think of themselves in terms of their careers. Is this a valid thing? I don't know because with 100 cases I don't think we can say it is something really solid. But when we talk to them, they always refer to the fact that "I was rethinking about this, or that I was not sure if I wanted to continue in this job or that situation". Sometimes they say: "Two years ago I started thinking about this". So you are not sure how close the connection is. Most of the time, they are demanding people for themselves and for others. [They] have their work as priority number one. Nothing else counts. Many [of them] have a couple of people that they talk to but not that many are close. -just working, working-relationships in the working environment. They get home, study all weekend, studying their work matters, something around their work. Nothing more. Nothing like gardening or...

The profile of claimants became even more significant when it was considered in conjunction with the duration and course of the condition. The early medical literature had suggested a duration of approximately two years (Salit 1985). But these insurers have seen CFS claims lasting as little as six months to as long as eleven years and counting. A few still expect the condition to last from one to three years. But the majority now think that the minimum duration is two years with an upper limit of eight years. In fact, many suspect that claims under two years are misdiagnoses. A few fear that the duration is indefinite.

> At first we thought the duration would be short, but it just went on and on. No one terminates. Its a guessing game. a waiting game. As people get older it is a vicious circle. Something else becomes primary.

The problem with the duration of the illness is that it means expensive payouts whether to a few young, highly paid professionals or to larger numbers of people over a wider occupational spectrum. [4].

The combined data set (N=289) from the two companies showed that 75.5% of claimants were women and 24.5% were men. The mean age at the time of filing a claim was 40.9 years (range 22.4-63.3 years) which is at or near the peak earning years of many people, hence the size of the monthly benefits. More importantly, the mean time remaining on the contracts of claimants was 22.3 years, although the mean duration of claims was only 1.7 years in 1993, (range 9 months to 12.2 years). Table III shows the mean monthly and annual costs of CFS claims, as well as the mean costs if claims were paid to the end of contracts, and the total annual costs of claims.

Table III Costs of CFS Claims to Two Companies (n=289)

Mean monthly payment (range)	$1,926 ($248 -$5,086)
Mean annual payment (range)	$23,112 ($2987- $61,043)
Total annual payments	$6,702,719.
Mean payment if claims continued to expiry of policies (range)	$504,627 ($4,707- $2,149,579)

[4] Data from two insurance companies are for group policies only. They do not include professionals such as doctors and lawyers who would belong to associations or carry individual policies

Had insurers anticipated the duration of these claims, they might have tried the traditional cost reduction measure of rehabilitation sooner. When they belatedly began such efforts, they found that many early claimants had "organized their life around disability", or had "become absorbed in their condition". Motivating them to attempt rehabilitation has proven very difficult. Frustrating experiences with rehabilitation has led some insurers to regard CFS claimants as exemplifying the operation of moral hazard, that is, the disincentives of disability insurance.

> In my experience I haven't seen too many go back to work yet...It is very rare that you see...a person [with CFS] that shows high motivation in the doctor's report or in your dealings with them...They adopt that sick process and it sort of snowballs and two years later they are no better off than they were. They just don't seem to want to try anything....We are not doctors, and we have no way of knowing...if that's normal progress of the chronic fatigue patient or is it normal for one that has disability insurance...

Other insurers reinforced this view by recounting cases where claimants returned to work only after exhausting disability benefits, as well as all other sources of financial assistance short of social welfare. But not all insurers regard CFS claimants as unmotivated.

> I have looked at these claims and tried to say "is this person motivated or are they not?" The evidence is that they probably are motivated and wish that they would get better and try hard to get better. I wonder if some of them are beating their head against the wall too much. So yes, I think motivation may be a factor but I don't think I could honestly say lack of motivation is a big factor in not getting back to work. I really don't know

Insurers neglected rehabilitation partly because they had no way of knowing that claims would last as long as they did. But, part of the neglect may have been related to the lack of firm knowledge about the treatments, prognosis, course, and duration of the condition to guide their expectations and efforts. Or as one respondent put it " the trouble with CFS is, it is difficult to say what rehab is, and what is appropriate." Although it cannot be said that successful rehabilitation is now possible, the medical literature on the subject is growing and insurers have recently undertaken many more efforts than previously. One obstacle to such efforts is the fact that policies for individuals (as opposed to group policies) generally do not stipulate mandatory rehabilitation. Some companies are now considering whether rehabilitation, within limits, should be a condition of individual policies.

As to the course of CFS, it does not bode well for a return to work and therefore a reduction in insurers' costs. The illness follows a relapsing and remitting course. Some chronic illnesses allow normal or near normal functioning during remissions. But remissions in CFS are marked by unpredictable day to day fluctuations in symptom severity and fluctuations even within a twenty four hour period. Relapses on the other hand, seem to be triggered by mental and physical demands, with thresholds of tolerance varying widely. These demands are of course generic to work to a greater or lesser extent. It seemed unlikely that CFS claimants would have prolonged productive periods when benefits could be reduced or terminated.

In fact, insurers know that some clients have relapsed after trying to return to work. Others seemed to have made a more successful return to the workforce, but the numbers are still too small and the time too short to judge whether recovery will be sustained. At this point cautious optimism seems most realistic.

> Initially [this client] went back to work part time. As far as I know three months later she is still at work. But that is not to say that in a month or two I won't get a request to meet her and find out quote unquote WHAT HAPPENED in capital letters.

The challenge for rehabilitation personnel is to find ways to increase activity and social integration gradually, without precipitating a relapse.

Tentative answers to the cost of claims were troubling although not alarming. If the data presented here is representative of companies with CFS claims, and if contracts run to term, the financial impact on insurers could be considerable.

Even before the decade ended, insurers were clearly not satisfied with their responses to CFS claims. Claimants were becoming more insistent on having their claims recognized as legitimate. Some medical consultants were counseling acceptance of CFS as a legitimate cause of disability. The hard line was becoming increasingly untenable.

> Initially we kept saying: "no, there is no evidence, so no benefits". We cannot keep doing that and ignore a condition that appears to be legitimate. Unfortunately, it is open to abuse because of the lack of objective evidence.

At the same time, the potentially large costs of these claims made it imperative for insurers to contain malingering and misdiagnosis to the extent that they could. The knowledge that they had been steadily accumulating through experience, the medical and support group literature, the popular media, and their own internal studies, would prove influential in attempts to address these competing issues. Several companies instituted changes in their approaches to adjudication and rehabilitation. For the moment they can only muse about underwriting since CFS has no known risk factors.

New Stategies in Dealing with CFS

To contain costs while recognizing legitimacy, insurers had to find better ways to discriminate among CFS, malingering and mental disorders and to assess limitations in cases of CFS. They began by scrutinizing the information provided by attending physicians and claimants even more carefully. Some companies also began to experiment with new ways of measuring limitations that blurred the lines between adjudication and rehabilitation.

Increased Rigor in Adjudication

Most insurers began to examine attending physicians' reports for evidence that CDC criteria were met. A few insurers continued to regard signs of the Epstein Barr virus (EBV) as lending weight to claims that are so heavily dependent on self reported symptoms.

> Unfortunately many cases that are diagnosed as CFS are regarded as subjective symptoms, the person says he is tired, the person says he can't concentrate, the person says he has aches and pains in his muscles, they say they have sleep disorders. They sleep hours, they wake up just as tired as if they hadn't slept, this is typical. Those are more difficult to really adjudicate. When you have a case of CFS where you have positive Epstein-Barr, positive, there's another test where it's positive, you have swollen glands. These are objective symptoms. Like any other disability with subjective symptoms, it opens the door to malingering, so there are people that can use that to be on disability. It is our responsibility to be able to identify those people.

But most would no longer accept EBV evidence as a sufficient indication of CFS.

> Physicians are not always familiar with the CDC criteria and we put the onus on claimants to justify the disability. The problem from the claimant's point of view is, how do they justify their disability objectively? They cannot. Sometimes you get lab studies from physicians saying: "he has the EB virus" and we go back and say "that does not do anything",. if you sample the population that has had mono, it is quite possible that they all have positive EBs. That is not enough, We need more. It is a lot of writing back and trying to get it pinned down. Then we have the psychiatric end to look at. So yes, we declined a lot of them because they are insufficiently prepared when they submit the claim. It is still a guessing game as far as we are concerned.

The above quote illustrates the impossible situation in which some insurers placed claimants: they continued to insist on objective evidence which they knew claimants probably could not produce. By rejecting EBV evidence, some insurers signaled they were no longer accepting just any kind of objective evidence. Some were equally unimpressed by neuroimaging findings that showed changes in cerebral blood flow of people with CFS. They pointed out that the patterns of changes were not specific to CFS but overlapped with other disorders. The irony of being inclined to accept overlap between CFS and mental disorders, but not between CFS and physical disorders, seems to have gone unnoticed.

> There are some changes in the MRI scan [of CFS claimants] but these are present in people who are depressed, and in another group of diseases and also in the normal population, you will see these plaques that have been described, whatever. Of course then there is blood flow difference on the SPECT scans and so forth. But I don't think any of these tests have been proven to be highly specific or sensitive.

To be fair, the medical profession had largely decided that EBV was no longer evidence of CFS and had also cautioned against interpreting neuro-imaging results as evidence of the condition since the relationship of findings to clinical symptoms was not clear. But these medical directives also fit with insurers' self interest in containing the number of claims. What was becoming clear was that insurers were defining more specifically what constituted 'right' and 'wrong' kinds of evidence, that attending physicians could use to support their patients' CFS claims.

In parallel with setting stricter guidelines for accepting attending physicians' reports, insurers instituted more thorough investigations of claimants' reports. They began with claimants' definitions of disability. Experiences with early claims had taught them that

high achieving professionals did not always define disability in ways that fit common perceptions of the term.

> We have to look into a lot of aspects more closely for [professionals] because there is a lot of money involved...Very often these people will tell us, they are involved [in work] 60 hours a week, they still consider that they are disabled. So there are some definite nuances in those policies.

Insurers also honed in on the psychosocial aspect of claimants' lives. They wanted to assess whether undiagnosed, and possibly treatable mental disorders, could account for claimants' disability. The CDC exclusion criteria and studies suggesting high overlap between CFS and mental disorders provided the rationale.

> When the person comes in and says chronic fatigue syndrome, we always ask for [more] background health history. If there is no mention [on the form] of depressive disorder or anxiety, or stress type disorders, then we will question the client themselves, just to see what they have been through in the past few years prior to the diagnosis. If we really feel that there is something in terms of psychological disorder then we will probably arrange for an independent medical examination or try to arrange through the attending doctor to refer to a psychologist or psychiatrist. But it is a difficult thing to distinguish. Sometimes you know there is something but you can't pinpoint it, and nobody will, no matter what you do, you just can't get at it. Nobody will say that there is something going on psychologically. You are just faced with the fact that that's the way it is and try to manage around it.

> There are a lot of intangibles that you do not look for in other conditions. If someone has a heart attack I will not question their motivation to go back to work within the period of recovery. With CFS you wonder. There are a lot of psychological factors that you do not have to consider in other conditions because there is proof- an EKG for example.

These in-depth examinations sometimes uncovered undiagnosed psychological disorders. As mentioned earlier, insurers had difficulties with psychological disorder both in terms of adjudicating claims and in terms of cost. But it was still important to identify these disorders because some could be treated even while claimants continued to work and because contracts that exclude these disorders are probably still in effect. While mental and emotional disorders were not always found, insurers frequently observed that claimants were leading harried lives with few social supports or other means of relieving stress. Several insurers placed these personal troubles in a larger context of general anxiety about the state of the economy and fears of job loss.

> We found a lot of cases where we had psychiatric consultation, that there is a underlying condition. Maybe social problems or the office...It compounds the problem. I think people are working more, two income families and so on, and people are just burned out. People just work too hard. I think that is the problem. We do not seem to take any moments in our personal or social lives, that is adding up. You cannot expect to be Superman forever. At one point, you have to withdraw. We are seeing people who are just finished, they do not seem to have the drive, they have used up all their energy. Life is getting more complicated than 30 years ago.

> Stress may be a significant component. Its hard to know but in these times with downsizing and lost jobs... people worry about having a job. For illness in general, the work environment is stressful, demands are greater, anxiety is high, job security doesn't mean much, people may not be exercising much, which is one way of diffusing stress.

Acknowledging stresses of the economic downturn allowed insurers to have some empathy for claimants. But it also activated their general world views about the relationship between recessions and claims. The result has been more frequent investigations into the economic health of sectors in which claimants work, and more particularly claimants' job status. For example, insurers want to know about downsizing, redundancies, and impending or actual job losses.

> The subjective [claims are] very difficult. It's a fact that the insurance business is open to malingering. The more the economy worsens, the more you'll see those. If someone knows a month and a half, two months ahead of time that their company is going to let go four thousand people, it's very tempting to try and go on disability. Our responsibility is to try and identify those people that are not truly disabled. If it is subjective, we will pursue further to get more information. And that's not just for CFS, that's for lower back pains, vertigo, headaches, migraines...

Some insurers introduced a second type of change to address the problems of measuring limitations in the face of fluctuating symptoms. They believe that daily diaries, or logs of what claimants actually do in different domains of life for each hour of the day could provide a more accurate picture of the relationship between symptoms and activities. Data from logs provide rough measures of general abilities to do activities of daily living rather than specific job activities, but they may reveal patterns of energy that would permit part time or modified work. These data may also serve as a baseline from which to assess improvement or deterioration. Diaries have been used in studies of illness experiences but they are not common in the insurance industry.

Diaries may have several drawbacks. If they must be kept for a long time, they may become quite onerous. Moreover, people keeping diaries may notice more symptoms as a result of being more focused on their sensations (Pennebaker and Skelton 1978). In turn, the awareness of symptoms may affect activities. And diaries do not overcome the biases that may be present in self reports. Data from this source is only as good as a claimant's willingness to be accurate and conscientious.

A more direct assessment of claimants' ability to perform "the essential duties of their work", can be obtained through work hardening programs. Some insurers claim positive results with these programs, although they find that the phase-in period for CFS claimants is longer and less smooth than is usual for most other disabilities. Others however do not believe that work hardening is a true measure of what claimants can or cannot do. They are trying to negotiate with employers to have claimants remain in their jobs without ever leaving. Three potential obstacles stand in the way of success of this approach. Symptom severity may simply preclude continued work. As well, companies that cover only the long term disability and not the elimination period, may learn of claims only after the claimant has been off work for several months or even up to two years. By then, the negative effects of prolonged disability on motivation may have set in.

> The problem with long term disability is that you often don't see a claim coming in until they have been disabled for several weeks and months. Then all of a sudden, beyond the terms of their waiting period as it were, -some it's 120 days, some it's 30 days- whatever the disability depending on the policy, you don't see it until it's almost too late. Mostly with group, we do see it early enough. We have enough warning to intervene.

Finally, employers' cooperation is critical but it cannot be assumed.

> We have experimented with getting to claimants early, during the first six months even sometimes before they leave their jobs, but that's very hard to catch. we try to visit those claimants, contact their employer to see if we can work something out. Flexibility in employment is important. The employment structure can kill motivation to try to stay on. We encourage employers to keep them on, but they are not prepared to do a lot. Their body language can tell you a lot. With tight budgets they are less tolerant. They don't see increased premiums as enough of a financial incentive to keep employees working. In fact they still want a reduction in their premiums. The last few years some have been more willing to accept a gradual return to work. The idea of early return or early intervention is that after two years people are absorbed in their condition and this pattern is hard to break.

Insurers may find daily diaries and keeping claimants at work in modified conditions useful for both adjudication and rehabilitation. A finding of total or partial disability may rest on results of these measures during the lag time between filing a claim and its disposition. These results may also provide a baseline for monitoring progress and rehabilitation efforts.

Finally, a few insurers have instituted a policy of routine surveillance of all CFS claimants to complement other means of assessing limitations. Normally, surveillance is reserved for cases of suspected fraud, appeals of rejected claims, and relapses after return to work. It is not clear what insurers hope to establish with surveillance of CFS claimants since as mentioned earlier, results of surveillance may be contested by resort to the fluctuating nature of symptoms. Moreover, many insurers currently profess that claimants do not have to be housebound to be credible. But suspicions aroused by leisure activities such as shopping or walking the dog several days in a row suggest that insurers have not yet worked out a coherent view of what it means 'not to be house bound'.

The changes that insurers introduced were variations on the basic process of adjudication. These changes suggest that adjudicating CFS has become more rigorous. Requiring that claimants meet the CDC case definition moves the case definition from being inclusion criteria for research samples to being the standard for clinical diagnosis. It will be interesting to see whether insurers will adopt the new case definition and whether future claimants will report fewer physical symptoms since these criteria have been eliminated. Collecting broader and more detailed information on claimants has resulted in identifying some cases of treatable psychological disorders that were misdiagnosed as CFS. Attempts to obtain more accurate measures of limitation and circumvent the inertia of prolonged disability have not been in place long enough, or tried with enough people to evaluate their effects. But they represent innovations in the industry that were sparked by the need to find effective ways to deal with CFS claims.

Rehabilitation: Timing and Alliances

In contrast with the modifications in adjudication, rehabilitation efforts changed radically in the late 1980s. Insurers adopted a three pronged approach targeting claimants' employers, and attending physicians. First, most insurers have now instituted rehabilitation efforts where little or nothing existed before. The prevailing wisdom favors early rehabilitation to avoid motivational problems of prolonged disability and thus reduce costs.

> Well in 1982 nobody really knew what this was all about and people were very inexperienced. And we hadn't done a good job of this case we hadn't really ...tried to help the person with a work hardening type of program- nothing. But now we act on them very, very quickly we start talking to them, start getting people involved in their case, visiting them, trying to make sure they exercise a little bit, make sure they visit the workplace that kind of stuff so I guess with experience you may be successful with returning them a little bit quicker

Rehabilitation personnel now meet with claimants to assess their abilities, motivation, and readiness to return to work. They encourage healthy lifestyles, light exercise and good nutrition. Some try to motivate claimants by pointing out that there is no guarantee of passing the definitional change to long term disability at the end of the elimination period. They find that CFS claimants "need a lot of encouragement". But heavy caseloads, favor telephone rather than personal contact. In general, rehabilitation personnel are more open than others in the industry to claimants' use of support groups to obtain information and reduce isolation. Many will advise claimants that such groups exist.

A second focus of rehabilitation work is to convince employers to modify work conditions so that claimants may return or remain on the job. Employers are most familiar with the disability paradigm of gall bladder surgery in which the employee is off work for a period of a few weeks to a few months. Therefore, they must be educated to have realistic expectations of employees with CFS and they may need incentives to accept a modified work performance. Insurers may agree to pay claimants' salaries in the short run, with a view to facilitating their return to work earlier than might have occurred otherwise.

> Employers... don't expect such a long rehab period, they are used to people being off for gallbladders and coming back in a few weeks. These workers have to increase their work gradually. Employers may accept them back for part time as long as they are not paying, that

> is, we are paying the part time. If its retraining they don't like that. If they had been good employees they have better chances with their employers. I had one person who had attempted to return 4 days in a row. It lasted about 3 months

> Employers- are happy to see someone who is trying to get their employee back to work. When someone goes on long term disability, they have to put aside some special funds. For small companies it can be very costly if they have several employees on this fund. It gets depleted very quickly, and when they go to renew their group insurance, their premiums are going to go up. ...They are not used to having employees off for a year and a half, they are used to a gall bladder operation and you are back in three months. So I have to convince them its worth their while to get [the claimant] back

Although some employers are open to work modifications, insurers know that structural features of work production may stymie adaptations.

> If you start a [task] its going to have a time limit within which it needs to be completed which is a matter of days or weeks. And its very difficult to do that if you can only do it two hours a day. The job just never gets done the customer you are working for isn't happy. So employers are reticent to hire people back on a part time basis if they are irregular. They can't predict when they are going to be there when the job's going to get done...it becomes worse the higher you get in a management structure or whatever because other people start relying on that individual everyday and that's no good. So putting people back to work after they have started to recover from this disease is hard.

> we try to encourage employers to take that CFS patient on a gradual basis, not expect them to be full-time immediately....sometimes because of the employment situation, employers just do not have the opportunity to bring people back to work and try them on a trial basis. That is why we have [rehabilitation] coordinators come in. They try to educate the employer so that they understand that these people cannot be in a structured environment. You cannot expect them to do this every day for three days a week, you have to be careful and not be disappointed if certain things happen that you cannot predict. If we do not do this ahead of time, the employers are disappointed and they say "I can't rely on these people, they don't show up..." There is a lot of education involved.

The third element in rehabilitating CFS claimants is to enlist the cooperation of attending physicians. Insurers now want attending physicians "not only to certify, but to motivate" claimants to leave the sick role and return to work. They admit that claimants often trust attending physicians to act in their best interest, while the same cannot be said of how they feel about insurers. When doctors are willing to cooperate, insurers may suggest that the plan is promoted as if it were developed collaboratively between the doctor and the claimant.

> I went to see her physician. Fortunately he knew her well, he knew her before she got CFS and what kind of person she was. He wanted to help her too, so I said here is the plan. I want you to talk to her and encourage her to follow it, but, you have to make her think that you and she together, or she, came up with the idea and support her in following through.

This approach is not only pragmatic, it is a radical departure from insurers' world views about attending physicians and seeks to reverse a traditionally adversarial relationship.

> I think we need to continue to try and work with the medical community, because I think everybody goals are the same - to get people back to productive lifestyle. I think more of that could take place....That's difficult issue It pervades not just this condition . The physician may take his first allegiance to the patient and we recognize that. or else the patient would find another doctor. Any doctor I would go to I would expect to be my advocate. Well I wouldn't go to a doctor that I would expect would question my every complaint or question my word. I mean that would be silly so again yeah we are dealing with a difficult issue not just in chronic fatigue, but with any other subjective disability where you know the doctor, his first job is to look after his patient and secondly look after insurance issues.

But it may be difficult to forge alliances with attending physicians at the rehabilitation stage because insurers have often placed attending physicians in an unenviable situation. At underwriting, these doctors may contribute to denial of coverage for their patients by supplying negative health information to companies. The information they provide for disability benefits, may be met with skepticism and an independent medical examination of their patients. Moreover, at the definitional change insurers ask attending physicians to certify that their patients are unable to work in any occupation. When the current state of knowledge cannot clearly support such an assessment, physicians may feel that they are sentencing patients to hopelessness concerning their occupations and careers, solely to satisfy the administrative requirements of insurers. Insurers will have to work to change the uneasy relationship between themselves and doctors.

Changes in adjudication and rehabilitation in the late 1980s reflected a compromise position between broad acceptance and "looking for information to deny benefits". While insurers were more open to granting CFS legitimacy, they suspected that the number of claims was inflated by misdiagnosis and malingering. Some medical literature supported their positions and directed changes in adjudication and rehabilitation. At this stage, insurers have fewer cost containment options through underwriting. Underwriting relies on social epidemiological studies to identify illness prevalence[5] and risk, neither of which were available for CFS. But the condition has alerted some underwriters to look for

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[5]Prevalence studies have been conducted in Britain, the United States and Australia, but not in Canada.

symptom constellations in prospective clients' reports, even if there is no diagnosis. No other factors have been identified that would even remotely qualify as risks for CFS. A few insurers speculated that prospective clients with a known history of CFS would not be granted disability coverage. They were concerned about the emergence of psychological disorders or relapses. These concerns betray how close CFS is to mental disorders in the minds of some insurers. They also suggest that CFS has become de facto grounds for exclusion of coverage. However, individuals with a history of CFS who were at work at the time that a new group plan took effect, would receive coverage.

Summary and conclusions

Throughout the decade of the 1980s, insurers were integrating information from a number of sources and coming to some consensus on how to think about and handle CFS claims. The majority initially viewed the problem as a lack of objective evidence to support these claims. But by the mid 1980s insurers were facing another problem: strong social pressures from claimants to recognize unverifiable claims as legitimate. At the same time, insurers felt pressed to contain potentially large costs as claims increased in numbers and duration. To address these opposing demands, they instituted changes in adjudication and rehabilitation in the latter part of the decade. These changes were informed mainly by their experiences with CFS claims and selected medical literature on the condition.

This chapter has shown how structural elements of the insurance industry conditioned responses to CFS claims and how in turn, CFS revealed inadequacies in some of these elements. Insurers' goals, world views, and routine operations defined the core of their dealings with CFS. But they also took cues from external elements such as recessions and divided opinions in the medical profession.

Insurers' beliefs in moral hazard, the effect of recessions on unverifiable claims, and a disability concept that favored clear cut physical illness virtually assured that CFS

claims would arouse suspicions of fraud. But when they applied customary cost containment and fraud detection measures to CFS, the limits of these measures were highlighted. Screening for risks at underwriting had failed to signal CFS claimants as "claims waiting to happen". If anything, CFS seems to affect exactly the type of people that insurers traditionally court and whose business they want. Individual policy holders were productive, seemingly ambitious professional people at the time of applying for coverage. Members of group policies met the criteria for coverage and therefore the assumptions underlying these criteria. Detecting fraud at adjudication was also difficult because conventional methods of measuring limitations do not adequately determine abilities in conditions with a fluctuating pattern of symptoms. And the erratic and relapsing nature of the condition has confounded attempts to assess motivation and rehabilitation potential.

Besides revealing limitations in routine operations, CFS claims underlined insurers' ambivalent relations with clients and with their attending physicians. On the one hand, clients are insurers' raison d'être and insurers depend on attending physicians for information to issue policies and benefits and for continued monitoring. On the other, insurers' mistrust of clients is formalized in the concepts of moral hazard and adverse selection. Their mistrust of doctors is manifested in a popular belief that doctors' allegiance to patients will often override professional objectivity. Mistrust may not be evident during discreet investigations of prospective clients and seemingly straightforward claims, or in many run of the mill transactions with doctors. But in a contested illness such as CFS, the ambiguities and tensions arising from the conflict between dependence and mistrust are constantly at the surface. As individuals pass from clients to claimants through such illnesses, insurers' relations with clients and with their attending physicians may become frankly adversarial.

Finally, threats to profits have led to a few attempts to assess the impact of CFS claims. As mentioned earlier, at the 1990 meeting of medical officers of life and health insurance companies in North America, there was a perception that the numbers were

increasing alarmingly. In an effort to bring some perspective to the situation, the assistant medical director of the company with the greatest experience in group health claims in Canada, reported the results of a study of his company at this meeting. The study showed that in 1989 only 88 claims out of 20,000 were for CFS. Of these, fully one half the number of claimants were found to have conditions other than CFS that explained the disability (Lechky 1990). In the interviews, several insurers mentioned a more recent study of the industry's experience with CFS commissioned in 1994[6]. Although they had hoped for a nationwide quantitative study of the impact of these claims, only twelve companies participated of a possible 150 that cover life and disability insurance. A third study that was mentioned suggested a positive association between support group membership and not returning to work.

Until the late 1980s the number of claims for CFS was small and, in terms of absolute numbers, remains so today. But absolute numbers alone do not tell the whole story of the impact of these claims on the industry. Insurers continue to be concerned by the demographic profile of claimants, the length and relapsing nature of the condition, the lack of objective findings, the rise of support groups, and what they see as a growing medical and non medical industry around the condition. The financial impact of claims on some companies has been considerable. Barring breakthroughs in treatment, or proof of massive malingering, the impact may continue to be felt well into the twenty first century, since some claims made in the 1980s are based on contracts that run until claimants are sixty five. Chronic fatigue syndrome shows why disability compensation is so heavily weighted toward "illnesses with identifiable disease".

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[6]The company that was contracted to do the survey refused my request for a copy of the report. They cited ethical reasons since participants had not been informed at the time of their entry into the study that results would be available to people who were not members of the Canadian Life and Health Insurance Association (CLHIA). The low participation rate was mentioned in their written response to my request.

CHAPTER 5

FAMILY AND FRIENDS: BEARING THE COSTS OF CARING

So far I have shown that doctors are concerned with the difficulties of diagnosing and treating CFS. Insurers, on the other hand, worry about the legitimacy and costs of CFS related disability. By comparison, friends and relatives are preoccupied with how the illness affects their own and sufferers' day to day lives. By virtue of their social location, the intimates of people with CFS become "wise persons" in the Goffmanian sense. Such persons are privy to many details of sufferers' illness experiences and more or less sympathetic to their plight (Goffman 1963: 28-31). They see sufferers at close quarters, over time, and during periods when the illness may be more or less severe. They often observe costs to sufferers that are hidden from doctors and insurers. This chapter shows how such close observations, affective relationships, and shared histories with sufferers contributed to the effects of CFS on significant others and to their definitions of the problem.

The literature on lay conceptions of illness is germane to the analysis of significant others' definitions of what was wrong with sufferers. Such conceptions have been variously termed lay constructions of illness (Freidson 1970), lay explanatory models (Kleinman 1980), illness representations (Leventhal et al. 1980; Bishop and Converse 1986), common-sense models of illness (Meyer et al 1985), and common-sense representations of illness (Lau et al. 1989). Illness models may develop from personal or vicarious experiences (Meyer et al. 1985), the popular media (Kleinman 1980), and medical information. They may consist of general structures or schemas (Leventhal et al. 1980; Bishop and Converse 1986; Kleinman 1980) and/or prototypes of specific illnesses (Bishop and Converse 1986) against which subsequent illness episodes are judged. Several

authors suggest that lay illness schemas include: symptoms, cause, course and treatment (Leventhal et al. 1980; Bishop and Converse 1986; Kleinman 1980) a label (Meyer et al 1985; Leventhal et al. 1980; Bishop and Converse 1986) and pathophysiology (Kleinman 1980). Lay models may be vague (Kleinman 1980) and changeable (Baumann et al. 1989: Kleinman 1980). Friends' and relatives' illness models may significantly affect how they react to the sick person, including counsel to seek professional help (Freidson 1970).

The literature on family burden suggests useful analytic categories for studying the impact of CFS on significant others. The two major categories of illness burden are subjective and objective burden. Subjective burden refers to the negative feelings that family members [or close others] experience from the ill person's presence, behavior, and dependency (Noh and Turner 1987) or from actual caregiving duties (Horwitz and Reinhard 1995). This aspect of burden, sometimes known as the emotional cost of caring (Kessler and McLeod 1984), includes worry, strain (Noh and Turner 1987) grief, resentment (Horwitz and Reinhard 1995), depression, and somatization (Kessler and McLeod 1984). Objective burden on the other hand, refers to difficulties that significant others may experience because of the sick person's diminished role performance and disruptions to household routines (Noh and Turner 1987). In a review of studies of family burdens in chronic mental illnesses, Gubman and Tessler (1987) reported that among other things, family caregivers may miss work, restrict social and leisure activities, and reduce attention to others. More recently, Ranelli and Hansen (1995) have found that family caregivers of chronically ill elderly people, may have to assume new roles that include patient advocacy, medication management, surrogate decision making, and intensified surveillance for further problems.

The objective and subjective burdens of caregiving may turn significant others into "hidden patients" (Haug 1994) or contribute to a sense of role captivity (Aneshensel et al. 1993). The latter refers to a feeling of being trapped in an unwanted relationship that only superficially resembles the one that existed before an illness (Aneshensel et al. 1993). But

Gubman & Tessler (1987) note that the normal course of close relationships entails some social costs. For this reason, they define burden as costs that outweigh the satisfactions of meeting the needs of loved ones, and that exceed what is expected of kin, given age, gender and social class grouping.

Besides these normative expectations, Gubman and Tessler (1987) reported that several other factors have been found to influence whether caregiving becomes a burden and the nature of the burden. These include illness variables such as type of onset, duration, severity, and predictability; role reversals; coresidency; the amount of contact with the sick person; social class; and availability and type of resources. Other authors have suggested that the time in the life course that illness appears (Rolland 1994; Moen et al. 1995) and cultural expectations of the ill person (Horwitz and Reinhard 1995) may also influence the amount and nature of burden experienced.

The chapter is divided into two main sections. The first section shows how significant others constructed definitions of sufferers' problems over the course of the illness. It also describes how different definitions led to different responses. The second section presents changes in friends' and families' roles and responsibilities as a result of the illness' duration, severity and unpredictability. It ends by highlighting how friends and families are affected by perceived transformations in sufferers' social identities.

Figuring Out What's Wrong

Before diagnosis, significant others had to decide whether sufferers were ill or had some other type of problem. As the situation continued, most began to think that sufferers were seriously ill. But when sufferers received the diagnosis of CFS, once again significant others were faced with trying to define what was wrong because of the uncertainties and controversies surrounding the condition. Regardless of the time in the course of the illness, significant others' definitions of sufferers' problems had two major

components 1) a characterization of the problem and 2) expectations of how sufferers should behave.

Before Diagnosis: Illness or Difficulty Coping?

Most significant others noticed something was wrong before sufferers received a diagnosis. At first, they variously believed sufferers were sick or unable to cope, or else they could not decide between these two explanations. However, there were situations in which illness was not in doubt. In a minority of cases, sufferers' symptoms were precipitous and severe enough to require emergency hospitalization. Then, significant others immediately believed sufferers were seriously ill.

> Concerns were a lot worse then- such as will it get worse? Is it life threatening? Will she deteriorate daily such as [in] muscular dystrophy? Will she just get more tired and eventually have two hours of energy a day?

In less dramatic circumstances, sufferers had a prolonged infectious illness or a series of discrete infections, following resolution of an earlier illness. In these cases, it seemed plausible to think of sufferers as still sick or not quite recovered. Significant others did not consider these situations normal, but they were not alarmed.

> I did not think it was life threatening. I thought it was some lingering problem with the hepatitis, being a liver problem, it was just taking her longer to shake it. It was in her system and it would not go away.

> She started off with an ear infection...[which] was eventually cured... but after three courses of antibiotics, which is highly unusual for something of that magnitude and she just never got better...

> He came home with infectious mononucleosis... a very, very severe case. He was in bed with a fever for days and days...he could not stand the light in his room,...he hated to take the covers off to get out of bed and go to the washroom because he would get chills...that was the start of everything. After that, he got better gradually but he never got better completely. ...He would go from one illness, one infection to another...There was a period of 2 years that he never got better and we could not figure out what was going on...

In this early prediagnostic stage, the most important factors in believing that sufferers were sick were the circumstances of the illness' onset and the seriousness of symptoms.

In contrast, when the first inkling of a problem was uncharacteristic, and often disagreeable behaviors, significant others believed that sufferers were simply finding it difficult to cope with stress. As "wise" persons, they were aware of current or recent stressful transitions in sufferers' lives such as: marriage, divorce, failed romantic relationships, death, illness in the family, the birth of children, children leaving home, emigration, and impending financial problems. Furthermore, as far as they knew, sufferers had not received any recent medical diagnoses. But knowing sufferers' medical and social histories and observing behaviors that were ambiguous as symptoms, allowed them to frame sufferers' problems as difficulty coping.

> At first I thought it was just part of adjusting to married life...living with another person who was not his parents. I thought it was due to stress from the preparation for our wedding, pressures from work...
>
> At first I believed that her illness was caused by overwork. She was taking night courses several nights per week, working at a job and visiting a sick parent.
>
> The first realization that I had that things were really out of kilter with her was...[when] we had a whole weekend [at her house]. She lost her temper completely...I thought she was just working out her life history with me, mad as hell about things...being mad, and irritable and angry with me...After, I thought to myself "why did I put myself through that?" I should have told her to knock it off...

But not all friends and relatives felt comfortable characterizing situations as difficulty coping when both symptoms and multiple stressors were present. When symptoms were ambiguous and characteristics of sufferers militated against being overwhelmed by stress, some significant others could not decide how to define the problem.

> When he started having some symptoms....it was hard to figure out if it was depression related to the whole family breakup or whether it was really physiological... Prior to developing all these symptoms [he] was very hard working.... It was work all week, work a lot of overtime...come home and work around the house. Not just a couple of hours but the full weekend, and go back to work...So it was a tremendous contrast to see him watch TV, sit down, sleep until noon...My sisters and brother were all moving out at the same time...[and] the split up with a woman that he had control over for 30 years, all of a sudden going their separate ways, I could relate it to a lot of things, and normally so. Who would not get depressed?

The stance of suspended judgment suggests that while the vantage point of "the wise" might furnish compelling reasons for framing the situation as a problem of coping, this same position could provide knowledge of the sufferer's character that could stay hasty conclusions. At this stage, except for those who thought that sufferers were seriously ill, most friends and relatives believed that it was only a matter of time before the sufferer would return to his or her usual self.

Revised Definitions: Serious Physical or Psychological Illness?

But sufferers did not return to their usual selves and significant others were forced to revise their definitions. Not only were symptoms persisting, but sufferers began to withdraw from social roles and to exhibit personality changes. Significant others interpreted these observations in light of their previous perceptions of sufferers. The description that follows shows how significant others viewed sufferers before and after the onset of illness.

Before becoming ill, people with CFS had been working, studying, or caring for young children at home. They were considered to be bright, hard working, and motivated people who demanded high standards of others and more of themselves. They were frequently described as "physically active", "involved in lots of sports", "extroverted", "engaged in community work", and having "lots of friends". Some were described as "sensitive", having "considerable inner resources", and "protective of others' feelings".

> He was lively and energetic...extremely extroverted -a people person, a brilliant student-multi-talented. He had the world in the palm of his hands...He is very sensitive, but he does not react overdramatically to things. He seemed to be a perfectly healthy young man, from every point of view.

> She is an extremely clever girl...an intellectual. She knows her own mind... She has always given the impression of being very strong and cool and calm...in fact she is supersensitive...her humor is wonderful, she is beautiful. She walks into a room and she is just beautiful-[she has] this bright way about her...

Illness brought striking personality changes. Sufferers who had previously taken heavy demands in stride were now unable to dismiss small irritants. They often seemed

"intolerant", "lacking in humor", "aggressive, angry", "cranky and tired all the time". Instead of their usual high energy, many now complained of being constantly exhausted. Some sufferers tried to explain what they were experiencing.

> He says it is like somebody has a straw and sucks the energy out of him...The way he explained it is that you go to bed at night and wake up in the morning and it is as if you have never gone to bed. As he said to me one time "it is like you have been out and had too much to drink the night before and you know how lousy you feel the next morning". But, he said, he had not even had a beer...

With time, the number and severity of symptoms increased. Sufferers continued to complain of persistent fatigue, weakness, exhaustion, tiredness, sore throats, food cravings, food and environmental sensitivities, and pain. Many had problems with memory and concentration. Sufferers who formerly slept six to eight hours a day were now sleeping fourteen to twenty. Others hardly seemed to sleep, or to do so only fitfully. A few reversed their diurnal rhythm so that they slept most of the day and remained awake at night. Some had to be awakened to eat. Excessive sleeping was seen as completely out of character- an indication that something was very wrong.

During the worst periods of their illness, some sufferers could barely talk. Their activity levels changed dramatically. Previously athletic persons now just sat. Low level engagement in sport activities often required days, even weeks, to recover. Many walked with a labored or staggering gait. Even basic self care activities seemed difficult or impossible to perform.

> He would not get out of bed. He lay there, not even watching TV because he could not even concentrate... He was totally non functional, he never left the house, taking a shower, coming downstairs, I had someone catering food for him. Coming downstairs and putting things in the microwave was all he could do.

Sufferers' involvement in social roles declined gradually. As a group, they had given a large part of their lives to work. Their friends and relatives regarded them as people who were "very busy, very successful", "if anything, too hardworking", "working on twenty four hour call and studying at the same time," and "working ridiculous hours." Some were working at more than one job. But as their physical and mental functioning deteriorated, they repeatedly failed to meet ever decreasing levels of demand. Some began a

painful process of discontinuing their major roles as students or workers. These behaviors were regarded as uncharacteristic for people who had a reputation for being determined and for getting things done. Their tendency was to 'push through' as Woodward (1993) found in her Australian sample of CFS sufferers.

> When he finally went to university, he would register for 4 subjects but he could only take 2 because he could not attend class. Then he registered for 2 subjects, he thought he could cope but the last time he was in university, he could only take one. He registered for his course, he came home and he was in bed for 2 solid weeks. I think that is when he realized that he could not continue.

The breadth and depth of changes in sufferers' personalities, social roles and functioning could only be observed by people who had a close, long-standing relationship with sufferers. And knowing sufferers as they did made it difficult for most friends and relatives to think of these changes as signifying anything but illness. In fact at this stage, most believed that sufferers had a serious, if not life threatening illness. They began to fear the possibility of cancer, acquired immune deficiency syndrome (AIDS), diabetes, manic depression, lupus, multiple sclerosis, and rheumatic heart disease. Some significant others dared not put labels to their frightening thoughts.

> I did not know what was wrong. All I knew was that she needed help. I would pray that we were not going to lose [her]...All I could think was to try to get from one doctor to another. To see who could help [her] or put a name on it or pin it to something. I would not even dare think of anything else-I couldn't. The darker side of the coin-I would not allow myself to think that.

A few had to face the possibility that sufferers had a serious mental disorder when such diagnoses were given. But as a group, these friends and relatives evaluated information for themselves and were not afraid to challenge either sufferers' or physicians' definitions.

> I thought that he was probably suffering from manic depression because of swings in mood...then seeing him hospitalized in a psychiatric unit for a month at a time, and being treated with manic depressive drugs, seeing him heavily sedated, talking to psychiatrists and getting their opinion...but then not seeing the manic depression respond to antidepressants. Then I became suspicious...I would say that within the first year of going back and forth to the hospital, I came to the realization that we were dealing with something more than manic depression.

A minority continued to search for benign explanations of what was wrong. They wondered, for example, if the easy fatigability and lack of stamina could be due simply to factors such as overweight.

Before diagnosis, significant others distinguished between illness and difficulty coping with stress on the basis of what Baumann et al. (1989) call health relevant and contextual cues. Plausible links to prior illness and the onset, severity, and duration of symptoms were health relevant cues that led some significant others to believe sufferers were ill. On the other hand, knowledge of stressors in sufferers' lives, together with ambiguous symptoms, provided the rationale for framing the problem as difficulty coping. These evaluations were relevant to significant others' treatment of sufferers.

When the problem was considered illness, friends and relatives readily granted sufferers exemptions from their usual roles and responsibilities. But when the problem was seen as one of coping, friends and relatives understood sufferers' distress but were less sympathetic. They wondered why sufferers could not "pull themselves together and get out of it". They showed little tolerance for sufferers' irritability or angry outbursts. Their patience was further taxed if sufferers claimed illness, but failed to seek appropriate help.

> I was the one who pushed him...to go and see someone. Then he was not sure if he was going to see someone and he would always deny going to see a doctor...that was hard for me to accept...There was anger and a feeling "if you are not going to help yourself, then I am not going to sit here and waste my time either, holding your hand".

They clearly did not expect these situations to be long term, and saw little reason for exemptions from major roles. These findings are consistent with those of Blackwell (1967) who reported that the extent of societal agreement about admission to the sick role decreases as the social elements of the malfunction increase.

As friends and families shifted from thinking of the problem as acute and time limited to being serious and chronic, many became deeply worried. The illnesses they suspected suggested that they were bracing themselves, if not for the worst, at least for the long haul. Fear and guilt for not believing sufferers replaced previous frustration, anger, and impatience. Regardless of how serious they thought the problem was, most concluded

that a diagnosis and appropriate treatments were now priorities in view of the persistence of symptoms. To this end, several tapped their own social and professional contacts for advice.

> The GP had referred us to a specialist, as somebody who maybe could find out the problem... We had one more important appointment that we thought would make a difference and that was with a rheumatologist... Finally, my in-laws spoke to a hematologist who ...listened to the whole story....then I got a call from him telling me he had already made the appointment with a doctor for me.

By defining sufferers' problems as illness and counseling professional care, significant others acted as a lay referral system (Freidson 1970).

After Diagnosis: Views about CFS

Significant others were relieved to discover that sufferers had neither cancer nor AIDS. But the diagnosis of CFS brought fresh concerns to those who believed the immune system might be involved. Their relief was blunted by fears that an immune disorder could leave sufferers vulnerable to future life threatening illnesses. Some were simply "scared to death of anything to do with the immune system". Undoubtedly, widespread public information about the immune system and AIDS heightened their diffuse or more focused fears. Some questioned the illness' reality and cause and, in time, some also questioned its duration. Several shifted and changed ideas many times as they tried to develop views of the illness that made sense to them. Years later many of aspects of their definitions remain tentative and subject to further change.

CFS-A Real Illness?

A substantial minority of friends and relatives questioned the reality of CFS. They wondered if CFS was simply a different name for psychological disorders, malingering, or medical ignorance. The psychological problems that they thought might be hidden by the label of CFS, included depression, 'nervous breakdown', or secondary gains.

> I don't remember... whether it was a self diagnosis or... a medical practitioner... For a long time I thought it was some form of depression...I'm not even sure whether it's something that's always there, in mild forms, or acute forms...I would say if I am skeptical about the syndrome to begin with, it's not that she is responsible for her fatigue, I think that she was responsible for that particular interpretation of the fatigue.

> Whatever happened to nervous breakdowns? I never hear about nervous breakdowns anymore. I think it [CFS] is a more a nervous illness than anything else.

Secondary gains are desired benefits, such as sympathy or sick role exemptions, that consciously or preconsciously motivate people to claim that they are sick (Slawson 1971). Some significant others surmised that CFS provided sufferers with acceptable ways of controlling their own lives or controlling others. For example, some thought that sufferers could use the illness as "a crutch" to explain failed relationships or as "an excuse not to be at a certain place at a certain time". A few questioned whether high functioning sufferers held on to the illness because of the esteem they gained from helping more dependent sufferers in support groups.

Unlike secondary gains, malingering refers to intentionally feigning illness for gain, often of a monetary nature (Webster's Seventh New Collegiate Dictionary 1963:512). Significant others who suspected malingering, noted the fact that sufferers were receiving disability compensation. They also noted inconsistencies among sufferers' claims of illness, their appearance and activities. Sufferers' claims of being too disabled to work seemed particularly dubious when they were able to perform other daily living activities and engage in leisure pursuits.

Finally, a few friends and relatives in health or related fields, wondered if CFS was merely a 'catch all' label that doctors used to hide their ignorance of what was wrong and to placate anxious patients. These friends and relatives suggested that the illness is so vaguely defined that "you can hook two or three different medical diagnoses and put Chronic Fatigue Syndrome on it". From their insider position as health professionals, they were a little cynical that doctors were giving patients a label "just to shut [them] up".

People who questioned the reality of the illness, eventually conceded that sufferers had been ill at one time with some sort of condition that was predominantly psychological.

They were more or less willing to label the illness CFS. However, they remained skeptical of its duration.

CFS - A Real Physical Illness

In contrast with the group that questioned the reality of CFS, another group of significant others were convinced from the outset that CFS was a real physical illness. Although some considered different physical causes at different times, no one in this group believed that psychosocial factors contributed to the illness. Their accounts suggest three elements in beliefs about a physical cause of CFS. First, they could link the onset of symptoms to antecedent physical factors such as viral illnesses, possible exposure to toxins or allergens, and physical wear on the body. For example, when a sufferer became ill shortly after moving into a new building, relatives strongly suspected that sick building syndrome, radon gas, and allergies to carpet glue were likely sources of CFS. In several cases, media reports, support groups, medical journals, or health professionals strengthened such beliefs. These sources provided other ideas of physical causes that significant others also incorporated into their way of thinking about CFS.

> It developed into something that we do not know...it is difficult because it changes. It is a retrovirus, it is in the DNA.

> Maybe in the back of my mind I am thinking well it's a virus, but after reading a lot... I'm not so sure either. People are talking about yeast infections, things of that nature...I really do believe that, to some degree, it has to do with the immunity system itself...it's a speed up of the immunity system itself...but its almost like its running at such high speeds that you're weakened enough just to catch any type of virus. And when that happens you fight it.

Second, this group of significant others had personally seen sufferers in physical distress. They described sufferers as "thin and pale", "in pain", "looking sick, exhausted, and tired". Some of these interpretations suggest culturally learned meanings of the language of the body, since external referents for pain, looking sick, and exhaustion may be subtle or highly ambiguous. As one mother observed: "There were times when he did not look well. I could always tell by the eyes- when they were bright". Her comment about

the appearance of the eyes may seem idiosyncratic, but others also believed that the eyes revealed hidden physical distress. In other cases, relatives found it harrowing to witness body language that left little doubt about its message. One mother remembering the worst times with her young adult son had this to say:

> He had so much pain initially in his legs...that he would cry and be in agony. I remember specifically, he asked one of his brothers to sit on his legs. He thought the weight might ease his terrible pain that he was having such a hard time to cope with...He has had headaches where his veins are throbbing, you can see them. He was just beside himself and he wanted me to stay beside him and hold his hand. He did not know how to cope any longer.

Another recounted:

> He couldn't walk straight, he was all bent over. You looked in his eyes, you saw this boy was in terrible pain and that went on day after day.

A third element in beliefs in a physical cause of CFS, was the lack of compelling reasons to consider competing explanations. The accounts of these significant others were striking for the lack of reference to stressful life events or unusual demands in the life of sufferers when the illness began. All of these significant others knew that a physical cause has not been established and that psychological causes have been proposed. But taken together, the three elements of plausible physical antecedents, signs of physical distress, and lack of undue stress in sufferers' lives, probably made it easier for them to discount psychological causes.

> There are certain areas that I discounted immediately. One was psychological because I don't believe it's a psychosomatic disease. A lot of people would say, "doesn't she have a form of depression?". And I say no, its not depression. It's depressing, but it's not depression. That really is what it all boils down to, it's a very depressing condition.

CFS-An Illness of Many Causes

The remaining respondents attributed CFS to a combination of factors. Multicausal models grew out of general beliefs about illness as a product of mind and body, or shifts in thinking about CFS, or both. General beliefs about illness were expressed in statements such as: "I believe in a holistic approach...if it hurts here (pointing to his head) it can end up hurting there (pointing to his body)". Another said: "I'm a believer that your mind has a lot more to do with illness than people think. I go so far as to say that even colds have more

to do with your mental health than people believe". Implicit in these beliefs about the unity of mind and body are notions of individual responsibility for causing and maintaining illness. The corollary is that the individual has the capacity to change an illness' course and prognosis.

One person held an unusual general belief about illness that incorporated non Western causal mechanisms. In this perspective, illness enters the body when a person's spiritual state is damaged by physical or social stress.

> ...he did easy twenty hours a week of sports for six years. Every single one of those hours, there was body contact made and I believe that had a lot to do with it. Also he was not a well baby from the minute he was born. I believe that it was an accumulation of all these things. The physical wear down of the body, the physical impact, the body slamming all the time,...I thought he had a virus that had done some kind of transmutation...when I concluded that he had chronic fatigue syndrome I was trying to match it with how it comes into a person's life. I could understand how come he got it...There were times when the school wasn't there looking after my child, to make sure that a problem didn't occur. I believe that all those things did have an effect... not from the psychological point of view, but from the spiritual point of view, which brought the emotional hole in his etheric body[1], which allowed for this physical disease to enter. I think he needed and still needs time out from this world. Are we talking stress? Yes we're talking stress.

Besides such general beliefs, significant others' accounts showed three patterns of shifts in thinking about the cause of CFS. The first type showed a shift from only physical or psychological causes to a multicausal model with the emphasis kept on their original belief. For example, some continued to think of CFS as primarily physical, but conceded a role for stress. In such cases, they did not believe that stress was a direct cause of CFS, rather that it increased susceptibility to the illness or enhanced its symptoms.

> At first I thought it was a virus... Then I was told... it could be stress-related.... My mother was so involved in so many things...., she was president of a [sports] association...She had a lot of stress at work... my sister and I were always on the go, ... We were not model kids but we were not terrible kids. But we gave her some times of stress, that would definitely be a factor. From what I understand of it now, it is a virus that can be advanced by things such as stress which obviously weakens our system and makes us more susceptible to fatigue and colds and whatever. But...I believe it's basically a virus. It's just enhanced by any other factor... I've read articles about it, I've seen videocassettes that she taped on W5 or 60 minutes and doctors opinions of it.

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[1] The etheric body is thought to be a magnetic field that produces an aura of the light spectrum surrounding the physical body of individuals. If this field is damaged illnesses may enter the body. Different illnesses produce different colors of the spectrum over specific areas of the body.

In contrast, those who retained a psychological emphasis, considered stress the key element in the development of CFS. Some catalogued stressors in sufferers' lives extending back to childhood in which themes of loss and multiple conflicting role demands were prominent. Sufferers had faced situations such as the death of a parent, sole responsibility for making difficult decisions about elderly parents, conflicts between work role and marital or parent roles, divorce, parental remarriage, and undesired relocations.

> I [thought] she was just working things out with me...looking back...I think she was breaking away late...I can't really say it was an illness, but it could have been a start right there...I still do not know what CFS is, nobody does. What caused it? She is a terrible perfectionist, she has been totally worn down by her children...I've had the feeling that [she] had the shock of her life after [her first child]. After the second, she was in hospital on antibiotics [for an illness which] might have contributed somewhat. She has always seen herself as a career person...I feel that it was all too much for her...she is not happy spreading herself all over the place.... I guess I blame motherhood.

> When he got sick with pneumonia...it lingered. I felt he was overworked and depressed and anxious from work...Finally they diagnosed CFS...I think its probably a depression at not being able to accomplish what he thought he could do and living under an expectation of success. I think because he was run down and depressed he couldn't snap out of it. I've heard Epstein Barr, different things.

> ..he cared a lot for his aging parents ...He made all the decisions... His other brothers and sisters were not supportive...I think it [CFS] is a combination of some psychological/psychiatric diagnoses as well as some physical ailment neurological/cognitive...I was happy when he went for his NMR[2] because I figured if there was anything tumor wise, it would show...but all the tests he has had have come back clear. Again, that is one reason why it is reinforcing to me that there are a lot of psychological aspects there...

Some significant others believed that sufferers had blamed themselves for these events, felt that they had failed, or that their aspirations had been thwarted. They believed that such feelings were especially difficult for sufferers who were "strong willed", "controlling" personalities, used to having their way and being in charge; people for whom "second place wasn't good enough". This triad of: stressful events, appraisals of failure or being thwarted, and controlling personalities were the main reasons why these significant others continued to regard CFS as largely, if not totally, psychological. Infectious illnesses were considered minor contributors at best, and often reported as an afterthought or in response to questions about whether sufferers had had such illnesses shortly before the onset of CFS.

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[2]NMR-nuclear magnetic resonance imaging.

A second type of shift in thinking about the cause of CFS, showed that significant others changed their emphasis from psychological to physical. They were concerned with whether and how they could continue the relationship when sufferers found psychological characterizations of CFS stigmatizing. They were able to give more weight to physical causes than they had previously done by re-analyzing the circumstances of the illness' onset, reinterpreting ambiguous behaviors as physical distress, and taking the trouble to learn more about findings from sophisticated medical technology.

> I have read that in many instances, CFS follows an episode of flu or another illness...He had what I was told was a bad flu...he had broken off a very serious emotional relationship...Those were the only two precipitating factors. [In the beginning] I think it took a couple of years before I understood and became convinced...that this is a real illness... the onset, came on just like that...it was not a gradual depressive episode...I feel very convinced of it now, but I was not convinced at the beginning...[when people say it is stress] I tell them it is not stress. It is a physical illness...I can see that when he gets up in the morning, he walks around holding onto the walls, he can hardly move.

> I have picked him up off the street here with police officers, because he had overdosed. I have been to the emergency room at 3 o'clock in the morning hoping he would come out of the overdose. I have also seen his X rays and his SPECT scans[3], I have been with him for various tests so I know what he has. And I read a bit...There are indications now that there are lesions in the brains of Chronic Fatigue Syndrome patients. I think that it is going to come out very soon that this is a viral induced illness and somehow it does cause lesions in the brain... Look at AIDS. Nobody knew what it was when it first came out. People probably denied it. At one time they thought that cancer was consumption...I believe that the cause is viral. Initially I thought that the problem was psychological. I thought that, given the stresses in this guy's life.... My personal belief is that it could be a combination of viral, physical and/or psychological make up.

Personal observations and a commitment to the relationship with sufferers were perhaps the key factors in changing the emphasis from psychological to physical causes, but the medical literature and analogies with other illnesses that were once shrouded in ignorance, were also salient.

Malingering or CFS?

In the third pattern of shift in ideas about the cause of CFS, friends and relatives did not begin from thinking of the illness as either physical or psychological. Rather, they believed that sufferers were malingering or had illnesses outside of biomedical models.

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[3]SPECT scan or single photon emission computed tomography (SPECT) scan has demonstrated decreased blood perfusion in some areas of the brain of CFS patients.

Technically, malingering cannot be considered a cause of illness, since by definition there is no illness. But malingering has been perceived as the motivation behind symptom complaints and claims for the existence of CFS, and in that sense it can be considered a cause of symptom onset or duration. For example, several relatives and friends indicated that people inside and outside of the family "won't give it [CFS] the time of day" or "thought that she might be faking it, it was not that bad". Such ideas however, were not immutable.

One respondent who met a sufferer only after the illness developed, illustrated how suspicions of malingering could be softened if not dispelled altogether. He began by recounting:

> I am a real skeptic because I am like other people you can't see it, you look fine...I think my understanding of the disease has gone through a lot of evolution, from one point of really resenting him for not working to trying to really understand it...I've seen programs, read tons of literature and I'm more informed than the average person.

He became more open to the possibility that sufferers were not malingering after making considerable efforts to learn about the illness through support group meetings and various media. By comparing his observations of sufferers with media stereotypes of who gets the illness and with popular theories implicating stress and the environment in CFS, he began to think that psychosocial or even physical causes were plausible.

> It's largely people in high stress fields, nursing, teaching. He was very busy, very successful. And I'm not sure if its a combination of burnout..But I think that's one of the common factors...I think people who get this condition are susceptible to environmental conditions I think its probably a severe case of some sort of allergy, or combination of allergies...He's very sensitive to things. When I am going out for the evening I have to put cologne on...the very last second or else it will drive him crazy. When I first met him, he couldn't go outside in the sun. Heat was a real problem-a lot of things. Smoke in bars never seemed to bother him.... I've gone to some of their [support] meetings and they all seem to have the same sort of characteristic, cologne or other chemicals.

However, he was also aware that for a while, the notion of CFS as a contagious illness had gained currency in the media. Despite considerable skepticism that CFS could be a physical illness, when he thought there was a chance, however remote, that the illness might be due to a contagious virus, he decided to hedge his bets.

> At one point the whole notion of contagion came up, and he assured me that it wasn't contagious...I thought I was going to move out. But then I thought this is a kind of disease I'm

> not going to get. Because of my physical predisposition and my mental predisposition I wouldn't allow myself to get a disease because I still attach a lot to the psychological aspect. I am still a little skeptical. He looks fine, he's gotten more active...I do believe that at one time he was ill...and he couldn't move. Now when I hear [of] people with it I think I am more open in accepting it. No I don't think my thinking has changed.

The prospect of 'catching' the disease led him to consider moving out of the home he shared with the sufferer. His decision to stay rested on reassurance from his ill roommate and rationalizing that he was not susceptible to a "psychological" disorder. His belief that sufferers were malingering was attenuated. But in the end, he could not quite let go of his doubts. He conceded that at one time his roommate was probably ill, but now it was not illness that kept him mired in the sick role, rather it was a lack of confidence. For him, the primary issue had shifted from the cause of CFS to its duration.

CFS or Chi Disease?

Finally, the most unusual cause proposed for CFS implicated "chi disease"[4] -an illness unknown to Western biomedicine. This attribution was made by matching sufferers' symptoms with a prototype of this illness and by noting that symptoms followed meditation practices that involve moving energy around the body. Chi disease is thought to result from improper meditation practices.

> The last summer [that] he got sick he couldn't do a certain type of meditation, and when he started meditating again he got sick...I don't think that the actual practices were wrong, but he was in the "moving energy around" meditation...I am not sure if he was taking it from qualified teachers...you don't know what happens when you release something like this...So, I think that had a lot to do with it. I don't know how. I can't explain it, but there's definitely a link in his case...

The person who offered this explanation also provided a good illustration of how unstable ideas about CFS can be. He offered a range of attributions that people may consider when

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[4] Chi disease. Chi, or energy is thought to travel through the nerves. Proper chi gung practices are believed to strengthen the nerves, while improper techniques may overload them leading to the breakdown of all body systems. If not done under proper supervision too much chi, packing chi, and practices that use chi gung to develop sexual power may cause injury and symptoms ranging from internal hemorrhaging to mental illness. Practitioners may experience cold sweats, involuntary tremors, extreme sensitivity to cold and loss of vitality (Frantzis 1992).

medicine provides little direction. At various points, he had considered the role of social stress, the possibility of a contagious virus, noxious environmental stimuli, immune dysfunction, and personality. He went on to say:

> Something went wrong maybe it was because that was a particularly stressful point in his life...his business wasn't doing too well, he had to take a second job, he was living in a place where he didn't sleep well because of the noise from the traffic. All those factors combined I think made his immune system a little weaker. Maybe the combination of unproven methods he was doing in meditation...He may not have CFS as its known...I read martial arts publications. There's a practitioner of meditation who is talking about chi disease And that sounded more like what [he] had...There's some kind of imbalance in his immune system or some system in there. That's my take...When I first heard about CFS... through [him] and people on the radio, there was a high incidence of those who were vaccinated. My idea was that it was a disease going around and you could catch the virus. I was scared to death that I'd catch it from him. And [then] they said that it primarily affected people in industries where you met a lot of the general public like doctors and teachers...I don't think he caught it off a toilet seat. He didn't pick up a germ and got sick...I came to the conclusion that it was more a combination of stress and bad sleeping habits and screwing around with something you didn't know about.

His 'conclusion' however, was not as definitive as it sounds. His parting words questioned the possibility of a role for personality and environmental sensitivities in the development of CFS.

> Do you notice that the people who have it have a particular personality type? ...you do hear of people who claim to have been just normal, allegedly successful people, who suddenly got this foul disease. I don't know if any super successful people have it- CEOs of companies for example...If you found out more of the personality types beforehand it might help. Maybe more people are sensitive to the environment than others. There are a lot of environmental conditions...

In summary, friends and relatives' variously defined CFS as a physical illness, an illness of many causes acting together, malingering, and chi disease. Combined models emphasized either physical or psychological factors and were often highly unstable. Like the definitions in the prediagnostic stages, definitions of CFS had implications for friends and relatives' willingness to grant sick role exemptions and provide a supportive relationship. As long as the illness was considered malingering, the predominant reaction was resentment. If the situation could be reframed, a cordial coexistence became possible.

> I'd come home, he'd be on the couch watching TV. or in his bed or on the phone and I resented that for a long time. He seemed to be making a very good living doing nothing and I was busting my butt trying to make ends meet...long gone are the days when I would envy his kind of situation. I'd be bored out of my mind. Boredom takes up a large part of his life. And if you wonder why I'm still here, [5 years later] we aren't friends, but we are friends. I'm detached enough that we can do things that we want to do together but we really lead separate lives

If significant others suspected secondary gains, they often felt frustrated or angry with sufferers. In such cases, some lashed out at sufferers or circumscribed the relationship by distancing themselves. Sometimes this was the only way to protect the relationship.

> I did say..."You are not crippled, You are going through some problems, you are letting yourself go downhill"...there was a serious distancing. then there was a coming together....Now there is a little bit more of a distance....I do feel a certain amount of guilt... wondering if it is my [professional] background ...that is seeing it loud and clear, where you are saying "stop! You've had all the tests there is nothing. And if there is nothing physical, then let's do some [psychological treatment] sessions and go regularly and follow through. If that does not work, then try the acupuncture"

But at other times, their doubts caused sufferers to pull back from the relationship.

> ..and that [belief about cause] is part of what led to the breakdown in our relationship. I did not know what it was and said that to him. How could I know?...In the first year of his illness, he totally shut me out, so that we virtually lived here together without speaking to each other. We communicated with notes. I went to see a therapist because of my distress over that...I was in tears because he was saying "you don't understand me, you can't help me. I want you out of my life...[he] and I were very close before he got sick. Whether he thought I did not handle his illness well or whether it was because he was thrust back into a dependency situation with me...He understands what it was but I never understood clearly. I have had to learn to deal with that. The 2 major stressful aspects of the whole thing for me have been the illness itself and knowing that [he] was so sick, as well as what it has done to our relationship. It has been absolutely devastating.

The effects of attributing CFS to physical causes cannot be known from these accounts. However, one may surmise that the concordance between physical and real[5], would provide succor to the sufferer and protect the relationship between sufferers and their intimates. There is some indication from these data that a shift from a psychological to a physical cause contributed to the repair of a relationship.

This section identified social and cultural bases of significant others' definitions of sufferers' problems. It indicated how they updated their views of what was wrong (Baumann et al. 1989) through familiarity with sufferers, personal observations, new medical information, and the media. It also showed how these views affected their relationships with sufferers and their willingness to grant them sick role exemptions. The next section describes the impact of being close to someone with CFS.

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[5] There is no necessary relationship between psychological and not real in my view and, I believe in the view of several of these subjects.

The Costs of Caring: Altered Lives, Turbulent Emotions

The lives of significant others were altered with changes in sufferers' physical and social abilities over the course of the illness. Friends and relatives remembered the early days of sufferers' illness as a time of unremitting distress. Following this period, which could last from months to years, sufferers seemed to improve gradually to a plateau somewhere below their pre-illness levels of functioning and feelings of well being. But remissions and exacerbations marked the course leading to improvement. During remissions, sufferers had "good days and bad days" and times of day when they felt better or worse.

Depending on whether they lived with sufferers and on the nature of the relationship, significant others provided instrumental and emotional support and made changes in their own lives to accommodate sufferers' needs. These acts of caregiving sometimes brought on intense or prolonged negative emotions and a sense of disorientation as significant others felt their way through a poorly understood situation. Support and accommodations may be considered objective burden, while the emotions associated with these acts may be construed as subjective burden (Noh &Turner 1987; Horwitz and Reinhard 1995). The first part of this section describes the ways in which significant others altered their work, home, and social life because of CFS sufferers and their feelings about these changes. The second part describes the emotional burden, not of caregiving per se, but of caring about sufferers. By emotional burden, I refer to the pain that people close to sufferers feel as they watch the deleterious effects of the illness on sufferers' physical and mental health, and on their social identities. This emotional burden was inferred from significant others' use of terms such as "hard", "difficult" "terrible" "painful" or phrases that indicated worry, strained relations, coping efforts or struggles to find their bearings in this strange situation.

Work Disruptions

Mothers of sufferers reported the most substantial impact on their work. They firmly believed that it was their job to care for their ill adult children. To assume this responsibility, mothers variously retired early, exited the work force for a few years, and rearranged schedules to permit daily visits home during working hours. These mothers regarded such accommodations as necessary in light of the exigencies of the situation. Fortunately, their family and work structures or financial situation allowed them to make the necessary adjustments. Even so, it was far from easy to give up desired work, juggle schedules regardless of available latitude and discretionary time, and bear the economic costs of foregoing work.

> I stopped working but I plan to continue. It just seemed that I couldn't because she was sleeping all the time. I really thought it was my job to get her up, to see that she got to eat. Now...she is feeling better... I think I will try [to work]-not much, but something for my mental health. I will need that.

It is noteworthy that among relatives, only mothers interrupted or otherwise made major ongoing accommodations in their paid work situations to care for their ill children. However, other relatives occasionally interrupted their work to accompany sufferers to time consuming medical appointments. And a friend who shared work with a sufferer, assumed a disproportionate workload, especially during exacerbations.

> [he] can't do the volume of work that I do....sometimes he seems to have difficulty carrying on, not so much a social conversation, but business conversations, especially when we're in a situation where we have to ask a lot of questions....Most of the work we have done lately, I think I have done about 75 percent and he has done about 25 percent.

For a substantial minority of significant others, being close to a CFS sufferer meant disrupting their work, with mothers bearing the brunt. Extensive parental, and especially maternal support and caregiving to ill adult children has also been found by Horwitz and Reinhard (1995).

Household Disruptions

Significant others who were coresident with sufferers had to decide how to share domestic responsibilities and how to use the home. Some well spouses reported shifts in the household, and sometimes, gender division of labor. Husbands took on household chores such as ironing and cooking that they would not otherwise have done. Wives of sufferers on the other hand, were less willing, or perhaps able, to fix things and do the heavy lifting that their husbands had done before becoming ill. One wife explained how the division of labor had been allocated before her husband's illness and the difficulties that now arose:

> [after he became ill] I had complete responsibility for the children, household everything. I can keep the interior of the house okay, but I am not a handy person that can be fixing up. The deal was I run the vacuum, you run the lawn mower. He fixes up things around the house.

Some spouses resented the additional contributions that they were forced to make. Others found these new responsibilities were constant reminders of their partners' illness and limitations. Most simply accepted the fact.

In some households, it was a well sibling who complained about new chores that he or she had to assume, while a roommate of one sufferer humorously described how chores were organized in his situation.

> Now the reason why we've lived together for five years is largely because our division of labor, from my point of view, is perfect. For example, in the kitchen there's a double sink. One is his, one is mine. My dishes can sit in the sink for a week or his can sit for a week and there's no argument about it. He does have a bath off his bedroom which helps a lot, so I take care of the main bathroom, and even there there's a division of labor, I keep the bath tub clean, he keeps the tiles around it clean. No room for squabbling, we don't squabble. I think I'm kind of lazy, so he might have a few complaints.

But in general significant others found it more difficult to change their normal use of homes shared with sufferers than to negotiate the household division of labor. In some cases, the usual flow of traffic and activities in the home had to be curtailed. For instance, young children could not play as freely as before and telephones had to be answered immediately because they bothered sufferers who were often asleep even in the daytime.

Some significant others felt caught between the conflicting needs of the sufferer and others in the home.

> it was difficult because I was always trying to keep everything quiet... he could hear me, even with the door closed...When we are thinking of going to bed at 11 or 12 at night, that is his usual wake up time. (because of insomnia) He is more alert and awake then... It made it very difficult in the home because when I needed to be up, my husband was up in the morning and people were calling...and the general activities [were going on], it was all very stressful. In the back of my mind, I was always thinking that he needed his sleep. I would try to keep my husband quiet on the phone...I was always closing doors and keeping people quiet. It was a balancing act. He found it very stressful for him also because he could hear any activities in the house, even if the TV was on.

Others found that home was no longer a retreat during illness, since it meant being cooped up with homebound sufferers.

> I remember a turning point...I became ill with the flu, so I took two days off...I went back the third day and I was still kind of sick...people asked me why I was back when I was still sick. I said the only thing worse than coming back...when I was ill, was staying home a third day with an ill roommate, because he would drive me crazy.

And most could no longer take it for granted that home was a place for social activities. Inevitably, people who were coresident with sufferers reduced the frequency or duration of entertaining at home. The most common reasons for these decisions were sufferer's lack of stamina and therefore limited participation, their low tolerance for noise, and the lack of privacy with a homebound sufferer.

> ...My father...obviously missed going out to dinner and going to other people's houses or having people for dinner. By eight thirty, nine o'clock my mother would be so tired that it would be basically over and dinners used to last until midnight.....it was hard for us because we were a family that used to have people over all the time...we had lots of parties. It changed our lifestyle a lot because we would have friends here and they wouldn't be used to it and they wouldn't understand that at ten thirty my Mom would come downstairs and ask us to leave because she was trying to sleep and she sleeps very lightly

Adolescent children and young adult roommates moved much of their social life outside the home. Most spouses, however, gradually slipped into a more constricted social life as they reduced social activities both within and outside the home. Spouses who tried to maintain previous patterns of social activities, found their ill partners could not participate meaningfully. Some increasingly chose to engage in separate activities. Although separate activities are normal in family relationships, when they are too extensive they may threaten family, and particularly, marital bonds.

> We would get invited places, he would do it, but half the time he was depressed and exhausted and maybe not as social as he normally was. At family events he would go off to sleep. [We were] almost leading separate lives in a way...What went through my mind was why was I even married?...it wasn't so much that we were fighting, but doing our own thing...

The previous lifestyles of significant others and the accommodations they were willing to make, determined the extent to which their social lives at home were affected by sufferers' illness.

It was one thing for significant others to adapt to sufferers' chronic debility, it was another to deal with the havoc created by the unpredictability of their symptoms. Friends and family came to know all too well that plans frequently had to be arranged or rearranged to fit the ill person's periods of feeling better. They experienced a mix of confusion, sadness and exasperation as they found that spontaneous social activity was no longer possible and even planned activity was not certain to be realized.

> I can recall at an early stage in our relationship when we used to go to restaurants and it was a shock to go into a restaurant and get out of it after two seconds, because she felt that she couldn't breathe properly, couldn't hack the smell....very often we came out of a place without having even ordered. That, to me, was very unusual.

Some found it depressing that they could not invite sufferers to a simple dinner without worrying about a possible relapse. As they became more familiar with the unpredictability of symptoms, significant others learnt to react with muted enthusiasm to plans with sufferers that would have been exciting in the past.

> It was quite shocking to me when she phoned and said she wanted to come with me down South...,I said "why are you coming?". Another time, I would have said "isn't that wonderful!". She said that she thought she should go and she is coming with me. I am looking forward to it, I am very excited. But I am saying to myself "don't blow this out of proportion" because she could well be ill the whole time she is down there. I have grown to accept that..

Clearly significant others had not bargained for many of the problems of living with a CFS sufferer. Recognizing what the illness meant came only episodically and over time, as different situations arose.

The Impact of Watching Sufferers' Social Identities Erode

Because of shared histories and continuing close contact with sufferers, significant others saw not only the physical but the social transformation of sufferers. They saw more or less permanent changes in sufferers' social roles, functioning, and personality. These categories and attributes define individuals to the world and mediate their relations with others. They constitute a social identity[6] (Goffman 1963). It was disorienting for significant others to watch sufferers' social identities being stripped away by withdrawal from major roles, failures to meet or maintain age and status norms, and unattractive personality changes.

The term disorienting was used by one spouse to describe the divide that he sensed between what he thought was normal and what had become normal for his ill wife. Other relatives and friends experienced similar dissonance as they compared their actual and expected relationships with sufferers, and their perceptions of who the sufferer had become with who he or she used to be. The common feeling was uncertainty of how to think about or relate to sufferers. These feelings are consistent with the definition of disorientation as losing one's bearings or being displaced from normal positions and relationships (Webster's Seventh New Collegiate Dictionary 1963: 240). The sense of disorientation dominated reactions to sufferers' changing social identities, but it was often mixed with ambivalence, sadness, pain, anger, and guilt.

Concerns and Hopes for Sufferers' Social Reintegration

Friends and family knew that occupational roles did not totally define sufferers. But the importance of these roles was evident as they watched how difficult it was for sufferers

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[6] Goffman defines social identity as characteristics of the self that define an individual to intimates and others in the outside world. These attributes and categories constitute virtual or actual social identities that mediate relations between people. The social identity is particularly important when one individual in an interaction bears a visible or discreditable stigma.

to retreat from work and school. A minority saw sufferers who relinquished these roles immediately when illness was sudden and severe. More typically, they saw sufferers struggling on for several months until things came to a head. Some reported that sufferers stopped working only after it became clear that they: might endanger the lives of others, were unable to meet the demands of a job promotion, or were simply too weak to continue. Significant others found that sufferers who held on to their occupational identity paid dearly. They worked and slept. They had little or no energy left over for family and social life. They were "push[ing] themselves and doing it for everybody." They were able to continue working only because they were self employed or worked in part time jobs that allowed some flexibility and discretionary time.

Significant others described a similar situation for sufferers who were students. These sufferers often tried desperately to continue their studies and stopped only when it became impossible to deny their inability to carry on or when a parent intervened and insisted on a halt to school.

> When he tried to do home schooling last year, the little that he did was so devastating on his well being, his physical body- it took him two months to recover...The first exam he took he got 98%. He had absolutely no problem with the work. The physical demand was just too great. He couldn't sit in a chair alone and then he couldn't sit in a chair and move his hand. Not only that...it's very hard to concentrate. He would be totally wiped out after a session. It wasn't worth it to me to have my child go through math and suffer so physically. That's why he's not doing any home schooling at this point.

At first, most friends and relatives accepted sufferers' need for relief from occupational roles. Indeed, they thought it was necessary. But later, if sufferers showed considerable improvement but failed to resume occupational roles, significant others experienced the sense of disorientation. These feelings were heightened if sufferers rebuffed their attempts to encourage occupational reintegration. In such cases, some friends and relatives found it increasingly difficult to remain sympathetic and supportive. They wavered between being baffled and being angry. Some tried to take the edge off their frustration by expressing faith in the person's character, or by attributing sufferers' resistance to lack of confidence or to underestimating their level of improvement.

> We have wondered if [he] should not...use this period for some positive thing...There are a lot of things I think that he should be able to do...and I said "well, maybe during this period you could study a little bit, read...he does get his back up a little bit when you suggest something to him....As far as getting him to do things, we don't do that anymore, because he will when he is able. We know him well enough for that.

> We've had our arguments about it. I can remember one New Year's day; [I said] "so what's you new year's resolution this year?" And he said: "like, get a job". Well, okay...but I do believe there was a time when he was ill... and he couldn't move. I think maybe [he is] still not 100% but I think now he's probably well enough to work. Now the problem is, that he's been out of the work force for five or six years now you have to make that mental step. It's difficult. You've lost your self confidence...I see his disability cheque coming in from the government every month- I see my income tax taken off of my paycheck and see this all gone to him. Sometimes I feel gypped- that he is a young man-get out there and contribute!

Some had observed sufferers devoting considerable time to learning about their illness yet asserting that they could not work because of impaired concentration. In an effort to rationalize such discrepancies and reorient themselves to the sufferer they knew, friends and family noted that learning about the illness had taken place over a long period of time, while the workplace demanded sustained concentration for several hours a day. These significant others further wondered whether employers would discriminate against people with a history of CFS and whether sufferers had been reluctant to seek work because they anticipated this reaction. Despite these rationalizations, they could not help worrying that sufferers might become comfortably entrenched in their sick role lifestyles.

Significant others recognized that with disengagement from work and school, sufferers had lost not only a major identifying label but also the social relationships that come with institutional membership.

> His own peer group haven't stuck by him, but he's part of a group of younger kids, of my younger son's group. That's because his brother brings them home...so they come to the house....and they have lots to share with him [sufferer]. But if his brother couldn't bring them, they're not there...that's what happened with his own peer group.

They reported that sufferers also lost friends because they could no longer meet age, development, and status norms that contribute to a social identity. Some sufferers had had to give up such taken for granted activities as driving a car, graduating, socializing with friends, dating or forming more intimate relationships. Several mothers poignantly noted

that their ill adolescent or young adult children were set apart from their peers because they could not meet these expectations.

> That is the hardest thing to watch. My son, who last year turned sixteen and who wanted so badly to get his driver's license and he couldn't even go to get a learner's permit....because of the pain that he was in... the fact that he's going on seventeen and this would be his graduating year. It would be a year that would be spent much more involved in growing as a young man, than he's capable of doing, because of the disease and staying home.... It certainly has put a damper on him going out and getting involved at that other level, fitting yourself in boy/girl type of stuff. The car business...We keep talking about it, he's going to try it now, on his birthday. But this is for me, very sad... He was so excited before it happened, about turning sixteen and being able to go for his driver's permit...There was no way. That's been the big impact on his life, as far as I'm concerned. Doing what a seventeen year old boy should do.

> He is a very outgoing person and he has lots of friends. They would be calling him and in order to keep them, he wanted to be there with them. He would go out to things and he would be in bed for 2 or 3 days, so sick that he could hardly stand it. Gradually, it took a long period of learning to realize that he could no longer think about keeping friendships that way, if that was the only way. But it is not. People who are true friends have really stuck by him. At that time, just like any other young person learning what the world is all about, that is what he tried to do.

It was often painful for significant others to see how deeply the loss of friendships had hurt sufferers.

The Threat of Role Captivity or Acceptance of Burdens: The Effect on Spouses

Unlike occupational roles, sufferers' roles in the family that contribute to their social identity were not lost, but they were sometimes threatened, strained, or transformed. For example, some husbands and wives were dissatisfied with their ill spouses' participation in household tasks and in the couple's social life. They were not sure whether their ill spouses would return to work and contribute to the family income as expected. On an affective level, they believed their ill spouses were no longer contributing to the interdependency and mutual companionship expected in marriage. They reported that ill spouses were often withdrawn and uncommunicative because of depression or physical debility. Frustrated by these changes, some well spouses felt that their life was no longer fulfilling and began to wonder whether there was any difference between being married and being single.

> I would ask him how he feels and he would say, "don't ask me that question because I don't want to tell you how bad I feel every day". It was so bad all the time...

> At times I feel like I'm still living alone. Sometimes it just gets the better of me. Seeing things like plates in the sink, during the day, not washed. There's that aspect of it, but at the same time, she tries to make sure that she makes supper. It depends on the day and how I get, how my day has been.

These well spouses were not unwilling to give affective support, but they believed that they were being asked to give more than "the normal caring relationship [expected] in a marriage" and getting very little in return. For these spouses, there was a real threat of experiencing role captivity (Aneshensel 1993) as the relationship became increasingly unlike the one that had existed before the illness or the one that had been idealized.

Had the illness been temporary, husbands and wives of sufferers might have viewed changes in their ill spouses as no more than irritants and inconveniences. But as the illness dragged on, some well spouses began to dread the possibility that these changes were going to become permanent. They began to wonder "Is this what our life is going to be like from now on"? To cope with these feelings, some tried to find a balanced perspective or escape in work, others sought out supportive social relationships or 'turned a blind eye' to the illness' implications. Older well spouses and those who had been married for more than five years at the time of the illness' onset, seemed to deal with its implications with greater equanimity than those who were younger or married for less time. Perhaps the latter group had less realistic expectations of marriage and were still in the process of establishing a solid relationship. Under these conditions, the added strain of a strange, unexpected and prolonged illness might have been more difficult to manage. The time in the family life cycle that chronic illness emerges has implications for how well families cope (Rolland 1994; Moen et al. 1995).

Altering Dreams and Normative Expectation: The Effect on Parents

Like spouses, parents of sufferers had to adjust their expectations. They had anticipated self supporting adult children with whom they would have a companionate relationship. In their view, financial independence and independent living arrangements were part of the normative world of young adults. Instead, many parents began to worry

that in the near or distant future, they might have financially dependent adult children who had been thwarted from realizing their potential.

> It is going to be more and more difficult as it goes on. He has to live, how is he going to manage? We will be as supportive as we can, but it is not the sort of thing you anticipate in your sixties- to have a dependent son. Not that he is...he does not want to be, but we will just have to deal with that if it comes along...

> It was the idea of this vibrant, bright, energetic young man whose life was coming to an end. his active, interesting life, his potential for all sorts of things just grinding to a halt. It was terrible. It is still terrible. There is no future, His future is that of a severely handicapped person...last year we talked about financial arrangements [for the future].

Moreover, they felt that present circumstances voided the norm of young adult children living independently. Some suggested that their ill child return to the parental home after years of living away. Others accepted that there would be a delay in the normal launching time for their ill children. Some tried to ensure that children living on their own felt unreservedly welcome to visit.

> He knows home is home and he comes here anytime. I just want him to feel that he can come over any time. But sometimes he says that he doesn't want the family to see him like that. I said that families don't always have to see each other when they are at their best. What is a family if you have to stay away when you don't feel well?

One problem with having ill adult children live in their parents' home is that young adulthood is often a time of tension between two opposing forces in families. In the natural history of families, centrifugal forces operate at the time of launching children. On the other hand, chronic and/or severe illnesses tend to unleash centripetal forces in the family, so that the ill person can receive support and care (Rolland 1994). Tension between these forces was a recurring feature of parents' accounts. For instance, despite an intellectual commitment to the concept of independence, parents felt painfully excluded as they watched their ill children distance themselves physically or emotionally.

> After about two years and when he knew what his diagnosis was and he began to read up on these things...I noticed a difference in the way he would act towards me in regard to his illness...it began to be more of a pulling away from my care...Emotionally it was a very hard time for me because I sensed this, I sensed his hurt, I sensed his pain, his need and I also sensed him pulling away. Maybe he did not want to be a burden, but that was very hard.

> ...before the illness... I was his confidant and he trusted me completely. That was wonderful. I find him to be very careful, he does not allow himself to be too open. It is very painful...this is very hard and it continues to be hard. I have had to deal with my anger towards him and the guilt I feel about being angry with him, toward someone who is so sick. It has been agonizing.

> Every day I have to gauge how open he is, I had to learn to cut back from a very close interacting relationship to being completely passive and just be guided by whatever signals he was giving, by how much he was ready.

And, when sufferers made it clear that issues related to the illness or its effects were off-limits for discussion, parents had to struggle to figure out how to be supportive without being intrusive. They had to restrain spontaneous reactions and became uncharacteristically cautious with their children.

Some parents mourned the loss of a close relationship with their children, never being sure whether to blame the illness, or to accept the distancing as a part of normal development. Others fretted that a companionate relationship could be unduly burdensome for their ill child. But coming to terms with the possibility that they might not have the relationship that they had imagined with an adult child, left some parents with a keen sense of loss, even a feeling of being cheated.

> I guess I feel a very great sense of loss because I would like to be able to depend on her and I can't, or at least I feel I can't... I am feeling cheated, maybe that word is too strong but I am feeling that I am getting to the age where I would like ...just to be able to say " leave the kids and come for the weekend"... I think I had a very big sense of loneliness from this too, and no one understands. I have not talked to other mothers. I did go to the support group but I found nothing for myself...She is finding it different with me too. She has been used to me always being her strongest supporter. I used to say "try this and that", but now she may not have the health to do those things. Now I am trying not to be protective, but to be reasonable and I have had to come to terms with the fact that she is ill. I don't think of her as being ill and unable to cope with anything but I think of her illness as putting limitations on her and I do not want to put anything on her that she cannot handle. [I have become] protective and also maybe not as honest as I used to be. I might be a little more careful in what I say to her, trying not to hurt her feelings. I am not dishonest with her but I might hesitate to say something or maybe not say something as quickly. It is to protect her feelings. In a way I feel that I have the same protective position as when she was little. I feel like I am not taking care of her. Let's face it, she is taking care of herself and doing it very well but I guess I expected a different relationship at this point. I only have one daughter and it would be nice to take the day off and go shopping.

Parents found the redefinition of their roles and learning how to respond to their ill adult children profoundly disorienting. Neither previous parental roles nor expected relations with their adult children seemed to provide satisfactory guides. Most are still struggling to find a sure course to deal with their ill children. Their sense of disorientation emerged not only from changes in relations, but also from watching the changing social identity of their children as they retreated from normative social engagements and personal

achievements. Parents' distress at seeing this type of change seemed the most profound of all significant others. Parents' concerns about ill adult children not fulfilling their potential, have been attributed to cultural expectations of achievement (Horwitz and Reinhard 1995) and fears of downward social mobility (Gubman 1985 cited in Gubman and Tessler 1987:237).

To deal with what they imagined were the long term social implications of their children's illness, and changes that they did not understand, some parents turned to their faith or adopted a philosophical stance. Others entered therapy. Some cried when they were alone. A few tried support groups, and although they found it useful to know that their child was not alone, and that symptom unpredictability was the norm, none attended more than one session. These groups catered to sufferers and their spouses. They did not have other parents.

Many parents of sufferers experienced depression, emotional pain, frustration and helplessness. The limits of their protection and help was made very clear by the intractability of the illness. Their emotional burden seemed to be the most unremitting of all significant others. As a group, they were also the ones who most frequently mentioned that they were coping alone with the illness. They had no reference group of other parents of CFS sufferers and not all faced the illness with the support of a partner. In some cases they faced rebukes from other family members for their support of sufferers. Still, they continued to provide instrumental and emotional support, made or contemplated long term financial provisions when they could, and tried to discuss reintegration into society with their children. Gubman and Tessler (1987) have suggested that parents may find it more difficult than other relatives to cope with ill adult children because they may be less willing than a sibling or spouse to leave the situation.

Letting Go and Preserving Pre-illness Images of Parents: The Effect on Adult Children

If we shift now to the perspective of adult children of sufferers, the same preoccupation with social identities emerged. These people were adolescents at the time their parents became ill. They remembered their parents as competent, accomplished and 'take charge' persons. They wanted to preserve that social identity. They believed that an ill parent could maintain a positive social identity, by fashioning a new satisfactory life around the illness' limitations.

> She is more irritable and it's understandable. Of course the brunt of it comes down on [the family]. That's the negative aspect. The positive aspect is that she is able do things that she never had the opportunity to do if she had continued working... She launched herself in many more projects, to make her self-worth, to feel well. I think that helps her mentally, in dealing with it. Because she's able to do things that give her value...We see our mother a lot more and sometimes that's good, sometimes that's bad. If she's having a bad day, it's pretty annoying. But when she's having a good day, she's a lot of fun, we play cards, go out to lunch...We get to see her a lot more.

But an ill parent's social identity could be diminished by dependency or embracing the sick role.

> I always felt that he was looking for someone to confirm this [CFS] someone to say "yes you have this, and you will not be able to do this", instead of saying "I am not pleased with this, I do not want to live like this". Or even accepting the fact that if I have this, I can only be active for four hours. Then fine, I will do my four hours. I found he let the disease take control of him, instead of him taking control of the disease....Some things were hard for me to accept. He was a young man with his life ahead of him, And there was the fact that he needed to be surrounded by people all the time because his kids did not take him under their wing. They were there to support him but on an independent basis like helping him move, set up apartments, things like that. He wanted someone to take care of him and be there 24 hours a day. That was my impression and I was not going to be part of that.

In the eyes of adult children of sufferers, ill parents' social identities could be affirmed or eroded depending on how they coped with CFS. And to some extent adult children's perceptions shaped the quality of their relationship with an ill parent.

Defending Sufferers from Social Stigma

The above analysis shows significant others' awareness of changes in sufferers' social identities that came with severed occupational ties, shrinking reference groups , and marginalized family roles. Where significant others had once seen considerable potential,

high motivation and overcommitment; they now saw insecurity, blighted potential, and resistance to social integration. While they had once portrayed sufferers as vibrant, energetic, friendly and outgoing; they now described them as withdrawn, handicapped, dependent, limited, and in need of protection. This was the portrait that the closest, even if sometimes ambivalent, significant others drew of sufferers after months and years of CFS. But they knew that some observers including other family members, neighbors, and doctors, saw sufferers more cynically as lazy malingerers.

> You may be missing a point because each person in our family has reacted differently. Many of the other members in the family have denied it for their own reasons and still, even after 4 years when he will tell a brother or sister that he is not feeling well, the reaction is "oh what's wrong, how come?"....when they look at him, they look at a big man..., who once in a while can go out and run 4 or 5 miles..He always takes care of himself, he is well groomed and so on. They see a superficial side of him, which leads them to believe that he is OK and that maybe he is faking it.

> It is a very difficult thing because for example, my neighbors say he looks well, and he does now but he just cannot do certain things...People have said: " Maybe he should just get in there and work. Everybody gets tired". I say "I don't know, it is strange to me, I can't understand it, it is beyond my comprehension". He seems OK, yet he is not OK. Until you walk a mile in someone else's shoes, you will never know. Except that some people do not accept [that]. They say he is lazy and does not want to work, which is not [his] style....

One dilemma that many friends and relatives faced was that, to a point, they understood why others hold a negative image of sufferers. They knew that the ill person often looked well, seemed to selectively engage in leisure over work pursuits, 'played up' the illness, or masked how they were truly feeling.

> When you are sick, you are at home in bed and running a fever, but he is downtown, going out with friends in the evening....I am not saying that he should go around trying to appear sick. But sometimes, I know how grating it is when somebody seems to be having a good time without doing things, when you are working your tail off. I know how I would be if I were still working 8 to 10 hours a day and I saw somebody sauntering in and out. I would have great difficulty with that.

> Whenever people ask how she is, she always says "I am fine". She looks fine and she is bright eyed. I think she encourages the doubt that people have by her responses. I think she should be more honest with them about how she really feels and then people will know how much she has to prepare for a certain social activity. If we go to a party or a dance, she has to spend 2 or 3 hours in bed before we go out. The next day she needs an extra few hours in bed because she will try to recuperate. That is the side that they don't know and I think she should let people know.

In effect, friends and relatives were saying that sufferers often contributed to the negative image that others hold of them because of their appearance, behaviors, and ritual

expressions of social niceties. Understanding these reactions did not make them easier to accept. To counter these assertions, friends and relatives often had to fall back on what they knew of the sufferer's character, their own civility and the perspective that with so little known about the illness, judgments were at best premature, at worst insensitive. Sometimes they avoided people who inquired about the sufferer, not out of concern, but as an opening to deliver pejorative comments. When they could not avoid hearing discrediting statements about sufferers, friends and relatives were thrust into a buffer role. Sometimes this meant keeping the peace between resentful siblings for example, sometimes it meant strains or ruptures in relations with others.

> It has been a source of great tension for him, and for me because in some cases I have had to stand up for him with family members. I actually walked out in disgust from a family gathering because of the types of reactions he received from his siblings. They are completely in the dark ages about the illness.

> ...we had a huge fight where I just burst into tears and ran from the room. That is not like me at all. I have not spoken to my sister in law since then and that was 5 years ago. It was very painful for my husband because it was his younger sister. It was a major family rupture which, it is very clear to me, was based on how angry I was with them for refusing to accept [his] illness.

For their pains they were often branded with a courtesy stigma (Goffman 1963), that is, they too were perceived negatively because of their alliance with the sufferer. Caring for a family member with a socially stigmatized condition magnifies the burden of caregiving (Horwitz and Reinhard 1995).

Relatives were particularly critical of doctors who reacted negatively to sufferers. One person recalled telling a doctor about his sister's CFS. "The doctor turned and rolled his eyes and that really pissed me off. That type of attitude is her worst enemy". But the most bruising encounter with doctors was recounted by a mother whose son was given a psychiatric label following an incident in which she had insisted on having him tested for rheumatic fever. She believed that the psychiatric label was the answer to her challenge to the bureaucracy. Neither mother nor son were informed of the label, but it was communicated to her son's general practitioner and, as a result, to all subsequent referrals. She recalled a particularly offensive consultation:

> He [son] was so angry with this female doctor, I think it was really good for him when one day he said to me "If I could, I would kill her", because he got the feeling out that he had. But it was so strong for him. He's never, ever said anything like that before....

Almost two years after the incident her anger was palpable as she continued:

> ....the very hardest thing for us has been the medical community...you feel that you're being pinpointed, being left out in the dark, being pigeonholed...You're going where you think you're getting help and instead you're really put in a little hole and told "crazy you".

Significant others were all too aware that in some quarters sufferers' social identities were being tainted. It was no wonder they were concerned that sufferers might have difficulty reintegrating socially if their history of CFS was known.

> The integration within society, concerns me. I do not feel that it is a condition that is accepted. It is a diagnosis that if you believe in it, then you get the support. If you do not, psychiatric problems are not accepted in society, but they are more so accepted than something that is new and has a psychiatric/psychological component. That bothers me with regards to his integration within society. I find him very open about it and not as discreet as he should be at times.... If he is in the middle of a crowd, he should not be ashamed of it, but he has a lack of discretion at times. It seems to me that he will be judged a lot, which will interfere with his ability to integrate himself within society.

But even loving and sympathetic friends and relatives were not immune to slipping in and out of characterizing sufferers in ways that were sometimes stigmatizing. In the end, friends and relatives knew that their own recognition of the illness and defense of sufferers' claims was an act of faith. As one parent put it: "Some days you see him functioning normally and you shake your head and say 'I don't understand'. And I don't. I really don't- but I have to believe".

Some significant others feared that sufferers would commit suicide. They had watched sufferers become increasingly despondent and withdrawn after months or years of physical distress, uncertainty about resuming abandoned roles, and strained relationships with others. Some knew that sufferers had made several suicide attempts. Fears of sufferers' suicide haunted some relatives for years. Eventually some felt sufficiently reassured that the sufferer would not commit suicide. But a few remained wary.

> Suicidal was one that I thought about. I thought that one day he would be so depressed, he would jump or he would withdraw himself totally and get into trouble. Being committed to a psychiatric unit was another possibility. Should he be committed? And total deterioration, to a

> point where there would be total withdrawal. And you would get the phone call that he had been emaciated and gone in his apartment. That was immediately after [diagnosis].
>
> I was afraid that he was going to commit suicide. I used to come home from work and check if there was a light under his door, if I could hear him. He kept his door closed and he still does...Three years into his illness I said to his brother..."I am afraid". I voiced that fear and he said "[he] would never do that". I realized that I needed to believe that and I realized that he was right, so I put that fear out of my mind. I was terrified of that for the first three years because it was so bad.
>
> ...the last time I had to go the hospital with him for a suicide attempt was last summer. Again he had taken just enough pills to say "hey I am doing this". I don't think it was genuine. But I think that if he does it, there is a good chance he will do it again and that scares me.

Even when fears of suicide subsided, most friends and relatives remained concerned about sufferers' mental health.

> I think the greatest concern was her being in despair...often I've seen her crying because she thinks that she's going to stay like this all her life. [saying] "I used to be a normal person...I used to work and have a social life....now I have to live with sickness...It makes things difficult and different"...the first thing [was] trying to make her understand that even if there are restrictions, her life is not over. There's something else to it..

These concerns decreased as the length of remissions increased. In more difficult times, friends and relatives tried to be present, watchful and solicitous. They tried to boost sufferers' morale by pointing out accomplishments and expressing confidence that things would improve. But their narratives conveyed how frightening and difficult it was for them to watch the sufferers' emotional distress. Several reported being psychologically affected by sufferers' moods. And, they noted that their own ability to cope and support the sufferer depended on other concurrent stresses in their lives.

Friends and relatives faced the day to day vagaries of CFS in tandem with sufferers. Most have seen improvement in the sufferer's condition over time, but they have learnt that it is an illusion to view periods of respite as a cure. The long term implications for themselves and the ill person remain a troubling emotional burden. Some significant others have also been deeply affected by negative reactions aimed at the ill person. They have found little to guide them through the uncharted territory of being close to someone with a strange and suspect illness. Where they saw suffering and undesired changes, others saw weakness and dissembling. They have tried to extend emotional and instrumental support within the limits of their own personal situations and what the sufferer would

allow. At the same time, many needed support themselves to deal with bewildering changes in their roles and relationships with the ill person and with changes in sufferers themselves. These experiences brought about a sense of disorientation, feelings of loss, frustration, anger, worry and sadness. Family members grieved for what was, what should be and what might have been. Over time, they have reoriented their relationship with sufferers by taking their cues from the ill person and by evaluating his or her patterns of behavior. They have learnt to mute enthusiasm, trade spontaneity for more deliberate planning, change their own activity patterns and assume new responsibilities. Although they try hard, they know that at a given time they may not always respond in ways that are best for sufferers because there could be a lag between their own and sufferers' perceptions and evaluations.

Summary and conclusions

Friends and relatives of sufferers measured the course of CFS by both biological and social parameters. The most critical biological elements were the onset, severity, duration, cause and unpredictability of symptoms. Significant social elements included the long process of defining the situation, watching the illness ravage sufferers' social identities, and adjusting to the implications of being close to a CFS sufferer.

Significant others' initial and subsequent definitions of sufferers' problems were shaped by general ideas of what constitutes illness and by their positions as "wise" persons. Illness has a "look", "symptoms", "cause", and associated "behaviors" that friends and family searched for, even though these elements may not have been present unambiguously in CFS. Initially, they drew on their knowledge of sufferers' medical and psychosocial histories to decide whether sufferers were sick or under severe stress. This finding is in line with Baumann and colleagues (1989) who suggest that lay people use heuristics involving health relevant and contextual cues to differentiate between illness and stress. Subsequently, some significant others drew on knowledge of sufferers' pre-illness personalities to re-evaluate persistent symptoms, subtle body language, and changes in

function as signs of illness. Most could do so because most had a shared personal history with sufferers that predated the illness. Health professionals in close contact with stigmatized sufferers may also occupy the position of "wise " persons (Goffman 1963). But even if physicians knew sufferers before they developed CFS, their contact was usually episodic and circumscribed; their knowledge of sufferers was pieced together in a professional relationship rather than grounded in day to day living. But the social location of friends and family of CFS sufferers allowed access to qualitatively different information from that which was available to treating professionals

Significant others' definitions of CFS exposed a range of mainstream and more peripheral cultural explanations of illness that may be drawn on to understand a condition that does not neatly fit existing biomedical categories. Their attributions included such currently popular ideas as sick building syndrome, radon gas, and immune dysfunction, as well as the more traditional causes- viruses, depression, and stress. With the lack of medical consensus about CFS, friends and relatives selected from competing hypotheses to confirm their own views of the illness. On this point they were similar to doctors and insurers. The inclusion of chi disease and damage to the etheric body as explanations of CFS indicates the incursions of Eastern, or as some say, New Age ideas into the social discourse on illness. Such ideas extend the spectrum of friends' and relatives' explanations beyond those of doctors and insurers. The instability of attributions reflected a search for cause that made sense, so that friends and family could assign responsibility, bring closure, decide on the illness' legitimacy, and direct their expectations and behaviors.

The significance of definitions lies in their social implications. Believing that sufferers had a legitimate illness, whether physical or psychological, allowed many friends and relatives to provide support and grant exemptions from roles and responsibilities. Similarly, believing that sufferers were malingering or claiming illness for secondary gains brought resentment, strains and distancing to the relationship. Believing that the illness was chronic had further social implications. It brought disruptions and strains to the lives of

friends and relatives many of whom gave up social roles, adapted their daily living activities around the sufferer, and restricted their social life. Some took on advocacy roles and intensified surveillance for further problems that Ranelli and Hansen (1995) described in a different context of caregiving. As a result of watching unexpected and undesired changes in their loved ones, several significant others bore a heavy emotional burden. They clearly illustrated the burden that may accrue from network events (Kessler and McLeod 1984), that is, the emotional costs of caring about what happens to people in one's social network.

Over time, the hardships of chronic illness or incapacity may result in rejecting and avoiding sufferers who expect or demand too much (Freidson 1970; Jones et al. 1984; Scott 1970; Goffman 1963). But in this sample, no significant others rejected the sufferer outright. Rather, they negotiated an ongoing relationship by accepting what they did not understand, by trying to understand, if not excuse, the sufferer's continued occupancy in the sick role, or by deciding that any advantage of the sick role was more than offset by the disadvantages. These efforts and perspectives helped to defuse resentment or envy of the sufferer's sick role exemptions.

Most of these family and friends concealed the toll on themselves from sufferers, provided practical and emotional support, defended sufferers against pejorative labeling and assumed responsibility for maintaining relations with the sufferer. To bridge distances between themselves and sufferers, significant others tried discussion, deferred to the ill person, and sometimes undertook extensive research to gain a better understanding of CFS and its implications. Others drew boundaries to demarcate the extent and nature of the burden that they were willing to assume. Without such boundaries, significant others might well have become "hidden patients" (Haug 1993), or experienced a sense of role captivity (Aneshensel et al. 1993). These boundaries likely protected significant others and the relationship with sufferers.

The responses of significant others show that burdens do not necessarily lead to rejection and stigmatization. Rather burdens may be weighed against the importance of safeguarding the health of the sufferer and the relationship with them. The impact of CFS on the lifeworld of significant others, meant not only burden but a heightened awareness of the value of the sufferer. This valuing, expressed through the considerable practical assistance and interpretive work of significant others, offsets tendencies to reject sufferers when the source, duration and severity of distress and disability were in doubt. To significant others the meanings of CFS as disability, burden, stigma, and in this case legitimate illness as well, were linked in complex ways.

CHAPTER 6

SUFFERERS' EXPERIENCES: STIGMA IN THE SEARCH FOR VALIDATION

Previous chapters have presented doctors' insurers' and significant others' perspectives on CFS and their experiences with sufferers. This chapter focuses on sufferers' search for legitimation of their distress from the medical and disability compensation systems, and from their social network. When sufferers first became ill, they expected a clear, treatable diagnosis, short-term disability compensation, and understanding from family and friends. They had no reason to believe that they would be blamed for their illness or denied exemption from their usual roles. They had no way of knowing that their search for relief from suffering would become a fight for recognition of their distress and its label. Or that to the extent that they found recognition, it would prove neither universal nor necessarily stable.

I begin with sufferers' encounters with physicians although both theoretical (Freidson 1970) and empirical literature (Litman and Venters 1979; Ross et al 1990; Schor et al 1987) suggest that when people are trying to determine whether they are ill, they often consult family first. If this was true of CFS sufferers in this study, none mentioned it. Rather, they placed physicians in a pivotal role. Perhaps this was a function of the retrospective nature of their accounts. Perhaps it was an acknowledgment of physicians' impact on their own and others' conceptions of and reactions to CFS.

The Search for Medical Legitimation

Sufferers' experiences with physicians can be divided into a prediagnostic and a post diagnostic phase. During the prediagnostic phase, sufferers consulted mainstream general practitioners and were sometimes obliged to see company doctors. In the post diagnostic phase, many broadened their help seeking to include alternative practitioners. The main purpose of help seeking in each phase was symptom relief. But in each phase, some sufferers found they also had to defend themselves from doctors' stigmatizing reactions. This section shows that both symptom experiences and negative reactions from doctors contributed to the extensive help seeking that has earned CFS sufferers the label of "doctor shoppers".

Help Seeking in the Prediagnostic Phase

Sufferers' initial encounters with doctors began like many ordinary consultations for minor illnesses. They were looking for a diagnosis and treatment of distressing symptoms. A small minority went directly to hospital emergency rooms because of alarming symptoms such as blindness or diffuse, wracking pain. But in most cases, sufferers were experiencing persistent or severe 'flu like symptoms. The majority were diagnosed with an infectious illness and treated accordingly. The remaining cases were normalized by attributing symptoms to current stresses such as overwork. At this point, both doctors and sufferers agreed on the source of symptoms and expected an early resolution. And sufferers readily obtained medical certificates for work or school absences.

Instead of abating as expected, symptoms persisted or recurred. And a pattern of frequent visits to doctors soon developed.

> I started feeling like I had just run a marathon... Tremendous fatigue and exhaustion which did not go away with rest, even prolonged rest, and physical collapse. I had a very busy schedule, I was doing 2 jobs... I had had 1 or 2 bouts with fatigue in the previous year...then, I kept getting cold after cold after cold, getting these down periods more and more often...I found myself going to the doctor more and more often.... until towards the end of the following year...he called me in. He said "look, you are coming far too often with complaints of colds and sickness, your periods of

> being healthy between colds are getting shorter and shorter. I think there is a real underlying cause that we should look into. Would you be willing to go to a specialist?". That is how I got started...He took out my medical file and it was obvious that something was not right.
>
> I went to the doctor because of...nausea, a sore throat and lightheadedness...he could not find anything wrong with me, so I tried to keep working That was in November 1986. At Christmas 1986, it hit me very hard. I was taking a lot of time off work. There were many symptoms; fevers, dizziness, a lot of nausea, general malaise, feeling very sick. It was a big problem because how do you describe that to a doctor, when you just feel sick all over? At times it was so intense I would think 'just get me to a hospital because something is very wrong'. But I kept going back to the doctor and he kept telling me I was fine. It did not make sense to me at that time because I felt so sick. That is when the nightmare began.

Despite increased medical consultation, sufferers did not improve. Attempts to resume or maintain regular occupational schedules were not successful. They needed additional medical certificates to extend work or school absences or to justify a reduced work load.

At this point, sufferers' experiences with doctors diverged into two distinct patterns. In the first, sufferers continued to receive medical certificates and remained in the practice of their regular doctors. When they later became familiar with the difficult trajectory of some of their fellow sufferers, many members of this group referred to themselves as "one of the lucky ones". Woodward (1993) also identified a group of "lucky sufferers" in her Australian sample. Those sufferers received an early diagnosis of CFS and were spared some of the problems of being disbelieved. In a second pattern, a substantial minority of sufferers were refused further medical certificates and left the practice of their regular doctors. They then embarked on a path of extensive help seeking during which they were often labeled "lazy or crazy". Such negative responses often stimulated sufferers to find doctors who would not only believe them but who would also offer them an acceptable diagnosis.

The "Lucky" Sufferers

"Lucky" sufferers had their symptoms explained in one of three ways. Some were told they had a clear infectious illness complete with corroborating physical evidence. Others received a provisional diagnosis because their case was considered somewhat unusual. These sufferers were often referred for consultations which failed to clarify the

diagnosis. The remaining sufferers were diagnosed with a reactive depression which was thought to result from a recent physical injury or social stresses. Most sufferers accepted these explanations because they fit with circumstances preceding the illness.

But some did not agree that depression could explain their symptoms. They discounted that hypothesis because they felt they had no reason to be depressed or because their current symptoms did not match common prototypes of depression. Some submitted to mental health examinations to assure themselves, or insurance companies, that they were not depressed. These sufferers were particularly satisfied if it was officially confirmed that depression did not convincingly explain their symptoms.

> The traditional doctors always like to send you off to the psychiatrists. I saw a few psychiatrists but they could not find anything wrong with me. They said it was not in their field and I felt that way myself. You know yourself that you are sick physically.
>
> And then of course seeing all kinds of doctors, they were leaning to depression and I wouldn't believe it. At that point my marriage was strong, I had a real peaceful life because of my relationship with God. I knew I wasn't depressed. No one could convince me of it. But after this being repeated several times. I thought let me see a psychologist. I went to see a psychologist and he told me that I wasn't depressed. It wasn't because of stress, because of the way I handle things. I think [I saw him] for a period of eight weeks and he saw no reason to continue.

Although they had no definite physical explanation, these sufferers had it on good authority that their problem was not mental or emotional.

The lack of a definite diagnosis could have prodded "lucky" sufferers to seek other doctors. But their regular doctors gave them something that, in retrospect, may have been as valuable as a diagnosis: these doctors believed that sufferers were sick. And they were committed to diagnosing and managing the illness.

> I have a lot of confidence in him. I am very comfortable with him.. We did not know what was wrong with me and one morning he called me. He had been jogging and he said "I just realized what is wrong with you, you do not have enough sodium in your blood"[1]. He was trying to find out what was wrong with me...He did work hard on me.

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[1] Low sodium or hyponatremia would have been discovered on the most basic of blood tests early on in any investigation. The point is not that the doctor was negligent or that the sufferer did not comprehend the possible significance of this information. Rather, it shows a doctor sufficiently committed to a case, that he thinks of it conciously or not, while out jogging. Telling the patient this anecdote contributed to her perception of the doctor as caring.

This type of validation allowed sufferers to maintain their sense of integrity. But it did not relieve their symptoms.

Lack of effective treatment could have been another stimulus for "lucky" sufferers to seek the services of other doctors. But these sufferers did not believe another doctor would provide better care and saw no reason to move on. As a result, they went through a relatively quiescent period with regards to help seeking until they, or their doctors, heard of CFS and reconsidered the case in light of this information. The time between the first symptoms and the diagnosis of CFS lasted from a few months, especially after the late 1980s, to nineteen years according to one account.

The Discredited Sufferers.

In contrast with the relatively unremarkable relationship with doctors described above, other sufferers who continued to request medical certificates were met with grudging agreement or bluntly told that they were shirkers. This type of reaction prompted one sufferer to conclude that the medical establishment turns on patients who do not get better.

> I started coming down with what looked like the flu with ear infections, sinusitis and throat infection...I was feeling increasingly being unable to walk, I was having sweats and chills. The first course of antibiotics which he gave me did nothing so he put me on a second course. It got to the point where I was unable to get up and that's how I stopped going to work. Not that I was paralyzed, but my body just could not move. And when I told him that, he said it was in my head, that there was nothing wrong with me and that there was no reason why I shouldn't be going in to work. At this point, my husband was coming with me because I could barely walk, he had to half carry me up the stairs. And this doctor kept on saying that it was in my head.

> My GP at the time was not supportive at all. When I tried to return [to work] for a while -I was off for two weeks, I had caught a virus- I'd return and I would keep having to leave work halfway through the day. When I told her that I didn't think I could work a full day, she reluctantly gave me a note saying that I could work half time for a month. She said "Now I want to see you more often". It was sort of accusatory.

Many felt bitter and betrayed by such negative reactions particularly if theirs had been a long standing doctor-patient relationship. They had neither bargained for a prolonged illness nor having their character impugned. They could not accept being told that: there was "nothing wrong", they were "malingering", or they had minor infectious illnesses

while their symptoms were worsening. They responded by leaving the practice of their regular doctors and turned to their social networks for help in finding new general practitioners.

Once they found new doctors, many sufferers found that previous tests were repeated and sometimes new tests were added. Sufferers were tested for a range of infectious illnesses including Epstein Barr virus (EBV), hepatitis, Coxsackie virus, AIDS and tuberculosis; endocrine disorders such as diabetes and hypothyroidism; environmental toxicity; and non infectious immune disorders most notably cancer and lupus erythematosus. A few underwent spinal taps, sleep studies, and imaging procedures such as MRI and SPECT scans. Several were referred to specialists in the areas of neurology, infectious diseases, immunology, psychiatry, rheumatology, endocrinology, and gastroenterology. For the first time, both doctors and sufferers began to consider the possibility of life threatening illnesses such as cancer or AIDS.

More often than not, test results were negative, non specific or of uncertain clinical significance. If abnormalities were found, doctors could not specify the links between these findings and sufferers' symptoms. Sufferers were told there was nothing wrong. They variously interpreted "nothing wrong" to mean that: specialists had found no abnormalities in the body systems they had investigated; that doctors were trying to reassure them there was no cause for concern; and that doctors thought they were malingering or psychologically disturbed. While they could accept specialists' reports, they were not reassured by well meaning doctors who suggested there was no cause for concern. The insistent distress of symptoms, and increasing inability to perform basic self care functions told them otherwise. Moreover, sufferers were often chagrined to discover how little significance was accorded to abnormal laboratory findings. Without a background of medical knowledge and clinical experience to put such findings in perspective, many clung to abnormal findings as evidence of illness.

When sufferers interpreted "nothing wrong" to mean that they were considered to be malingerers or psychologically disturbed, they felt belittled and estranged from doctors. The message was usually unmistakable even when leveled obliquely.

> I was told "what you need is a good man in your life". Part of the illness though is that when you receive new information, it may take 2 hours for you to sort it out....Once I told a doctor "I feel like this disease is a cross between Alzheimer's and the Village Idiot"...maybe the GP thinks I am to blame if I don't have a man in my life [laughs]

> I saw someone ...when I lost ten pounds... and had the flu and she told me to stop carrying a purse, stop picking up my children and there was nothing wrong. Which was really tough. But since then I've worn a belt which does in fact help. I'm not carrying a purse, especially when you have aching shoulders most of the time...But she was pretty harsh. She was looking at "get on with things"

However, not all sufferers who consulted new doctors were told there was nothing wrong. Some were given physical or psychological diagnoses. Unlike "lucky' sufferers, who were content with physical diagnoses even if they did not respond to treatment, these sufferers soon discarded such diagnoses if treatments were not effective. Many also rejected a diagnosis of depression and moved on to find other doctors.

But some sufferers accepted a diagnosis of depression. One of these related the cost of this decision. After being repeatedly told that she was depressed or faking, she agreed to psychotherapy. Gradually, she began to distrust her perceptions and bodily experiences and became increasingly unsure of herself. As her sense of agency waned, she temporarily stopped further help seeking.

> The other neurologist said "if your brain scan is normal don't come back". Then I went to a psychiatrist. I sat there once a month for years, going on about these symptoms... totally convinced that I am a basket case because I can't understand why I am slurring my speech, why I can't read a newspaper, my concentration stopped there....I went to visit my mother...everyone there could see me getting sicker... So they sent me to an internist....I thought 'this is my only hope'.... He said "...there is absolutely nothing wrong with you". When I left his office, that was the end of me and the end of my self-esteem. Since he was God, and God just told me it's all in my head, I didn't know what to do after that. Again humiliated...The psychiatrist kept saying he knew there was something wrong. He wanted me to go to a friend of his who was a family physician. I said "I can't, I've given up, I don't know what's wrong and I just don't want to go through that embarrassment and humiliation anymore. I've had enough".

But unlike "lucky" sufferers who stopped seeking help because they were content with their doctors, this sufferer stopped because she felt beaten. Her account shows that in some

cases a psychological diagnosis may stall, rather than precipitate, help seeking efforts. Ware (1992) has used the term delegitimation to describe the repeated discounting or trivialization of illness experience. Previous research has shown that CFS sufferers may react to medical delegitimation by further help seeking (Ware 1992), by passively accepting their doctors' definitions, or by fighting to change doctors' attitudes and behaviors (Wheeler 1992). The distrust of one's perceptions following delegitimating experiences has previously been noted among sufferers with other contested illnesses including CFS (Ware 1992), chronic facial pain (Lennon et al. 1989), and repetition strain injury (Ewan et al. 1991; Reid et al. 1991).

Some sufferers unwittingly accepted diagnoses that have a strong, though not transparent, psychological connotation.

> I had an appointment with a specialist... He looked over everything and said I had a functional illness. At the time I didn't quite understand. I understand now that it's a, he was saying that I had an emotional illness. It was a mental illness. That's what I understand functional to mean now. He said I had fallen between the cracks of physical and emotional and he described it through the stress I had gone through and we had moved, I had left my job and stuff like that.

Interestingly, the one psychological diagnosis that some sufferers seemed to willing to accept was that of anxiety. Perhaps they were more willing to admit to anxiety because it can be understood as a concomitant of the striving, competing, and achieving that society values, while depression may imply giving up, withdrawal and inability to cope.

Experiences with Company Doctors

In the pre diagnostic phase, some "discredited" as well as "lucky" sufferers had to report to company doctors after missing more than a certain number of work days. During these encounters, some sufferers raised the possibility that their illness was work related. In response, some company doctors ordered thorough investigations for environmental toxicity. Sufferers reported that these doctors continued to treat them sympathetically even if no toxic contamination was found.

> I would frequently visit the doctor at work. He told me "I am your doctor at work. My main purpose is to see [that] you get better...you have all kinds of specialists but you don't have

> anybody to regulate any medications that you're on. I recommend you find a good GP to do that". I went to one GP that someone recommended and he looked at the case and he said "Oh I hate these kinds of cases [medically unexplained symptoms]". He hemmed and hawed and I said "I don't think you're what I am looking for". So I went back to [the company doctor] and he says "I [know] a doctor...[who] will take your case and he'll study it give you a lot of time, you won't be in and out in five minutes". So I set it up and I really like him.

But other sufferers found that their company doctors dismissed suggestions of a possible toxic work environment. These doctors ignored requests to investigate, suggested sufferers were faking, and in one case even threatened to recommend job termination.

> When I left work they sent me to a company doctor. That was one of the worst experiences of my life. I think I was there for three hours being questioned....He didn't question you, he interrogated you. But that's what they are there for..."absolutely, under no circumstances" he said. He did not believe anything I said and he did not believe I was ill or anything like that. Therefore, I was fired and not going to be paid anything. And I thought this was unbelievable, I will not stand for this.

Sufferers whose complaints of illness triggered investigations of the work environment described themselves as good and loyal employees and gave concrete examples of how they had improved their company's performance. Those who were rebuffed also believed that they were good workers, but they admitted to being openly critical of working conditions. They had no credits with their companies. In light of these differences in sufferers' accounts, it seems reasonable to suggest that differences in company doctors' reactions might have been due to sufferers' conduct as employees rather than any lack of merit in questions about the source of their illness.

The prediagnostic phase ended when sufferers received a diagnosis of CFS or one of its earlier labels- chronic Epstein Barr virus (CEBV), myalgic encephalomyelitis (ME) post infectious neuromyasthenia syndrome (PINS) or post viral fatigue syndrome (PVFS). The particular label depended on whether the diagnosis was given in the early or late 1980s and after. But all these diagnoses were updated to CFS by the early 1990s as both the medical community and sufferers became more aware of the condition. In several instances, sufferers were diagnosed only after they had suggested CFS to doctors. These sufferers had usually learnt of the condition through media reports or people in their social network. They felt an instant recognition when they heard its symptoms: "I had eighty percent of the symptoms", "the diagnosis sounded right", and "I felt I was reading

myself". Their experiences are in line with the finding that lay people will more readily identify a particular illness if symptoms closely match common prototypes of that illness (Bishop and Converse 1986).

Once sufferers believed that they knew what was wrong, they went looking for doctors to confirm their idea. Ironically, one sufferer learnt of CFS while perusing a magazine article in his doctor's waiting room.

> Dr. _____ told me there was nothing wrong. One day I took a cover of Newsweek from his waiting room and I said "How come this is on the cover of Newsweek and you tell me there is nothing wrong?". He said "I did not say there was nothing wrong but it is a combination of psychological and physical", which is not what he said

Sufferers who learnt of the condition through CFS support groups or associations, sometimes approached doctors that these groups endorsed as knowledgeable and sympathetic. But some sufferers believed that these doctors did not give the label indiscriminately.

> Another reason why I like Dr. ____, he has found people who do not have it...I know someone who has been to see him and he hasn't been diagnosed with it...he's a support group leader... I find a lot of doctors are accepting CFS, it's becoming a 'catchall'.

Help Seeking in the Post Diagnostic Phase

The diagnosis brought mixed reactions. On the one hand, most sufferers were relieved to find they had a recognized condition. On the other, those who were familiar with the controversy surrounding CFS were dismayed to receive the diagnosis. One woman angrily told her doctor that she could not have CFS because she was not a "yuppie". Another repeated several times: "This is so controversial. If it had happened to someone next to me at work, I don't think I would have believed them. I had to have this to believe [in its existence]". Ironically, while some sufferers viewed a diagnosis as validating their claims of illness, the validity of this particular diagnosis was itself in question. And

the "lucky" sufferers who had earlier been spared the necessity of seeking validation, were now relinquishing their previous diagnoses for one that was, at best, partially legitimated.

Skeptical Doctors

If sufferers had any illusions about the legitimacy of CFS within medical circles, they were soon dispelled. Sufferers were dismayed to find their illness dismissed by some doctors as "bunk" or "all in the head", "non existent" and "not real". Several felt "brushed off" or blamed for not being able to "forget about it [CFS]" and get on with their lives. Such attitudes seemed as out of touch with the reality of the situation as "telling someone to run a marathon when they have a broken leg". Many sufferers were also shocked to hear other physicians disparaging the diagnosing doctor, in effect awarding a courtesy stigma[2] to a professional colleague.

> The endocrinologist suggested that it was the "yuppie flu". And when I went to [GP] he said, "this is what these people think?" He got very upset with me. He said that illness doesn't exist and he doesn't know where these people are coming from, but if this is what I want to believe that's fine with him. At that time he was filling out my notes for work and he threw my paper at me and said there is nothing more he can do... And he walked out of his office and said "you know I really believe there is nothing wrong with you"....I went to see staff health.... but the GP there said it was in my head. That all it was, was an ear infection and that I was trying to make more of it, than it was.

> I went to a female [specialist] for a second opinion about whether or not the [surgery] was necessary. My concern was anesthesia. I did not want to bring it up to her, but I felt I had to. She dismissed it rather out of hand, although she did explain that she did not know very much about it [CFS]. But she characterized it as a waste paper basket diagnosis. I was really feeling...When you get that reaction from a professional, it makes you feel so useless. It is hard to describe the feeling inside you. I was going to her for the surgery because I did like her manner other than that. But when she threw that one, I said no.

> I had one of the [insurance] experts at least, and even my cardiologist sneering when they heard the name of Dr. _____who is a specialist in Chronic Fatigue. I do not think that they take his testimony seriously, which is why I had to get a backup from Dr. _____.

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[2]People who do not possess a stigmatizing attribute may be stigmatized because of their association with and sympathy towards people with the attribute. Family and friends of stigmatized persons as well as treating professionals are often the target of stigma by association. Goffman defined this kind of stigma as a courtesy stigma.

Sufferers rarely forgot skeptical doctors. Most simply left their practice or refused to become their patients. But others retrospectively explained doctors' skeptical behaviors as a function of the medical ignorance of CFS that was widespread until the late 1980s. A few went further and re-established contact with previously disbelieving doctors, for the purpose of educating them about the condition.

> ....doctors have a set schedule. They give you antibiotics if you have a bacterial infection. If you have a virus, there is nothing they can do for you. If you break your arm, they fix it. Or they refer people to other doctors if they have mental problems, and they will get medication. They do not deal with problems that do not fit those categories. They do not look up CFS in their textbooks to find out what to do. They never learned that in their schooling so it gives them discomfort or uncertainty. They were not taught how to deal with those things. I look at them and I have empathy for them. The MD I had when I first got ill, I was tempted not to go to him through the years. There was a period when I did not see him but then I realized that he is just a doctor doing his best from where he has come from, so I felt it was my place to keep a rapport. I got him to get some of the reports that come out every 3 months, so he could keep up on some of the advances. Then it came to the point where he got interested a little. Now I see him once or twice a year for my regular check-up and we spend a lot of time with him asking me questions about the illness so he can be more able to help others. I still keep that tie although he does not serve me the greatest purpose for my health. I see it as an important contact.

A diagnosis of CFS created another dilemma for sufferers. Not only did they have a contested illness, but this illness had no reliable treatments. Since there was "nothing to be done", some doctors refused to follow the case. But sufferers were not easily deterred. The news of no treatment only redirected their search. Now they were looking for clinical trials and doctors who were willing to manage their case. They were not necessarily searching for doctors who offered a cure, although some did, but doctors who would support them over the long haul. In this quest, some quickly rejected doctors who seemed skeptical of the condition or those who were unwilling to give their time. Some screened prospective doctors by making their needs known at the outset and gauging the response.

> When I was looking for doctors, one said to me "If I see you it is going to take 3 hours to do a work up on you, and I make $60. If I see 30 other people, I am going to make $900. I do not have time, please go see another doctor". So I started to tell doctors "finish your clinic, I do not care when my appointment is, see all your other patients, I need time with you. If you do not have time today, I will wait and I will come back the next day at the end of the clinic". They look me in the eye and they see that I am serious, and that I am seriously ill.

A minority bluntly stated that they neither expected nor sought support from doctors.

> When you are talking to them, they look at you and say "yeah right, it's in his head". You can see it and I am not stupid. They are not taking you seriously. So I say to myself "why am I doing this?". They have a bad attitude, they are too interested in making money. They are not there to

> help the person, it is sad to say but one thing that I have learned is that doctors are out to make money.

Supportive Doctors

Eventually however, most sufferers found doctors who were at least somewhat helpful and supportive. Sufferers described these doctors as good listeners, non judgmental, and sympathetic. When sufferers were plagued with doubts about their illness' reality, as invariably happened, these doctors reassured them by pointing to clinical findings.

> You keep hitting this wall of unknowns as to the cause and a wall of people telling you [that] you must be faking, you keep needing to double check. Dr.____. has been wonderful. So many times I'll say "do you think I should just try harder?" And she'll say "no, I think you're very clinically ill at the moment. I just examined you, remember?" But I always seek that kind of affirmation... because I know if she says it, she's never babied me or been terribly protective, if I didn't need it... she...has watched me go up and down with these attacks.... so if [she] sees it and I'm insecure about it. I just do a reality check, and then it's OK, what can I do now to balance myself?

> So I said to my baseline doctor "do you think this is psychological?" Not in a way like do YOU think, but rather should I be looking at a psychologist? She said " you don't have sore throats and swollen lymph nodes from something that is psychological".

Sufferers found supportive doctors more egalitarian in their approach than other doctors with whom they had previous experiences. According to sufferers, these doctors took time to explain tests, the illness, and its management and sometimes shared the latest research findings with them.

> The first time I met him, I could see he believed me, which put me at ease. He was empathetic. He was very supportive and he did not put me at a distance. He didn't treat me like a doctor/patient...When he ordered the blood test, he got the results very quickly....He called me himself and he told me not to worry, that it was not life threatening but he did find something and to come back to the office. It was nice because he was sitting at the opposite side of the desk and I was sitting in the patient's chair. When he came around with the results, he sat down in the other chair and explained to me how it all worked so I would understand exactly. I thought that was really nice. I felt content that I had found somebody who at least believed me and could maybe refer me to some people.

They were also receptive when sufferers brought them literature.

Some supportive doctors encouraged sufferers' self care efforts. For example, one sufferer reported that his doctor was pleased because "I made up a computer schedule and tracked where I was...on a scale from +10 to -10, half hour by half hour, which I did for three months. I wrote down how I was feeling physically, mentally and [my] mood- entries

such as 'I dragged myself out of bed this morning at 7:30, was able to dress this morning, forgot to wash today.'" Other supportive doctors offered treatment programs. Typically, these programs consisted of general counseling about healthy lifestyles including the need to remain socially integrated, concrete suggestions and guidelines for managing symptoms, and suggestions to seek psychological help as a means of coping with the impact of the illness. By putting psychological treatments in this perspective, these doctors allowed patients who felt the need, to request psychological referrals without fear that they would be seen as admitting to a psychological disorder.

> She had suggested that I might want to see someone [psychiatrist] two or three months before that and I said no. I didn't need to go to anybody, I had this all in control, don't worry. And then all of a sudden, I felt like I was losing control of everything and I couldn't handle it. I called her one day and I said "fine I will go and see a psychiatrist, I can't cope with this". That was a very hard time for me, to admit that I could not cope with it. It was recognizing that I needed something that was going to bring my spirits up, so that I could cope better. But it was not going to go away, so I better get my mental outlook up, because I am going to have to deal with this and how it's affecting us, so let's get on with it.

Sufferers found that these doctors embodied several important characteristics: they were sensitive, their judgments were highly credible, and they inspired trust. Sufferers' accounts suggested that these doctors knew when to reassure, when to be firm, when to orient sufferers to what they could expect, and when they needed hope. These doctors' judgments were anchored to specific details of sufferers' accounts which reflected careful listening. They earned sufferers' trust by critically assessing new treatments, examining options with sufferers, and proceeding only if both parties agreed and there was a good chance that treatment would help. While many sufferers clearly welcomed this kind of partnership approach, it also meant shared responsibility for outcomes.

Several sufferers attributed the support and understanding that these doctors showed to experience in caring for other CFS patients. Many also mentioned that these doctors published, lectured, and were involved in research, whether on CFS or on other illnesses. But the most important credentials of supportive doctors were not those from academia or clinical experience with CFS. Some sufferers found that doctors who were thought to be well informed about CFS abandoned patients after making the diagnosis,

because they said nothing could be done. They may have been knowledgeable but they did not understand sufferers' experiences. They did not understand how frightening it was to go through the experience of having a poorly understood illness without medical support. In contrast, some doctors who were less well informed about the illness were willing to listen to sufferers, explain what they knew, and discuss ways to cope and manage. They offered sufferers time and respect. Their commitment contributed to sufferers' sense that they were worthy of being helped. Their suggestions for management gave sufferers hope and a measure of control over lives that had gone amok. Their openness and availability provided a safe place to risk exposing insecurities. Finally, in the eyes of sufferers, these doctors showed a discriminating approach to new ideas and to patients, that lent credibility to their judgments

Alternative Care Practitioners

Sufferer's accounts made it clear that finding a diagnosis and a supportive doctor reduced the need to continue seeking medical help. But finding effective treatment remained an elusive goal that drove some to seek out clinical trials and doctors willing to experiment with medications approved for other illnesses. The search for treatment also brought a minority of sufferers into the world of alternative practitioners. But as Pawluch (1996) points out these practitioners are hardly true alternatives to mainstream medicine in North America. Most sick people do not leave mainstream medicine and cross over to these systems of health and healing. Rather they complement their regular doctor's care with therapies offered by these practitioners.

With nothing to lose, several sufferers tried a range of healers practicing Eastern and Western complementary therapies. They received various hands-on therapies from osteopaths, chiropractors, massage therapists, personal trainers, and faith healers. They also saw homeopaths, naturopaths, herbalists, and diet counselors. They consulted hypnotists, color therapists, iridologists, and energy healers. Some sufferers took up

Yoga, Tai chi, macrobiotic and other diets, and primal screaming. Others submitted to reiki, shiatsu, zero balancing and craniosacral therapy. Some sufferers were a little sheepish as they admitted the type of alternative practitioners they had consulted. A few were treated with exotic machines such as the vibratoner and the Reumark[3] machine.

> Reumark (?) machines- it is a type of electrical pulse machine with a hoola hoop. Tubes are put onto one's body. One side is negative and one is positive. It is supposed to help cancer and other things. Each machine costs about $6000. It was invented by someone at_____. There are seminars and people can come to your house with a machine and charge $10 a shot.

Sufferers were attracted to these diverse healers by a common element- an holistic approach. They found these healers were largely unconcerned with labels but they tended to both mind and body whether they were offering a cure or symptom relief. Their approach of combining concrete action with empathy resonated with sufferers' ideas of what a health care practitioner should be. Their positive approach gave sufferers hope that it was possible to overcome the illness. In some respects they were similar to supportive doctors, but they had no authority to legitimate illness and grant certification that some sufferers required.

Alternative care practitioners also exposed sufferers to various philosophies and fresh perspectives on the source and meanings of illness. The most common new idea gleaned from many of these therapies was that energy blockage could be a source of illness.

> I go to somebody who does reiki. It's... similar to therapeutic touch. It's based again on Japanese...but the principles of opening up energy levels and the chakras and the whole oriental medical model. I see her, not as regularly [as I would like] because I can't afford all this...I have had someone do craniosacral work with me which is based on osteopathy....I liked the way she looked at it. She said it often happens in families where cancer auto-immune diseases, diabetes, exist. And she says [it happens to] some people, and it's usually strong people, who plough ahead and maybe not stop long enough to smell the flowers in the process. But they get hit with these things and by recovering, they are getting around something a lot worse and I've always felt that about this illness... I liked it. I hung on to that and I wrote it down, to think of it that way.

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[3]The person who described this machine was not sure of the spelling of the name.

Sufferers' evaluations of these therapies were mixed. Some were declared "absolutely useless", "not helpful", and "possibly harmful". Other sufferers experienced temporary effectiveness which reinforced their beliefs in these therapies.

> [The] osteopath...works on my muscles... But one of the other problems I have is that I get these spasms and I get them in my brain, I can feel it behind my eye in my muscles.... I went to her last week. And usually when I go to a sports physiotherapist or the osteopath I'll be getting spasms and my body will be shaking like my arms and different areas But last week she worked on... my head and the spasms just totally stopped for 10-15 minutes. It was very good.

> I did bioenergetics recently and it sort of turned into primal screaming. I came home and I was exhausted. I let the shaking happen and noises came out of me. It got my energy flowing again...I took a personal development course last year called Insight...there were a lot of closed eye emotional processes. I shook a lot when we did that. I experienced a lot of energy coming down to me. For 5 days after, I did not feel like my normal self from before, but I was not sure if I was sick anymore. On the first day, I thought I should leave because I did not think I would make it. And I got healed, whether it is a spiritual healing, I do not know. There might be a psychological element and in a case like that, I would have had a chance for emotional release, so if there is some unconscious element, maybe there was some extra-personal element.

Most could not pursue these therapies regularly because of their costs. Instead, they followed the therapies for a while, stopped, and returned when they felt a specific need. Several sufferers were impressed with the fact that, unlike their regular doctors, these therapists called periodically to find out how they were managing.

Are CFS Sufferers "Doctor Shoppers"?

What started off as an ordinary consultation for diagnosis and treatment became an extraordinary journey that changed the lives of CFS sufferers. In the early days, sufferers and doctors agreed on the definition of the problem. But when the illness did not resolve, many doctors shifted from definitions that sufferers found acceptable to those they found pejorative. These discredited sufferers expanded the purpose of help seeking to include not only diagnosis and treatment but validation of their illness. In their search for validation, they used health care resources intensively and extensively. This pattern of use probably contributes to the image of CFS sufferers as people who use a disproportionate share of health care resources relative to the gravity of their condition. Indeed, CFS sufferers are often labeled "doctor shoppers". Such a characterization obscures the provider driven

nature of much of the CFS sufferer's use of health resources and structural features of the Canadian health care system that facilitate such use. Thus CFS sufferers' pattern of help seeking in this phase warrants a closer examination.

Without a doubt, worsening distress from symptoms and repeated unacceptable diagnoses were the major reasons why sufferers continued seeking medical help. But structural elements of the Canadian health care system also contributed to sufferers' high use of resources. This publicly funded system allows users unimpeded access to some doctors, and restricted access to others as well as to medical tests. Individuals may consult primary care physicians, such as general practitioners, unrestrained by geography, finances, or systemic gate keeping. The lay referral system often plays the largest part in finding these doctors. However, the health care system designates primary care physicians as gatekeepers to specialists. Thus, when specialists are involved, the professional referral system plays a significant role in the number of doctors that an individual sees. A few sufferers reported breaching their general practitioner's gate keeping role and successfully consulting several specialists directly. Under the Canadian system, specialists usually send patients back to their general practitioners once they have completed their investigations. But they may refer patients whose problems they cannot solve to other specialists and thus contribute to the number of doctors seen.

Theoretically then, sufferers control the use of health care resources only at the point of consulting a general practitioner. Doctors on the other hand, control access to specialists and to medical testing. Sufferers' reports consistently suggested that on average, they saw as many doctors through professional referrals as they did on their own initiative. And they admitted to consulting from one doctor to estimates of more than one hundred, although not all were seen in the prediagnostic period. These findings suggest there is truth to the charge that CFS sufferers use considerable health resources. But they also suggest that the health care system and professionals contribute to much of that use through unrestrained access at the level of primary care, and through referrals, and testing.

Part of the reason for seeing so many doctors was that neither specialists nor general practitioners were initially looking for CFS. But even if they were, sufferers still face a high probability of seeing at least a few different doctors since CFS is a diagnosis of exclusion.

> At that point they were not looking for Chronic Fatigue. They were looking for some kind of infectious disease...They were not trying to understand the problem. That was not their mandate. They were told to put me through a bunch of blood tests and make sure that I did not have AIDS or something like that....Chronic Fatigue is a diagnosis of elimination. That is why it takes years to find it. You have to go through everyone. When you do not have an infectious disease, you do not have AIDS and you do not have cancer, you have Chronic Fatigue or the Epstein-Barr virus.

A final factor to examine as a possible contribution to extensive help seeking in the pre-diagnostic phase is the relatively long period between the onset of distressing symptoms and a diagnosis of CFS. Among sufferers in this study, diagnosis took from several months to nineteen years. But it was not simply a case of having ample time to pursue doctors for symptoms that had no appropriate labels. The length of time till diagnosis was not a reliable predictor of the number of doctors consulted. In fact, most people who waited more than five years for a diagnosis consulted only a few doctors. In all but one of these cases, symptoms began between 1974-1980, well before chronic EBV or ME were widely used diagnoses. These sufferers did not pursue more doctors because they were confident that their doctors were knowledgeable and were doing all that was possible. Or they accepted plausible alternate diagnoses related to accidents, neurological disorders, or depression.

On the other hand, several people who were diagnosed within a year and a half saw a large number of doctors in the prediagnostic period. In all but one case, their symptoms began in the late 1980s and early 1990s. Although none reported more than a passing familiarity with CFS, usually just prior to diagnosis, a stronger consumerist orientation towards health care in the late 1980s and higher expectations of medicine's abilities to provide answers, may have played a role in the extent of their help seeking.

After diagnosis, some sufferers again embarked on another round of help seeking for the purpose of finding treatment and supportive doctors that they could rely on over

time. During this period, some expanded their search to alternative therapies, driven by desperation and by disillusionment with the medical establishment. Eventually most found caring doctors, but in general, they would never again regard the medical system as they did before their illness. Then, they had naive expectations of doctors and medicine. Now they have seen the limits of modern medicine, conflicts within the profession, and the willingness of doctors to dismiss patients. But they also discovered their own power. They were largely educated people who could, and did, read the same medical journals as physicians. Although they did not have the training and experience to interpret all that they read in the same way as doctors, they were not afraid to question, challenge or educate doctors. Indeed some felt it was their duty to do so. Their experiences have left them wary of future encounters with doctors. But it also prepared them to voice their disagreements, to assert their needs, to screen potential doctors, and to leave the practice of doctors who they found offensive.

Perhaps the key feature of sufferers' experiences with doctors was the way in which doctors defined sufferers' problem. Medical definitions have real consequences to sufferers because of doctors' cultural authority to define illness. Their definitions can affect sufferers' self esteem and identity, their social and familial relationships, and their ability to collect disability compensation. The next section shows how the confluence of doctors' and insurers' definitions affected sufferers who sought disability compensation.

Seeking Disability Compensation

Eligible sufferers applied for disability benefits when they could no longer work. Some were eligible for benefits from private insurance plans, government programs, or both[4]. For example, government unemployment insurance might pay the first few months

[4]Seventeen of the forty two sufferers were receiving benefits at time of the interviews, or had done so in the past. Benefits were paid, wholly or in part, by eight private insurance companies and the federal and Québec government

of short term disability, then private insurance plans would take over. Or private insurance might pay during the elimination period which typically lasts for one or two years. But eligible sufferers would have to apply for the Canada or Québec disability pension plans if they moved beyond the elimination period to long term disability. Both governments and companies would then adjust their payments to take account of the other's contribution.

At first, sufferers considered disability payments as a temporary means of financial support while they recovered. They felt entitled to benefits that they had paid for through government programs or to those purchased by their employers for workers' vocational disability. But the majority of sufferers found that at some point insurers disputed the entitlement. The major difficulties arose at the time of application and during the elimination period. These conflicts left many sufferers feeling intimidated and humiliated. Even the few who were satisfied overall with the treatment of their claims, recounted specific irritants and times when they felt they were treated disrespectfully.

Applying for Disability

During the application process, two major concerns surfaced for sufferers: how should their underlying condition be labeled and how should they handle rejected claims? The question of the label was more salient for claims filed from the late 1980s on. By this time, CFS was a more widely used diagnosis and anecdotes about insurers' negative responses to CFS disability claims were in common circulation. Some sufferers were alerted to problems of applying for disability based on CFS by their doctors who suggested

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disability pension plans. Two more people had recently made their initial applications for benefits and were awaiting the results. The others had either not applied or were not eligible because they had been part time workers, students, housewives, or self employed in technical trades.

alternative, though not unrelated, labels. Some sufferers were also advised to agree to rehabilitation to increase the odds of a favorable review. [5]

The label of the underlying condition was of less concern to sufferers who claimed disability in the mid seventies to early eighties. For these sufferers, the controversies about CFS were yet to come. Instead of CFS, their claims listed the cause of disability as chronic Epstein Barr syndrome, post viral fatigue, hepatitis B, various short term viral illnesses, and accident-related injuries. As long as no one questioned the label, some of these early claimants were content to leave the original causes cited for their disability undisturbed. Others from this early group revealed a strong desire to have their files reflect CFS as the true cause of their disability. But they have repressed the urge for fear they might lose benefits if their files were reopened. However, the label has become more of an issue for some early claimants whose doctors have updated the cause of disability to CFS in their progress reports to insurers. Some sufferers affected by this change have expressed considerable anxiety and worry about possible repercussions.

Inevitably, some claims were rejected. The first recourse was to appeal the decision. If the appeal was unsuccessful, sufferers could litigate. Appeals generally involved assessments by independent medical examiners (IMEs) of the insurer's choosing. To their great satisfaction, some sufferers had their disability confirmed by highly respected IMEs.

> The biggest mistake they ever made was sending me to Dr._____. It backfired....The first visit was quite long, it lasted almost 2 hours with a complete physical exam. Then he sent me to the lab and they took 16 tubes of blood. It was a process of elimination, he was looking for everything, viruses, lupus, multiple sclerosis...Then I came back and I had another follow-up visit 2 months later. I spent 45 minutes with him and [had] another exam, and more blood work. These were immune assays. It took about another 3 months, because many things had to be cultured and that takes time. Then I went back, and he did not give me other results but he said "you have post infectious neuromyasthenia or Chronic Fatigue Syndrome...you are quite ill and I am going to write a very strong letter to the insurance company."

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[5] These reports give some credence to insurers' claims that doctors are sophisticated in filling out forms to optimize their patients' chances of obtaining policies and benefits.

Others were not so fortunate. They often had to borrow money to sue their insurance companies and to maintain themselves financially while they awaited the outcome. But a successful suit might mean only a small retroactive lump sum, much of which would be used to pay back loans and legal fees.

> I got a lawyer. And it took a couple of years....When [the doctor] found the diagnosis then we went to litigation and they paid me my disability- retroactively- that was all gone anyways I had to pay back my brother, I had to pay the lawyer. I got really basically my monthly payments and that was nothing- no big salary or anything.

Nevertheless, victory made sufferers feel vindicated. They were able to recover some dignity lost by being dependent on family or social assistance. Successful litigation also taught sufferers that it was possible to win against insurers and it made them more willing to use this process again for benefit terminations that were perceived as unjust.

In the end, regardless of the labels used, all sufferers in the study who were covered by private or government plans received disability payments for a period of time and many still continue to do so. Yet the perception persists that insurance companies do not really believe in CFS. Sufferers are convinced that insurers stigmatize the condition and discriminate against claims which bear the label of CFS. This perception may be due in part to the frequency and type of demands for proof of disability that insurers requested.

The Cost of Benefits

An accepted claim bought sufferers a measure of financial independence. But the cost of benefits left some sufferers wondering if it was worth it. The steady stream of verification rituals that insurers use to justify the decision to pay, kept sufferers constantly on edge. The relentless flow of forms, medical follow up, independent medical examinations, together with delayed payments and surveillance, slowly curtailed sufferers' freedom to move, stole their sense of privacy, and whittled away at their self esteem.

Within a matter of months after payments began, sufferers felt inundated with paper work. It seemed to them that every month or so, they had to fill out forms declaring they had not gone back to work. A few who tried to return to part time work, felt harassed by monthly forms that asked: "How many hours can I return now? Could I do some other work?" These part-time workers, and others, contended that insurers' constant demands were not conducive to recovery.

Toward the end of the elimination period, some sufferers were asked to complete daily logs or other vocational rehabilitation assessment forms, which reflected a new practice by a few companies. Sufferers were generally suspicious of these new demands and wondered whether they should comply.

> I have now a form for me to tell them what I do from Monday to Thursday and he [sufferers' lawyer] said "its ridiculous" and I said, "I know its ridiculous", but that's for him to speak to them about it... I could fill it out and say what I do. I don't know what it is that they want, I haven't heard anything lately.

> I have received a vocational rehabilitation questionnaire recently, which I have not filled out. I am going to talk to a doctor about that. If that is a red herring and they want to pull me into something...They also have agreed to cover me as long as I see a psychiatrist and again, I've told the doctor "I have as much to say to a psychiatrist as I would a cardiologist". It's irrelevant, but anyway they have not followed up on that. I have the referral to see the psychiatrist, but until they get on my back again...

The most upsetting correspondence were letters which threatened to cut off benefits. Single people who lived alone felt desperate when they received such letters. One woman said: "I have to have a roof over my head. I can't go and live on the street. Plus, I know in myself that I am not fully recovered". But these letters inflicted extreme misery on people who were family breadwinners. One single parent recalled:

> The first three, four months they left me alone and then they started. Every month I'd get a letter.....if you get a letter saying that they are going to review the case or cut you off, they don't think you have it....Every time I got a letter from them saying they were going to cut me off, or they wanted more information, I'd go and see [my doctor] and say what do I do? He said don't worry about it, I'll take care of it, he took care of it and the cheques kept on coming...I never had a battle with them. I never had any personal contact with them. You get the letters and they are upsetting, you can't sleep for nights before you see Dr._____.. What am I going to do, if I don't get paid? I knew at the time it would be very difficult for me to work, because at the beginning I wasn't having any good days at all.

The flow of correspondence made sufferers feel that they were constantly being challenged to prove that they deserved benefits to which they felt entitled. Moreover, written communication effectively insulated insurers from the give and take of conversation that might have helped sufferers to make their case. Many sufferers had never talked directly to someone at their insurance company. But a few telephoned to clarify issues or to vent their frustration at not being believed.

> I called her up and shouted at her, "I am not lying, I am not faking OK?" I even said to her, "you can come yourself, come stay with me for a week you'll see, you'll understand!" and its almost like I always have to prove that I am telling the truth.

However, dialogue was a two edged sword. On the one hand, a sufferer might glean information that he or she believed was not normally available to claimants.

> I think they have very specific guidelines and they don't listen to anything else, I didn't know this, I think they have their own private guidelines [about] whether a claim is acceptable or not. I got this much out of the person on the phone, because I was crying. It was devastating for me. My husband is not rich and we need- with me working we are cutting right, with me not working, we're just, you know....I got on the phone and I got all emotional, and so the person I spoke to let me know a bit more, but I felt she was speaking to me almost in secret like she shouldn't be telling me...

On the other hand, sufferers might also reveal information that could be used against them later. In a subsequent conversation, this sufferer asked the hypothetical question: how would the company respond if the government disability programs to which she was required to apply, refused the claim of CFS?

> She said, "well did you get an answer?" and I said "no I didn't ...and I asked what would happen if the government refused me?" "Well, she said, "we have the same definition that they do. So if they refuse you, well, I hate to tell you this but why should we accept you?" I said "well are you aware that they have been refusing most, or almost all of the cases I have known with CFS, is that fair?". Now I was speaking innocently..., she held this in memory when I called her back, she says "Well you told me yourself that the government doesn't accept people with your illness, why is our company supposed to?". At this point, I started becoming paranoid, I was scared of even talking to them, because whatever I was saying was being used against me after.

Regular Medical Follow-up

Approximately every three to six months sufferers were asked to supply a follow up report from their regular doctors. Some learnt the hard way that insurers expected lengthy medical reports with explicit statements of their inability to work. Their doctors had

made the mistake of noting a slight improvement without specifying that sufferers remained vocationally disabled. Sufferers felt that such omissions put them at a disadvantage. They thought the word "improvement" was a cue for insurers to demand further information, an IME assessment, or to threaten benefit termination. They found themselves wondering whether their physicians were sufficiently sophisticated in the art of filling out insurance reports to provide the content and length that would ensure continued benefits.

Some discovered too late that although insurers might request physician reports only every three to six months, they expected more frequent follow up. However, insurers did not specify the frequency of follow up, but left it to doctors to decide. But they did use doctors' decisions on the frequency of follow up to judge the severity of illness and therefore disability.

> We are in a system where we are overspending on medical tests and Dr.____ is very conscious. I said: "is there nothing else?", and he said to me: "well, we've done everything what is there left to do?"... you have to understand that in three years...it was about [the only] 8 months where I had no tests done to me, no poking, no probing it was the first [time] where my doctor said, "go home, get well I will see you every 4 months" and this didn't work in my favor They said that every 4 months was not enough. I was not very ill, if my doctor said he only needed to see me every 4 months.

Situations like these led sufferers to conclude that insurers have hidden guidelines known only to themselves. They failed to see the point of more frequent follow up since there are neither diagnostic markers nor effective treatments for CFS.

Some were shocked to realize how little status their doctors held vis-a-vis insurers. Their regular doctors had to conduct follow up assessments and fill out forms, yet sufferers could be asked to see IMEs at any time. They found it perverse that a stranger would be better able to assess their abilities than someone who had known them before they became ill. Other sufferers were impressed with the stance of their doctors who refused to be put off by administrative personnel and insisted on communicating with the medical directors of companies. Although dialogue between doctors often resolved disputes in favor of the sufferer, it did not eliminate requests for sufferers to see IMEs.

Independent Medical Examiners

Sufferers could be sent to IMEs before their applications were accepted or at any time during the elimination period. Generally the independent medical examination involved at least one consultation with a psychiatrist and possibly with other specialists. Over the length of a claim, sufferers could undergo many such examinations. Companies made it very clear that if sufferers did not appear for a requested IME assessment, they did not stand a chance of being granted or maintaining their benefits. Sufferers endured IME assessments only because they were critical to insurers' decisions to pay disability benefits. If there was one word that sufferers repeatedly used to characterize these consultations it was "unprofessional".

Sufferers regarded IMEs as "unprofessional" for a number of reasons. First, some sufferers found that IMEs were unprepared for the examination. Then sufferers had to sit while "he read the chart in front of me". Second, some sufferers believed that IMEs were biased in favor of insurers. The examination was merely a formality to confirm insurers' hypotheses. They did not think it was professional for IMEs to deceive claimants into thinking otherwise. Third, some questioned the professional ethics of doctors who withheld assessments from sufferers that could be used to terminate benefits. To learn the results of the assessment, sufferers had to make a formal request to the company under the new Access to Information Act[6]..

> What I found negative in the experience was not the interaction, but that fact that these doctors cannot even tell you what they think is going on as you sit there. They report to the insurance company, not to you. So, even if they had something, it is totally a one directional dialogue. I

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[6] In January 1994- *the act respecting the protection of personal information in the private sector*- was passed into law. On the one hand, it aims to ensure the confidentiality of all personal information recorded in the files of private corporations in Québec and on the other, it allows individuals to have access to their files under specific conditions. The individual may have access free of charge, but transcripts require a small fee. The person may have information corrected and information not authorized by law deleted- since only personal information necessary to the purpose of a file may be recorded therein. Corporations must inform the public of where files may be accessed as well as the methods by which this may be done. (The Journal-vol 1 number 4 mar/apr 1994- supplement to L'infirmière du Québec p.4)

> spill it all out and they pick up the pieces to confirm the theory that the insurance company needs...Basically the interview was deceptive because they say "tell me everything" and at the end they say "I can't tell you, you will see it in my report". You never see the full report unless you request it as I did, but they are not helpful. It is sort of like a partnership game, and they are in partnership with the insurance company. Hopefully, your doctors are in partnership with you for your health.

> It was a joke- he [IME] he didn't ask me anything about how life was.. He concentrated on just a few things from the past and then he examined me...and at the end he said to me "Well since you've been married have you been feeling better?" And I said, "no". And he turned his back and once I was dressed he said to me "you can go now". And that was it. And I said, "aren't you going to give me an idea of what you think" and he said "I am not allowed. That's between me and the insurance company, that's none of your business". So I don't know what this guy wrote. Its the first time that I have gone to an expert and truly, truly felt that it was a setup. This man was not professional... before I left I said "can I ask do you see a lot of patients like me what are the results?" and he said "Aw don't worry, you're not gonna die". And shoved me out the door and that was it.

A few IMEs stepped outside the rigid role relationship with companies that seemed to be the norm, and gave grateful sufferers brief feedback from the examinations.

> By law we do not have the right to it [results of examination] Dr. _____was very generous, his office sent me a very brief form of some of my bloodwork, and the actual diagnosis, but it was very brief. That was sent to my doctor and I have been very fortunate.

> The only one that was probably more competent was the one ...who, when he made his report, noted the fibromyalgia for my physicians.

But even some of these doctors could make the visit unpleasant in other ways.

> He...asked me if he could teach 2 of his interns, if they could listen to my mitral valve prolapse. In the name of science, I let that go. He is the one who actually gave the name to fibromyalgia. No one had actually done it until I had said in passing that I ache all the time... He picked up on that. What I did resent is was that in doing his fibromyalgia test, he took his pen and circled the various spots on my body, so I came home tattooed, which I think is ethically invasive. ...He shocked me as he said "this is not in your head, you have..." Then having tattooed me, he went into fibromyalgia. He thought that it was quite uncanny that he would press on the same spot twice and I would say "ouch". He was into confirming, I guess I had not...realize[d] that people do not believe it [CFS] is a disease... he took the symptom...calling it fibromyalgia and then left it at that, instead of taking it further to Chronic Fatigue.

Fourth, sufferers felt they were treated unprofessionally when IMEs trivialized their condition by implying it was linked to their single marital status, dismissing it because it was not life threatening, and by making facile suggestions for treatments. One sufferer described an IME visit in which she was given 'the walking cure'.

> In his office in December of 1992, he said "get up and walk, get the cobwebs out". This guy was giving me the 'walking cure' for fibromyalgia or Chronic Fatigue. Basically these are the kind of doctors who think you are like a horse and if you get on your feet, you will be better

Finally, some sufferers regarded IMEs as unprofessional when they were openly insulting or performed perfunctory or seemingly irrelevant examinations. The most egregious example of these aspects of unprofessional behavior was reported in the following account:

> He was very difficult...very insulting, he not only insulted me and my family, he insulted my parents and Dr_____. The only reason I put up with it was because, as you well know, if the insurance company is paying you benefits and they say you have to go see someone, if you don't see that person., then your benefits get cut off because you are not being cooperative. So I was extremely cooperative by putting up with this for two hours and twenty minutes. I'd say "Dr.____., after doing many tests, has come up with the diagnosis of Epstein-Barr" and he said "well then, he does not know what he is doing". When he asked me what I worked at,... He went on a real tirade for about ten minutes [about her profession]...And then when he was examining me, which he spent exactly seven minutes out of the two hours and twenty [minutes] he said "you have 'knock knees'...back when you were young, your parents would not have cared enough to do anything about it anyway"...[he said] he didn't know why my family put up with me and if he had somebody in his family like that, he'd make sure that they were put somewhere. He was very unprofessional...I had a hemorrhage in my eye... and he was fascinated by that...and when he went to examine me, two thirds of the time was spent looking into my eye and... and he wrote to them and said they definitely should have a report on this, because this was a severe disability. He considered my eye a severe disability, but he didn't think that what I had would last long. Not to worry, it probably was nothing. I had only been sick at this point, for about three years...

Sufferers' recourse against this sort of behavior was to report IMEs to the insurance company, the College of Physicians and Surgeons, or both. Some sufferers made the initial inquiries and reports but did not follow through. They were too afraid of possible repercussions. Interestingly, Woodward (1993) found that doctors in the government medico-legal system were more accepting of CFS than general practitioners.

Surveillance

The paper work, follow up visits to doctors, and IME examinations were constant reminders to sufferers that they were not believed. But surveillance sent the most telling message: sufferers were suspected of fraud. Of course, sufferers were not informed of surveillance. But many suspected they were being monitored. Some of those who feared they might be under surveillance became virtual recluses. Those who verified that they had been under surveillance felt violated.

Fear of surveillance effectively deterred some sufferers from traveling outside the city limits. They felt like hostages. They believed that if the company tried to contact them

and could not do so, that would provide grounds for terminating benefits. Their feelings of restricted freedom of movement could also impact on their families around issues such as vacations.

> I have been ill for three and a half years. I have been within these four walls...I'm scared to even go away... in case they contact me to see an expert, This is three and a half years. I have not taken vacation. I don't feel well enough to go anywhere. But even if I should... I am not comfortable because I am always on strings that someone will contact me to be sent to a medical examination so I can get some money from these people... They don't allow you to get out. They don't allow you to just get well. They are putting one crowbar after another, one obstacle after another... Just when I start feeling a little secure and say to myself "Okay, now I can concentrate on getting well" something happens with the insurance company you know. It's a letter... another form to sign and another doctor to see... I am at the point, I'll be honest with you, I've been very sick all summer and I'm really thinking of taking the month of October... I just need to get away and to hell with them....I may be wrong, but I think they would hold it against me if I went away and they tried to contact me. In their mind's eye they would say "aha, she's sick, but she is not available. Where is she?". ...I am made to feel that if I am not lying in bed at home, I am not sick.

One sufferer became distraught while recounting what she had discovered about being under surveillance. She felt devastated by the methods used, the reach of the scrutiny, and the recommendation that surveillance be continued. The monitoring was carried out by telephone calls, parked cars, and video cameras. She suddenly understood the wrong numbers and no voices at the other end of the line when she answered the phone. But she felt they had gone well beyond the pale when they logged information on the whereabouts of her husband and children.

Payment Problems

The last major problem of the elimination period was the actual payments. Several sufferers reported delays, late cheques, and a sense that insurers were trying to stall on payments. Some sufferers whose claims were held up, had tried to go back to work on a part time basis. By the time their claims came through, it was based on their part time salary of a few months, rather than the full time salary that they had been earning for several years. These tactics left sufferers feeling that insurers would "do anything not to pay". The label "elimination period" seems apt in light of sufferers' accounts. Close to the end of this period, many noted more vigorous activity by the companies and in fact, some sufferers did not make it past this period into long term disability.

Once sufferers were accepted for long term disability however, there was usually a sharp drop in the amount of contact with insurers. These sufferers were asked for medical reports once a year or even once every two years. A small minority lost benefits after being on long term disability for a few years. And a few sufferers who had delayed applying to government insurance plans because they had not fully understood the relationship between these plans and private programs, had to repay the companies once the government accepted their claims. But for the most part they were left alone.

It should be said that some sufferers were satisfied with the way their claims had been handled overall. But even these sufferers had experienced difficulties with IMEs, delays in payments, and threatening letters. Most of these claims dated back to 1970s to mid 1980s and many showed objective evidence of an illness whether recognized as CFS or not. One such sufferer referred to herself as "blessed" because she had proof that she was ill. These few sufferers finally reached a stable agreement with companies, received regular payments, and were basically left alone. They had ready access to a high level of knowledge in the health, legal, and insurance fields. Some had been championed by their company doctors or companies in their efforts to obtain disability benefits.

By the time sufferers were interviewed, some were receiving long term disability, others were in the process of applying, and a few had lost their benefits at the end of the elimination period. Some of these sufferers had given up and gone back to work because it was "psychologically easier" than fighting the companies. But physically it was a daily struggle in energy management. These sufferers felt they had to settle for positions below their potential just to remain in the workforce. Even in these lower level positions, they felt vulnerable. They believed they were not competing against colleagues on a level playing field. Other sufferers whose benefits were terminated came to a settlement with their insurance companies, while a few were in the process of litigation.

Disability payments allowed sufferers to maintain financial independence and justify their occupancy in the sick role since a medically valid illness or injury is a necessary,

though not sufficient, condition for insurers to pay benefits. For this reason, the disability system has the potential to be a second, albeit indirect, source of legitimating illness. But the experiences of CFS sufferers suggest that, at best, only a tenuous relationship exists between insurers paying benefits and accepting CFS as a legitimate and disabling condition.

The Price of Unequal Power

Two factors put sufferers at a disadvantage in claiming compensation. First, many lacked the "know how" to negotiate the disability system. For example, some sufferers did not realize that the presentation of their case could increase the odds in their favor or raise warning flags to insurers. They naively assumed that their experiences would be enough to convince insurers of their claims. Others did not understand the relationship between government and private insurance and consequently delayed applications to government programs. Much to their surprise, they had to repay insurers when public benefits were approved. Moreover, sufferers expected the familiar model of the doctor-patient relationship, in which the doctor is the patient's advocate, to apply to their visits with IMEs. But IMEs do not have a doctor-patient relationship with sufferers. Instead, they have a client-consultant relationship with insurance companies. Lacking prior experience, sufferers had no patterned ways of interacting with insurers or with doctors hired by companies. Instead, they responded ad hoc, using trial and error to gain 'know how' which sometimes came too late to help their own case.

Sufferers were at a second disadvantage because of the economic power that insurers held over them. A rejected claim could renew dependence on family sometimes to the point of adult children returning to their parents' homes after years of living away. The alternative was social assistance which, in fact, was the fate of several sufferers who had once earned a good income and had once received a viable level of income replacement

from disability compensation. The high stakes made sufferers vulnerable. They felt they had little choice but to "put up" with disrespectful treatment from IMEs, constant demands for proof of disability, and delays in payment. Many understood insurers' position in trying to eliminate fraud, but they resented implications that linked them to such activities.

Cognizant of the unequal power relationship, many sufferers concluded that they had only limited recourse to contest rejections of their claims. They could appeal or litigate and some did so successfully. However, others found litigation daunting. In part, they hesitated because of the cost and in part they were intimidated by the perceived might of insurance companies. One sufferer recounted rumors that a company had a battery of twenty seven lawyers devoted to CFS cases. Their awareness of the unequal power relationship between themselves and insurers not only limited their options but exacerbated feelings of being harassed, beleaguered, and disparaged.

Sufferers' accounts showed that at some point all had encountered negative attitudes in their bid for compensation. They were nearly unanimous in their condemnation of IMEs. Their direct experience with symptoms and inability to function made them feel justified in claiming disability. But they were constantly being challenged about the truth of their statements. In the end, many were left with feelings of ambiguity about the experience and negative perceptions of insurers. One sufferer appealing the termination of long term benefits best expressed the overall feelings of many fellow claimants:

> Part of me wants the claim accepted because I need the money. It's not a lot of money, but it's enough to help pay for treatments. Holistic medicines are expensive and they are the only thing that help me, give me a certain amount of energy or at least ability to look after myself, my physical self. They do good. If I have no money, I can't get help. So I need the money for that. On the other hand, there's part of me that almost hopes that they don't come through. I know they are going to make my life miserable, they are going to make my life hell.

Searching for Validation in Social Networks

The two previous sections showed that sufferers needed official legitimation of their illness. But sufferers also wanted their claims of illness and related role disability to be

accepted by their family and friends. The mix of beliefs and reactions that they encountered from significant others posed several challenges for sufferers. They had to find ways to maintain the support of those who believed them and they had to find ways to deal with negative reactions from people with whom they had social ties.

Making Sense of Others' Belief and Disbelief

Sufferers surmised that some family members and friends believed them because "they knew me before I was ill". They felt these people would not judge them as being malingerers or depressed. One sufferer for example, reported that when a doctor suggested she might be depressed as a result of a lengthy infectious illness, her husband intervened and said: "With all due respect Dr.____, there's something you don't know, she's not that kind of girl". Other sufferers suggested that it was seeing the dramatic differences in their pre-illness and later levels of functioning that convinced family and friends to believe them.

> I was a very active person, whether its professionally, sports, culture, hobbies...At first [family and friends] said "studying is hard, its sixty or eighty hours a week, so it's understandable that you are tired". They did not realize it is a disease...My illness happened after I had left home...they just saw me once a month, they thought I was not getting better, I was deteriorating...they [saw] the difference. They realized "my God, she really is sick"

However, sufferers were not believed by everyone who knew them well. They were told that they were lazy or that their illness was "all in the head" by some family members and friends. Sufferers offered several explanations for these negative evaluations. Some openly stated that their families were dysfunctional and had long standing histories of not supporting their members. Some blamed doctors for influencing family beliefs. In a few cases, doctors had privately consulted with family members to explore the possibility that sufferers were depressed- a fact which sufferers learnt about later. Other sufferers suggested that negative family reactions had their origins in the family's limited experience with illness or "old school ideas". They implied that these factors might have influenced

what the family recognized as illness or contributed to unrealistic beliefs about members' vulnerability. In these families, "illness without identifiable disease" might have been construed as faking or psychological disorder. By explaining family reactions in terms of dysfunctional dynamics, doctors' influence, family's experience with illness, and old fashioned ideas, sufferers downplayed their impact. In truth, such responses wounded sufferers and created intrafamilial strains. But in some cases, skepticism from family changed over time. One sufferer reported:

> My family has a big problem with it because we never really had much illness in my family and my father comes from the 'old school'. Initially they had a lot of problems with it but they have come around. My dad knows a few other people who have it, one was a doctor. That seemed to spark the light. They are pretty good about it now.

The circumstances that led to this family's change of opinion were interesting for what they suggested about stigmatization and legitimation of a contested illness. If the family's illness belief was that "illness without identifiable disease" represents faking or psychological disorder as I have suggested above, members may not have wanted to be associated with such character flaws. However, the character issue was effectively disposed of when a highly credible individual whom they knew personally admitted to having CFS. If a doctor could have CFS, then the family could accept that one of their own might also have this illness. This family's behavior accords with the view that a contested illness may derive some legitimacy from the social status of those it afflicts[7]. The situation is a telling commentary on one of the more negative consequences that CFS sufferers face from people important to them. Their character alone may not be sufficient to lend credibility to their claims. It may take the high status of outsiders with the illness for families to grant a previously denied validity to one of its own members.

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[7]The relationship between legitimacy and social status has been noted by Abbey and Garfinkel (1992), Greenberg (1990) in the case of neurasthenia in the nineteenth century and Figlio (1978) in the case of chlorosis. They argue that these contested illnesses lost legitimacy as diffused from the restricted zone of the higher social classes through to the lower social classes. Abbey and Garfinkel predict a similar fate awaits CFS.

Instead of sufferers' character, their appearance sometimes became the issue in being believed. Some observed that they were not believed because they did not look sick. One sufferer who did "not look sick" remembered being asked if he was drunk when he fell down at work. Another stopped telling friends that she was sick because of their reactions to her appearance. She discerned accusations of malingering in comments about how well she looked.

> [They say] "Oh but you look good". I look so damn good that people who used to know me 4 years ago, and haven't seen me since don't recognize me. No one ages that much in 4 years or changes that much in 4 years. I am not stupid, even though people think they are doing you a favor by telling you, you look good. But in our society "you look good" means you're probably faking and you want our sympathy but you don't look sick. This is my interpretation of it. Because I know what people say. I have been around people, I know what people say. They may not say it to your face, but just by their response you know what they are thinking.

At first sufferers tried to explain, but eventually, some became "tired of defending themselves" or found they "could not stand the judgments" and terminated the friendships.

The Importance of Being Believed

Being believed helped sufferers to retain a positive self image. It also helped them to request and receive needed instrumental support from family members. Sufferers who were believed received financial assistance, and help with daily chores, personal care, and child care responsibilities.

> my mother she is very supportive. She wants me to go for meals, or she will cook for me, bring food...My brothers are there for me when I need them. Even take care of the kids, and they support me in every thing...My youngest brother came to the conference in Albany[8] with me, so I think he understands it a lot more.

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[8]The Albany conference took place in Albany, New York in 1992. The proceeds of this conference were published in January 1994 in a special issue of Clinical Infectious Diseases. This conference included clinicians and researchers in basic medical sciences such as virology. It synthesized much of the knowledge of CFS to that time, including history, epidemiology, causes investigated, and treatments that had been tried. Several subjects in the present study attended this conference.

Help with household responsibilities allowed some sufferers to work outside the home since most of their energy could be channeled into the performance of a single role. Financial help allowed others to maintain themselves without resort to social assistance and to successfully challenge insurers.

Sufferers who were believed also received emotional support from family. They credited such support with allowing them to persevere in seeking a diagnosis, staving off suicidal depression, restoring perspective that inevitably slipped, and generally weathering trying times.

> I cannot imagine having a family...reject you and being able to survive. You go through a period of low chronic depression when you finally realize this is not something that is going to go away...I would think that this must be a dreadful time when people would even go through thoughts of suicide. I never thought of suicide but sometimes I would lay in bed and I would cry. When am I going to get better? What is wrong with me? And nobody can answer. Sometimes my husband could be very sympathetic and other times, he would say "enough, enough". So then I would have to think, "your whole world is not the center of everybody else's world, just watch how much you are complaining". I wasn't being criticized for complaining but you do have to be aware that just because you are sick, doesn't mean that everyone in the world should listen to your illness all the time. That is very important because you do tend to start to dwell on it if you allow yourself to.

If only one or two family members believed the sufferer, instrumental or emotional support could be fragile. One sufferer regarded her mother as "the only one who believed [her]". She had "disowned her [doubting] siblings" because they "stepped on me, pushed me, and scuffed me right out". When her mother died, she tried to forge links with other family members but was "given the cold shoulder". This rebuff effectively halted further attempts to establish family contacts and left a deep void in her support system.

Some sufferers who were not believed, received virtually no help from family, no matter how desperate they felt.

> I could not get out of my apartment, I did not have any strength. I found it very difficult. I talked with my family and they said "you are lazy, go back to work, there is nothing wrong with you, it's all in your head" and I found it very difficult to take care of myself.

One woman found it difficult to lift heavy objects such as groceries. When she tried to enlist help from her son, his "eyes glaze over, and he walks away. His response is 'oh no,

not again'". He has pointedly told her that he does not believe she needs the help that she requests.

A small number of sufferers concealed their illness from their families, which made both being believed and receiving support for being ill a non issue. By concealing their illness, CFS sufferers may deprive themselves of much needed support (Ware 1992). However, since there was something clearly wrong with sufferers, whether they admitted it or not, their strange unexplained behaviors could create severe intrafamilial strains. One young man who lived with his parents refused to tell them that he had CFS on the grounds that they would not understand. Ignorant of the situation, but bewildered by his behavior, his parents have made many scathing comments about him lazing around. This sufferer became angry, brooding and irritable at home. He felt his parents' comments were unjustified since it was all he could do to keep a full-time job. However, he continues to live with his secret and the tensions it has caused.

Generally, sufferers did not expect the same kind or level of support from friends as they did from family. But being believed by friends was important because it is a prerequisite for preserving the relationship. And friends are an important means of social integration. During their worse periods, some CFS sufferers retreated into isolation and let friendships go. The phenomenon of "pulling in" that is, turning away from or sharply reducing social contacts, has been noted among people with a variety of chronic illnesses (Charmaz 1991). But in periods of remission, many sufferers craved the social connectedness that friends provide.

Friends also affirm that one is worth the trouble of being remembered, being included. But old friends also mirrored what sufferers had been like before becoming ill. That might have been a difficult reminder for some sufferers.

> I can't keep up to a lot of the occasions that ... recently, a couple of my girlfriends... [and I] wanted to go away for a few days...But ...with the rain and the cold, I just thought I'm really pushing it, I'm going to go away, we're going to stay up late yakking, I may not have a terribly comfortable bed and I'm just going to keep on and on, to keep up because these women are incredibly active...they both are in extremely good health. They're very loving and caring of me but they don't know how little I can really keep up in some ways. I can't go for a five mile walk

> in cold damp weather. I just pain terribly. So I started to feel stressed... Finally I said to myself, why are you doing this, they're close friends and then called them and said "can we delay this until the spring, when the weather is a little easier, November is a busy month..."

> My friends were moving up the corporate ladder and I had to give up everything. I was in bed for the first two years and that was very difficult. Unfortunately I had to learn the hard way to reprioritize what was important to me.

In sum, being believed by significant others legitimated sufferers' claims of illness and disability, earned them needed instrumental and emotional support, helped them to remain socially integrated, and affirmed their self worth.

Seeking Support for Role Change and Role Withdrawal

Many sufferers realized that being believed was not always enough to sustain instrumental and emotional support from others or to maintain social ties. They would also have to maintain some minimal, if unspecified, level of social involvement. In a study of women with breast cancer, Bloom and Kessler (1994) found a positive relationship between social involvement and perceived emotional support. Contact with others increases the availability of individuals to provide support (Bloom and Kessler 1994), but it also provides opportunities for mutual exchange (Minkler et al 1983) which may be critical to keeping relationships. Among CFS sufferers, the issue of exchange was particularly important in some roles.

Reactions to Claims of Work Disability

Sufferers who withdrew from work found support for their decision among family members who believed them. In many cases, this support has been unwavering over the months and years that the illness has lasted.

> My parents know me best. They see me pushing myself. They could see signs [of illness] before I did. When I gave up my job, they were so relieved. They have been great, very supportive. I talk to them everyday and if I don't sound so great, my mother knows. They will come over and help.

But with time, some previously sympathetic family members became less tolerant of sufferers' inability to return to some form of occupation or retraining.

The most negative responses to sufferers' withdrawal from work came from former colleagues who suggested sufferers were "crazy" or malingering. As offensive as these remarks were, many sufferers understood why they were made. They understood because "the stigmatized individual tends to hold the same beliefs about identity that we do...the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be" (Goffman 1963:7). Sufferers felt that before becoming ill, their reactions would have been similar to their colleagues because they too had worked even when ill and would not have been sympathetic to people claiming work disability.

> These are people who always worked. And I guess maybe I was like that too, you have your secure little job, you make a good salary you can afford this and that. They don't know what its like to be ill, aside from having a little cold or 'flu, during which most of us go into work because we want to show how strong we are...We all do that. I used to do that too and so you don't know what it is to lose everything- you've lost your job, to lose your self esteem, your health, and you can't do for yourself. At times, I have to wait for my husband to carry me to take a shower.... You can't tell these things to people.

Some sufferers thought that the name CFS compounded the problem since it hardly connotes a seriously debilitating condition that would warrant extended work absences. In this regard, one frustrated sufferer commented: "if I had to get something, why was it something with such a stupid name? It tends to make you want to say 'get up'".

<u>The Toll on Friendships</u>

As sufferers became increasingly unable to participate in activities or provide their usual level of support to others, many of their friends drifted away. Sufferers thought that both doubts about their illness and disability and the fact that "few people can tolerate that you can't keep up" led to loss of friends

> I read that we lose all our friends. If they do not drop us because they think we are 'lazy or crazy', they are just not patient enough because we cannot go out with them and join them. Or, we drop them because they keep putting us down.

Fearing social isolation, some sufferers tried to normalize the situation and carry on even while feeling pushed beyond their limits. Some concealed their illness from friends. Others were more open, but they still tried to keep commitments even when feeling ill, especially if there was an outlay of money or long planning involved.

> On cheap Tuesdays my husband, or this friend of mine who sees me frequently during the week, will say come we will go to a movie, I will buy tickets ahead of time to make sure we go in. And sometimes because I don't want to lose that money, or for her to lose that money, I force myself...Don't ask me what the movie was about, I won't remember. Even though I am not feeling well, I will go out but I won't enjoy it.

A few compromised by attending events or participating in activities for short periods only. They feared "if you stop and say you can't do it, you just get left out". Normalization shielded friendships from being tested by sufferers' inability to keep up.

Other sufferers tried to find a tolerable balance between normalization and retreat to the sick role. They came to this solution sometimes after years of trying to meet social obligations and paying the price in worsening symptoms and days of debilitation which they resented. Initially, sufferers were afraid to cancel commitments thinking that their friends would not understand the unpredictability of symptoms or the discrepancy between looking well and not being able to perform normally. Indeed some friends did not understand these aspects of the illness.

> They [friends] leave their whole day [open].... Sometimes when they see me hurting or very tired, then they say "ah! you are sick". In that period when I try to be cheerful, they say "oh you are normal, let's go jogging". They cannot get it into their heads, but then I cannot get it into my head, so how can I expect them to know the extent of what I can and cannot do.

To their relief however, sufferers found that some friends made accommodations that allowed the friendship to continue even if they did not understand all aspects of the illness.

Instead of keeping near normal routines, or finding a tolerable balance between their own and others' needs, some sufferers became social isolates. They variously explained this decision as due to lack of energy, a stable coping style, or a pre-emptive move to avoid possible rejection by friends. Some admitted they might be received more sympathetically than they imagined, but were unwilling to take the chance. At first, these sufferers were

still contacted by friends. But some refused to answer the phone or refused all invitations until friends stopped calling because "there wasn't any point". One woman, who did not want to explain her unavailability, kept her answering machine on at all times. "You cannot say you are in bed twenty four hours a day". If she returned calls, "I would lie and say I was out. I was so ashamed, I would lie. I knew they knew I was lying, but that was it". Her comments suggest that she did not think friends would believe she was that ill, and she could not bring herself to tell them that she could not keep up.

Other sufferers went into partial retreat. They let social ties go so that they could devote all their energies to a major role such as work. But individual friends did not always know or understand that they had not been singled out for slights and ended the friendship. Ruptured friendships based on these types of misunderstandings led many sufferers to comment, as much with anger as with regret, that having CFS had revealed their true friends.

> I've lost two friends. They are a couple. I guess it goes back to being healthy. We had a good relationship. I have been to dinner at their place on a few occasions. At that time, they did not have a car, I was driving them here and there, no problem...[then] I got sick. Through the first five months of my illness I worked and I just did not have any time or energy for anyone, or any time left or strength for myself at the end of the day. I got wind that he was upset because I had gone to their place for dinner so many times and...I had never reciprocated. Truth be known, during that time, I did not have anybody over, period. I went home and I just did nothing. And he never understood that and we never really totally reconciled those differences. It came up again recently and I said "that's it, if he can't understand what I am going through, then to hell with him"... I guess you could say he wasn't a real friend if he couldn't have an open mind to it in the first place.

Many sufferers came to a point when they wanted to increase their now diminished social circle and make new friends. But several revealed that they had become insecure about their social skills and they worried about strangers' reactions to CFS. As a result, some sufferers restricted their search for new friends to "safe" circles such as CFS support groups or church groups, where acceptance was more likely.

> People will associate with you, but don't want to become permanently associated with you...I went to a church group because they give me help...they didn't understand CFS but they took other things that were affecting my life, like being alone so much, being separated from my family, living alone which are important...It is very hard to find anyone who is accepting this illness...I

> find a lot of [sufferers] are very hesitant to people about this, because of the publicity it has had about being a psychiatric or mental illness.

Unmarried sufferers presented a special case of trying to make new social contacts through dating. Some simply refused to entertain the possibility of romantic relationships because of their condition. Others, clearly worried about the reactions of potential dates, admitted it was very difficult to make the first approach. A few women tried to solve the problem of approach by using the telephone dating lines. But even through this anonymous medium, self presentation became a source of anxiety. Some worried about giving impressions of being disoriented in conversations, about describing their appearance if they were overweight, and about disclosing why they were not working. One woman wondered how a date would react to seeing her arrive in a transport bus for the disabled. These women also doubted their ability to form accurate impressions of potential dates over the telephone. Some wondered whether they might be easy prey for depraved or ill intentioned men because they might not pick up the cues and warning signals that would help them to decide whether a caller was an appropriate date.

> I started to date for the first time in ten years.. I had no human contact for all those years, not even a hug...when I talk to people on the date lines -they are not appropriate but they are the only people I can talk to and I need to talk- every now and then I give in. When they ask what I look like and how much I weigh, and then they want to know why I am not working... I am embarrassed.

> Sure I would like to go on a date and find a guy and have a normal life. But because of this illness, we are slow mentally. This is a big city. Someone told me about the telephone personals (dating service) but talking on the phone makes me disoriented and then I get fluid in my lung. I would probably do myself in. I am not that quick mentally, unless I know through a friend that this person is safe...Number one, my muscles are weak and mentally... they could put anything past me. Eventually I get it, but it could be too late. That doesn't give me a lot of security to go out. And how would someone feel if I pulled up in a Wheel Trans bus?

Men who were actually in dating relationships had other problems. These relationships highlighted their past, their limitations, and their current feelings of insecurity.

> It's kind of made me a little bit more insecure about myself. A friend of mine said the other day -we were kind of seeing each other- and she said she'd be curious to see how I react to work and things like that, and what kind of guy I am when I am working. It kind of bothered me...that she was thinking that maybe I am a different person, because I am not working. Just generally, it makes me a little bit more insecure.

> Social relationships with women primarily... can be very embarrassing. People do not know who is contagious or not. If I say I have CFS, I am so used to the idea, but then I wonder what people will think of me...I am a smart person and intellectual life is important to me. I think certain aspects of intellectual sensitivity or acuteness are different from before. For me, it is my whole life and it is something I am very conscious of all the time...[CFS] changed my appearance very suddenly. I used to have cheeks. It bothers me...If you do not feel as sexually invigorated, it probably affects your self-worth. If you have cut back your activity so much, you stop thinking in terms of a scope of activity that would affect you. I had not been going out with someone for some time and all of a sudden I was. That is when I realized how limited I was. That led to many new feelings. Once you have been living at a low level and you try to do something normal, your ideas of self-worth come into play.

One man in a potentially serious relationship, tried to explain his limitations to his partner and felt crushed when she did not understand. He has resigned himself to the possibility that he might never marry and never have the family that he wanted. When disclosure results in social distancing, sufferers may become more wary of disclosing or entering new relationships for fear that rejection may be repeated. Fears of rejection, feelings of being different, of not being understood, of being seen as less desirable as dating partners are all elements of what it is to feel that one's identity is tainted, to feel that one is stigmatized.

Strains on Family Relationships

Having CFS affected sufferers' roles as parents, spouses, and simply as family members. Sufferers tried hardest to live up to their parenting role obligations. Several became emotional or cried when they spoke of how CFS had affected their parenting. It was deeply important to present themselves as strong role models and to provide a supportive emotional climate for their children. They did not want to be remembered as weak or sickly. To this end, one woman made sure that she never slept in the day time if her young son was home from school, no matter how great her fatigue. Other sufferers put priority on activities with their children. Most often, time together centered on sedentary activities such as homework, movies or board games. But some sufferers found creative ways to continue involvement in their children's physical activities. One man who could not play baseball with his son, took a course in coaching so that he could participate in a less strenuous way. But even with the best intentions, sufferers often fell short of their

goals. They found that younger children were not always tolerant when planned activities had to be canceled: "I say, 'I cannot go the park because I am sick'. Sometimes they say 'Oh, you are always sick'. Sometimes they understand". And they felt badly when older children worried about them or were forced to make radical lifestyle changes.

> I think the biggest aspect though was with my kids. They were very young, sixteen and seventeen. Our house was always filled with their friends and they had many activities [sports]. I was always a very active part,...All of a sudden, I had to drop out completely from everything. Life for them was very difficult... I always felt very bad that they literally had to change their whole lifestyle for a good two years. They could not have parties anymore. We had always encouraged that...At the beginning...I felt very guilty. That was the only time I felt guilty about being sick. I was depriving them of that but that was because that was so very important to me before getting ill, that they could have a home that was full of fun and laughter. But they adjusted to that. My daughter went away to university, she came back home, she was absolutely terrified that I had cancer and we were not telling her. They adjusted their lifestyle...We do a lot of things in different ways now... Playing cards, cribb tournaments, it's a different activity that we do now but it's still an involvement. As sick as I was, they still could do things with me. I have been very fortunate in that my husband and my kids have always been a very important part of everything. They have accepted it and we worked around it. The support I got was phenomenal.

With regards to their marital roles, several sufferers reported a number of changes. Some admitted that they had less frequent and less spontaneous sexual relations after becoming ill because " When you are too exhausted to get up in the morning, it is hard to be very affectionate and very loving". Others could no longer do tasks that facilitated a partner's career, including the organization of the couple's social life. Some wives felt they could no longer continue to do the cooking, cleaning, laundry and ironing that released their husbands from much of the day to day household work and personal maintenance. One man left his family "because of my illness, because I didn't think I was a human being anymore. I was unable to do normal functions". These changes in sufferers' spousal role activities created difficulties for their partners, but most couples eventually found ways to work out these issues. However, one sufferer's wife refused his request to return to the marital home.

While parental and spousal roles involve relationships with specific people, some sufferers spoke of playing more general roles in their families. For example, one woman

had been the mediator between her siblings and her parents. When she decided to relinquish this role because of her illness, reaction was swift.

> I was very much the mediator....sort of the voice to my parents. My parents would talk to me, then I would talk to my siblings. I stopped doing that to quite a degree now, because I had to work too hard and it was really detrimental to me...They didn't like it when I just stopped doing all of that liaison work. [my siblings] are both well and stronger than me...both are quite smart and they need to forge that relationship with our parents, I don't need to step in their territory. But everybody was comfortable with us that way. The patterns were set. It was... very scary for me to step back and not assume all the responsibility. I quickly had two siblings on my doorstep saying "why aren't you doing this anymore?" That was scary for me too, because what if they stopped liking me? But I was unwell enough that I knew I had to take care of me and they've come around, because underneath, we all love each other very much.

Finally, the valued family role that one sufferer occupied can only be guessed at from evocative comments suggesting the many expectations that were vested in him.

> It has been a very, very grave strain on my family. First because it has been very upsetting for them and also it has intruded on all of my familial relationships. They have not been able to depend on me in the way that they had become used to depending on me. I have not been the important module in my small family that I used to be. There has been a diminution in my ability to fulfill those relationships. Occasionally, when I feel a little better, a few hours of buoyancy comes out in my behavior and we are all sort of stunned and nostalgic for the person that I used to be.

Sufferers' accounts suggested that in most cases, support for their occupancy in the sick role, and therefore exemptions from their usual roles, was conditional. Freidson (1970) has argued that if Parsons (1951) was right, people with chronic illnesses should receive unconditional legitimation since they are not presumed to be responsible for their illness, and by definition they cannot get better and remove themselves from the sick role. However, Freidson (1970) observed that the chronically ill or permanently disabled, are in fact granted only conditional legitimation. They are expected to fulfill social roles to the extent possible. The experiences of CFS sufferers bears out this observation. They were expected to keep up some involvement in at least some social roles.

Keeping Long Term Support and Goodwill

Sufferers understood expectations to keep up and did not take it for granted that help would continue indefinitely. They realized that being believed was important to justify

requests for short term help. But for the longer term, keeping up and family goodwill or benevolence became critical. To preserve goodwill, sufferers carefully monitored family reactions and heeded feedback. When a family member reacted with exasperation for example, sufferers adjusted their behaviors. They used such reactions as a barometer of the toll that CFS was taking on others.

Other sufferers took a proactive approach to cultivate and preserve family goodwill. They solicited feedback so that they would know when they were in danger of going too far.

> I tell my son, "if you feel that I am being snappy or talking bad, just tell me". My wife will say "take it easy, it's not important, you should lie down for a half hour". Or she will cook something and I just cannot stand the sight of food. She will say "why are you eating it like you are eating your own flesh?" I guess I am very transparent these days. It is hard to hide. I have been very honest and open. I guess that has softened the impact. I say "I cannot go to the park because I am sick". Sometimes they say "oh you are always sick". Sometimes they understand.

Another way in which sufferers reduced the emotional toll of their illness on their families was to enter therapy so that they could unburden themselves to a professional helper. These paid, trained professionals cushioned families from having to absorb the pain, depression, and anger that often set in after sufferers were sick for a while.

Dependence on family goodwill made some sufferers insecure and guilty. Some ill spouses believed they had ruined their partner's lives and tried to mitigate the impact by contributing to the family income. This both reduced financial strains on the family and sufferers' total dependence on the goodwill of others. For example, some ill wives worked part time even at great physical cost, if their families needed the additional income. Others used their disability income replacement towards the family or to maintain themselves independently. Other ill wives worked not because the family needed the money but because they worried about the fragility of being dependent on their husbands' goodwill. They had seen the consequences to other sufferers whose marriages had failed and wanted to assure their own future. Some ill husbands assumed more household and child care responsibilities. In one case, this shift of responsibilities opened up new options for his wife.

> My wife is incredibly patient and understanding. But most of the people I know who have this are no longer married.... But I worked at that aspect in that I told my wife upfront what I was feeling and what I could not do. And what to expect...Also, when you are in pain 24 hours a day, it is hard to be smiling and positive all day long. I do snap. I am not as casual as I used to be and she has been very understanding. But we have taken advantage of the fact that... I am available at home. It has given her the opportunity to go back to [school].

Sufferers' accounts suggest that family goodwill might encompass believing sufferers or giving them the benefit of the doubt, tacit expectations of some level of role involvement on the part of sufferers, and a margin of tolerance to accommodate for sufferers' illness. Sufferers learned that family goodwill was a kind of capital that could be used up and not necessarily replenished. They also learnt that keeping family goodwill was an ongoing balancing act that required sensitivity to the amount support that could be requested, to the timing of such requests, and to ways of continuing to contribute to their families' functioning.

Friends and family could not provide official legitimation of illness in the way that doctors or insurers could. But they formed the context of sufferers' day to day lives. Their definitions of the problem and decisions to support sufferers over the long haul could make the difference between sufferers feeling they could carry on despite symptoms, unsympathetic doctors and insurers, or feeling that their lives were nearly unbearable. Friends and family were also important referent points for sufferers. Without their feedback, some sufferers did not realize how limited they had become. Other sufferers could not be certain of treatment effects without someone close to confirm their own observations.

Summary

This chapter has shown that CFS sufferers encountered both stigmatization and legitimation as they searched for answers about their distress and for acceptance of their claims of illness and disability. Although all found at least one supportive doctor, many also met doctors who disparaged and dismissed them. Negative reactions from doctors

contributed to extensive help seeking for which CFS sufferers are known. But structural features of the Canadian health care system facilitated sufferers' high use of medical care.

In the search for validation, sufferers' experiences with insurers seemed to be the most negative. Even when benefits were paid, the constant requests for proof of disability, disrespectful treatment from independent medical examiners, and surveillance made sufferers feel they were not believed. Their economic dependence on insurers and their perceptions of insurers' power to fend off litigation exacerbated feelings of vulnerability. Their inexperience in dealing with the disability compensation system put them at a further disadvantage relative to insurers. As to the reactions from family and friends, sufferers also found a mix of reactions. They lost friends and the support of some family members because of disbelief, the inability to keep up, and exhaustion of goodwill. Most were left with only a small coterie of family members and a few true friends from which to draw social support.

In response to being discredited by others sufferers used the classic strategies described by Goffman (1963) to deal with stigma. Some withdrew, others concealed the illness and passed for normal as much as possible, still others covered their stigma, meaning that although they disclosed its presence they tried to make it assume a small place in their relations with others. Some were very vocal and open because they were determined to remove the stigma from this illness. Some educated doctors and negotiated more equal doctor-patient relationships, litigated and won against insurers, and found ways to maintain enough social involvement and cultivate goodwill to keep the support of some family and friends.

CHAPTER 7

TOWARD VALIDATION: EXTERNAL REINFORCEMENT OF DIRECT EXPERIENCES AND COLLECTIVE ACTION

The previous chapter presented reactions that sufferers encountered from doctors, insurers and significant others. On the one hand, sufferers were implicitly or explicitly told that they were malingering, profiting from secondary gains, or denying a psychological illness. On the other, they received some measures of legitimation from diagnoses and medical care, disability compensation, and network support. But legitimation was often partial, tainted by ongoing doubts in the larger medical and disability systems and in sufferers' social networks. With little or no objective corroboration of illness and faced with skepticism from powerful and important others, how did sufferers maintain the conviction that they were sick? And why did they subsequently accept and cling to a contested illness as the appropriate definition of their problem? One aim of this final empirical chapter is to provide some insight into how sufferers came to determine they were sick and why they remain convinced that CFS is the correct diagnosis. A second purpose is to show how impaired physical and social functioning contributed to CFS sufferers' sense of a tainted identity independent of others' negative reactions. The chapter ends with a presentation of sufferers' attempts to manage the physical effects of CFS and the assault on their identities.

Defining the Problem as Illness

Illness may remain in the background of people's lives even when symptoms are present. But illness may be catapulted into the foreground by a crisis such as increased

symptom severity or the receipt of a diagnosis (Charmaz 1991). Some CFS sufferers experienced a crisis with the sudden onset of severe symptoms and immediately defined their distress as illness. But for many others, illness came into the foreground only after they had tolerated nagging symptoms for months or even years. This section deals with the latter sufferers. In deciding how to explain their distress, these sufferers interpreted symptoms in light of the then current context of their lives, changes in their physical and social functioning, and self assessments of possible secondary gain motives.

Contexts of Symptom Onset

Many sufferers did not initially regard their problems as illness. For a while, they could ignore their symptoms and many did. Some looked at their life situation at the time and recalled: "it was one of the best periods of my life". These sufferers were living very full lives- working hard, enjoying friends, family, and leisure pursuits, and participating in community activities. Many felt they were in "excellent physical and mental health", "in peak condition". Illness was the furthest thing from their minds.

But others who also considered the time just before illness as a good time in their lives normalized their symptoms. They admitted that they were "run down" by "living at a hundred miles per hour" or suffering from transient physical and psychosocial stresses. One man had worked nine double shifts in a row and cycled some twenty kilometers daily just before symptoms began. When he began to experience intense pain, both he and his doctor pointed to the immediate circumstances preceding the illness. But after a week of rest:

> I was still tired my muscles were still hurting and I went back to work and I lasted about 3 days. And then my muscles just got a lot worse to the point where my hands were closing up. All my muscles, every part of my body was in complete agony. My jaw, my legs I couldn't even lie in bed it was so painful I was lying in a lawn chair and I couldn't sleep...

After three months without relief from fatigue and pain, intense physical stress was no longer a plausible explanation for this sufferer. Like many others, he also discarded psychosocial stress as an explanation because he could find no correlation between increased stress and symptoms and because he considered himself well able to cope with stresses. In cases like these, illness was considered a distinct possibility within a relatively short period after symptoms appeared.

However, other sufferers initially accepted social stress as a reasonable explanation of their symptoms. Their symptoms arose during a time of significant adjustments to changing statuses, occupational and familial strains, or losses. Several were struggling with more than one of these problems. Some sufferers believed they were underemployed relative to their abilities while others were working at two jobs to make ends meet. One man thought he was a victim of reverse discrimination at work. Others were starting new jobs or chafing to leave the jobs they held. A few were newly married, others were in severely troubled marriages. Among the latter were sufferers living with an alcoholic spouse, a spouse who offered little emotional or instrumental support, and a spouse described as a child molester. Sufferers faced a number of other significant events shortly before symptoms began such as: the death of a close relative or spouse, an abortion, problems with various authorities, thwarted career training plans, a failing business, relocation for their own or their spouses' job, and injuries from motor vehicle accidents. In trying to determine the meaning of symptoms, sufferers took into account the psychosocial context of their lives and their coping effectiveness.

Symptom Experience

As the range and severity of symptoms increased, sufferers had a more compelling case for defining their problems as illness. They reported a plethora of somatic, cognitive, and emotional symptoms ranging over multiple body systems and across a wide variety of

physical and psychiatric disorders[1]. Symptoms included blurred vision, blindness, double vision, photosensitivity, facial neuralgia and paralysis, weakness or loss of power in the limbs, loss of balance, poor fine and gross motor coordination, falling, tingling, numbness and difficulty walking[2]. A few collapsed in the street or at work and were taken for being drunk. Cognitive symptoms were manifested in difficulty concentrating, poor memory and comprehension[3].

Their gastrointestinal problems included: nausea and vomiting, heartburn, diarrhea and constipation, loss of appetite and rapid weight losses or gains in the order of twenty five to forty five pounds. A few reported irregular heartbeats, chest pains and palpitations. Several mentioned experiencing one or more of the following: irritability, intolerance of small stresses, anxiety, panic attacks, depression, and emotional lability. Just under a quarter of the respondents had contemplated or tried to commit suicide. They frequently linked suicidal ideation or attempts to the difficulties of living with undiagnosed or unrelieved symptoms.

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[1] In all, sufferers reported almost ninety different symptoms that they thought were associated with CFS. Many were outside the symptoms described in the CDC case definition.

[2] A recent study confirming measureable gait abnormalties in a group of CFS patients relative to healthy sedentary people (Boda et al. 1995) indicates that some attention is being paid to symptoms that clinicians observe, and that many sufferers complain of, but which are not part of the official definition.

[3] Several studies have investigated the cognitive impairment that sufferers report. In a review of these studies, Brickman and Fins (1993) point to methodological problems and inconclusive results. For example, the authors report that studies measuring attention in CFS patients show normal attention (Millon et al. 1989) better performance than an age matched group (Altay and associates 1990) and impaired attention (Jones and Miller 1987). Major critiques of these studies include small sample size, meager instrumentation, failure to target specific cognitive functions likely to be affected by fatigue and using instruments normed against populations that are less well educated than the CFS subjects tested. Brickman and Fins report on their own unpublished data of a study designed to address some to the shortcomings they had identifed and found mild impairment in attention of CFS patients. Since Brickman's and Fins review, Marshall and associates (1996) have reported no deficits in sustained attention of CFS patients relative to healthy subjects and subjects from other patient groups. Memory, cognitive processing, language and visuomotor performance have also been studied with conflicting findings on several of these dimensions.

More general symptoms included: malaise, fatigue, all over body pain, joint pain, fevers, dry mouth, sore throats, swollen glands, chills, insomnia, excessive sleeping, night sweats, fainting, vertigo, vivid dreams, persistent coughs, hot or cold spells, muscle twitching, watery or dry eyes, muscle spasms, hair loss, early menopause, hyperventilation, intolerance to specific foods, medication and alcohol.

Sufferers further described strange sensations such as: 'sore veins', feeling like their bodies were 'dead', 'poisoned', or 'inflamed'. A few spoke of 'spasms in the brain', and one complained of 'a ropey feeling in the stomach'. Another sufferer 'couldn't stand the feel of clothing on [her] body'. She likened her acute pain to 'somebody shredding my cells, ripping my cells apart', and spoke of fevers that would leave a 'constant simmer in my body'. One person began to 'grow cysts, tumors and moles'. Another sufferer developed three persistent welts on his back (shown to me) measuring about four inches long by half an inch wide. Yet another experienced a sensation 'like my head was full, and couldn't take in any more stimuli'.

A composite list of symptoms such as that catalogued above, masks the experiences of individual sufferers and may mislead, since not all sufferers experienced all symptoms. As well, no individual experienced all symptoms at the same time or with the same level of intensity. Two accounts provide a better representation of the many symptoms that sufferers experienced. The second account was by far the most graphic and extensive of any sufferer. But many others described almost as many symptoms over the time they have had the illness.

> I had exhaustion, pain all over, arthritic type pain but no inflammation, so it is not arthritis. I had muscular pain all over. Everything hurt, even my eyeballs, my buttocks and my toes and everything in between...I had vertigo, I had to hold onto the walls as I walked down the street. I lost my balance, headaches daily, lightheadedness, a feeling that I was outside of my body, spaced out, heart palpitations. I lost my sight completely but it has returned...in the beginning especially, it was mainly blurriness....I would read words 1,3,5,7 and 9 instead of 1,2,3,4,5 and try and make sense of a sentence. Then I would read the sentence again, but skipping the same words. I might get it the third or fourth time if I went slowly. The eyes would skip over the words. I was paralyzed in the upper left quarter of my leg. It is still numb...I was like a Picasso painting, with one eye up here and one here. I had about 4 or 5 different visual problems....I had cognitive problems...memory, concentration [difficulties]...I am sure that my IQ has dropped 20%. ....I have inward tremors that never stop.

I couldn't move, I could get up for 5 minutes, go to the bathroom and then I just simply had to lie down. My body was as if I didn't have it anymore and I just would break out into a tremendous sweat and a malaise. I [was] unable to concentrate, nervous, emotionally labile, [unable] to complete my exercise program...sometimes depressed, knowing that I couldn't go the course of a day...

... I could not wear anything but 100% cotton. I couldn't tolerate the touch of a bra, the touch of a pair of pants, anything polyester, artificial, synthetic, just drove me crazy. The excruciating fatigue was a problem but for me, I had terrific fever. My body was like a constant boil, a simmer and a boil and I could be that way the entire day. Then my body would just go into chills. Over the years, this is gradually down to ...about 15 minutes. Those were terrible. Those are indescribable. People focus on the fatigue, but for me the real suffering was the fever...They were so deep... in your system, into your being, into your lymphatic system... It seemed to leave me with this constant simmer in my body.... yet my temperature was a 99 7 or a 99.6. But it was in my groin, under my breasts, through my neck, my chest...like it was somebody shredding up my cells.

I used to have acute pain, like somebody was ripping my cells apart. Then it would go away for about an hour and start again. I had [headaches] like your brain was swollen and even my eyes. The intensity [was] tremendous, it was like nothing in there was working, not only pain but discomfort. You couldn't close your eyes and it would go away. It was there and it would go when it was ready to go. It seemed to have a pattern, where I would have fatigue, then fevers, then pain in the body and then that would go, and the head symptoms would kick in...

I lost my sense of smell, my sense of taste, I am only just getting that back in these last 6 months. I lost my hair, my nails wouldn't grow, my skin had no vitality, not even the hair on my body grew very much. I suffered a lot of neurological symptoms, like I couldn't read one sentence and remember what I read. I couldn't look at a book. I couldn't tolerate any noise, not even television. I could not go out to a public place and hear the noise, it was like there was no barrier there to protect me, it was like it went right through me.

I couldn't write and I like to write. Numbers, forget it. I couldn't calculate if my change was correct. I would have to come home and spend 20 to 30 minutes figuring out my change. I would search for my words, I couldn't talk, process things, reason things, it just wasn't happening. My memory, I couldn't remember what the heck I had done the previous day. I really noticed that. That is when I started to keep a bit of a journal and try to keep track.

....Some days I would wake up, feel a sense of anxiety just come over me for no apparent reason. It would last for about an hour or two, go away, come and go maybe for a week and then it would not come back again. I had some depression. In the beginning I was depressed and I was seen for therapy for a couple of months...I would get little panic attacks sometimes, out of the blue they would come and go. I learned later that this is part of the disease....

I got rashes on the back of my arms, mostly the arms. I suffer a lot from constipation and diarrhea...I also suffer from allergies, I would just swell up in my throat, my tongue and eyelids... I have had the insomnia where it is like somebody injected ...caffeine into your head. You could be relaxed at 11 o'clock thinking 'I am going to go to sleep' and bang! out for 4 or 5 hours. Nothing would put me to sleep. I think the fact is you never knew what was going to happen next. The symptoms were severe. They talk a lot about having antibodies in this disease. I literally could feel an explosion going on inside of me, there was a lot of toxin, there was a lot of something in there. I could sit and time it. It would come and go and I would just try to calm down and not get too excited. I am saying it in the past tense but I still have the symptomatology of it, but it is not nearly as severe...I gained weight...Now I am 150 and I should be 125. There was not the visual acuteness. And perception of color. I have only noticed color in the last 6 months. To me color has an effect on you and with this disease, it didn't matter what was in the room. Now I see red and blue. Before it was like you were living in this hell and there is some sort of curtain between you and reality, you are locked in your body, in this hell

...I would get lightheaded, off balance sometimes, like I was drunk...I had nightmares, occasional ringing [in the ears]. At night my body temperature dropped and I got bone chills occasionally. I would have to get in the bathtub. I completely wore out a heating pad. Alcohol had no appeal to me... Night sweats, yes and when I had them I knew the next day would be a bad day. Now I only have one sweat and it's gone. A lot of tachycardia, 120 heart rate easily, associated with the fever and the intense malaise and a lot of palpitations....In the last 2 years I developed

> severe menstrual problems and have gone into early menopause, proven by blood work. My [libido] was affected. For 4 years, if the best looking thing in the world walked in, it would not have phased me. That slowly came back about 4 or 5 years later.... A very dry mouth at times and that gave me a lot of gingivitis (gum disease). Part of the disease is that you can't look after your teeth, do the basics
>
> ....When you had acute fatigue, you couldn't put your arm up to brush your hair. You couldn't get your head off the pillow. Sometimes that would last 7 to 10 days at a time. I had trained a lot but it seemed that the suffering from the neck up was the worst. Your body is down there and you can cope with that. Your brain, your head, your eyes, your neuropsychological and your physical symptoms...-I was given a gift of a very strong mind and that is the only reason I am sane today. In June 1991, I felt almost like I was hallucinating. There were mosquitoes in the room and I thought they were coming in to get me. My mind was totally, feeling very sick. Sometimes lack of coordination in my hands. I was in excellent physical health before the crunch. I had been training for 2 and half years; aerobics, weights, swimming, scuba diving, cycling. I lived with symptoms off and on before the crunch, attributing to them to stress. Had I not had a strong cardiovascular system, I don't think I would have made it through this, I would probably be close to an invalid or died. My physician is very protective of me. It was difficult when I wondered if I had AIDS. I told him several times that I would have prepared, been quite happy to die because the suffering got so bad. I would have preferred to die. I told him that in 1992. It seemed easier to die of AIDS.

Many sufferers who so eloquently and graphically described other symptoms struggled to convey what they meant by fatigue. One proposed: "the French term épuisé, means you are crushed, maybe that's a better word for it, not just fatigue but crushed, zapped." Others said: "It was a very distinctive feeling from being normally tired. It was a struggle to have the tension out from the fatigue"; "it's just something that a healthy person would never experience"; "unless you experience it, you cannot imagine it"; "it was like my pants were around my ankles".

> I feel it most in my lungs. I feel like I have run 10 miles. Usually you recover, but I feel like I have no possibility of recovery. It takes such a long time to get better. It is a total lethargy. I have no get up and go.
>
> [Its] a sick, sort of nauseating feeling in the very pit of the stomach that is so overwhelming that you become absolutely fatigued and it takes over. It's not tired, it's that whole thing that you're wrapped in this tremendous malaise and tiredness.

Had symptoms occurred singly or lasted for only a brief period, they might not have been interpreted as illness at all. At worst, they would have been regarded as minor acute illnesses. But in time, the number, severity, persistence, or recurrence of symptoms would intrude on sufferers' physical and social functioning and contribute to their belief that only illness could explain what they were experiencing.

Physical and Social Disability

Sufferers considered themselves to be fit and active before becoming ill. Many were sport enthusiasts who cycled, skied, or ran marathons. Some participated in the political or social life of their communities and all reported high levels of social involvement with friends and family. They described themselves as sexually attractive, "exuberant", "active", "very outgoing", "incredibly strong", " a very together person", "thriving on stress and risk" and as perfectionists. Many loved to travel and were interested in culture- the arts, music and theater. Some had excelled academically and had planned for dynamic careers and a good life. In short, most sufferers believed they were capable, intelligent and sociable. A minority admitted to being vulnerable, having difficulty handling stress, being plagued by a history of illness and leading more subdued lifestyles long before they had CFS. But these sufferers were no less committed to normative social roles.

Surprisingly, even in the face of severe symptoms and increasing physical and cognitive impairment, many sufferers continued their normal roles for several months or years.

> It was like it was 3 o'clock in the morning 24 hours a day. I could function but it was like when you get woken up in the middle of the night and you can do anything you need to do, but I felt like a zombie. It was pretty constant, I could get the adrenaline running to teach a class but I sleepwalked getting to and from the class. There were times I left my apartment and crossed many busy streets and found myself on a bus, not remembering how I got there.

> In the morning... it would take me maybe 2-3 hours to prepare myself for work like shower, shave and get dressed. My daughters would drive me in to town...and I would drive [from] wherever they got off to my place of work. I would work and meet them and they would drive me home. But I found that when I came home I was physically exhausted, sometimes I didn't have the energy to eat and went directly to bed.

But eventually a signal event such as a collapse at work or a sudden change in symptoms became the crisis that finally brought a definition of illness into the foreground.

> ... little things started happening like my throat would get sore for no reason... and I would feel pretty tired in the afternoon. I thought it was just from having had children. But it sort of lingered after they were sleeping well...I started to get little flues which I never had [before]... then a sinus infection for the first time... One day I woke up and my head was just pounding and I couldn't lift it up off the pillow. But before that my right arm had gone weak. I had had about a week of

> tingling in my extremities and feeling very weak...and then the headache...[which] just seemed profound. I had never had anything like that in my life...It just felt very wrong, that something was really wrong. I had actually, being exposed to somebody who developed viral encephalitis two weeks previous to that... and I felt right away that this must be encephalitis

In other cases, illness came to the fore when sufferers could no longer deny the drastic deterioration in their physical and social functioning.

> In the beginning, it was just a constant feeling of not feeling completely rested. Gradually that became worse. I could not work anymore. I actually tried to cut things out of my life that I thought were draining me. I was seeing somebody and I thought maybe he was draining me. It was more important for me to get done in school at the time, so I broke up the relationship with him. Then I realized that I was still not feeling well at all, though I did not realize why. I still felt totally drained so I cut my work hours down and then I dropped school and shortly thereafter, I dropped work...I could not participate in life really. I became a spectator. I had to give up everything. Financially, I lost my independence. I lost some friends over it, not friends that knew me before I was ill, they were friends that I had met from the transition of being just tired to becoming really ill. They all assumed I was depressed. They could not see the difference. My friends I have had all my life could see an incredible difference... I would not give in to the idea that it was a depression because I have been depressed. I know there are no physical...Well I guess there are, but in my heart I knew that this was an illness... I did not know what it was, I thought maybe I was not eating properly. I had no idea what was causing it. I was afraid that this was the beginning of AIDS or something like that....

The continued intertwining of symptoms and disability put sufferers' lives into a downward spiral.

As symptoms worsened, many sufferers withdrew from social activities with family and friends. The majority quit school and work for several months at least, although a few continued to work on an intermittent basis. Few recalled any "good days" during this time. At best, relief was occasional and then only for a few hours.

Those who lived with others had to renegotiate the existing household division of labor, and usually handed over most of their previous responsibilities. Those who lived alone simply left tasks undone. One woman reported doing almost no housework for ten years. Another eventually hired household help although she initially resisted this option because "who was I to have a cleaning lady?...[she] couldn't see my fever or swollen glands or cottonwool head and I'm lying there watching [her] work." Her comment highlights her awareness of the social expectation to justify occupancy in the sick role. And in this case, part of the problem was that bane of CFS sufferers -"not looking sick" or not

looking sick enough, in which case it was difficult to justify their exemptions from normal social roles.

In the most severe cases, sufferers became bedridden or wheel chair bound for months. Others reported being unable to: get up from a chair, walk, or lift their heads off a pillow. Some could not complete their daily personal hygiene unassisted. For others however, assistance with personal care became a line they would not cross. Instead, they made choices between "washing my hair or brushing my teeth", or took up to three hours daily to wash and dress. Some could barely talk and worried about what would happen if they needed to make an emergency telephone call. Others could not cook, clean their homes, or feed themselves. Minor exertion could result in several days in bed.

The contrast between their pre-illness levels of functioning and the levels of disability and dependence to which they had fallen made it increasingly difficult for sufferers to explain their impaired functioning as other than due to illness. Attempts at ignoring, normalizing, and "pushing through" (Woodward 1993) eventually failed. Illness had become intrusive, demanding continued attention and forced accommodation (Charmaz 1984 cited in Charmaz 1991: 42).

Some sufferers believed they had one more avenue to explore to lay to rest any self doubts. They tried to examine whether they had hidden motives of possible secondary gains from claiming illness. But they eliminated this hypothesis on the grounds that they were "workaholics" who "loved their jobs" and always "went to work even when sick". One man commented:

> My question to my friend who thinks I'm malingering. Why would I be doing this? If I wasn't happy at work and wanted time off work, I would have taken time off work. I would not have gone to the trouble of seeing twenty doctors. What is to be gained? If I don't get the problem licked in the next six months, I'll lose my car. I will not be able to apply for a new apartment unless my Dad signs the lease. Why would I do that? Yet there are still people questioning, because I don't look terribly ill...I am twenty eight years old, I want more out of life than this.

Of course, such examinations could have been self serving or exercises in self deception. But by considering their direct experience with symptoms, the circumstances in which they developed, their deleterious effects on valued roles and activities, and self assessments that

accentuated engagement in society, sufferers concluded they were ill. In Charmaz' (1991) words, illness had been pushed into the foreground of their lives.

Accepting CFS as the Definition of the Problem.

Accepting illness did not mean that sufferers would automatically accept the diagnosis of CFS. But as the previous chapter showed, many accepted the diagnosis because the symptoms resonated with their own distressing experiences. Moreover, sufferers might have thought that a medically recognized, even if not a completely accepted, diagnosis was better than worrying about cancer or AIDS, or being told they had a mental problem, or nothing seriously wrong. Charmaz (1991) suggests that a diagnosis following a long search and skeptical reactions confers legitimacy, restores others' trust in the ill person, and the ill person's trust in the validity of his or her own perceptions (p. 24). A diagnosis also gives meaning to inchoate suffering (Kirmayer 1994). In the case of CFS, Woodward (1993) found that the diagnosis helped sufferers to make sense of their world again and gave them direction for managing their lives. But some sufferers accepted the diagnosis only after reading about it (Woodward 1993).

But CFS was a contested diagnosis and thus did not confer complete legitimacy. Its existence and nature were being debated in medical and popular arenas. The social baggage attached to the label was at the heart of sufferers' reactions to having the illness. A few initially rejected the label, some still hide it, and others continue to worry about owning it. Was the coherence that the diagnosis brought (Woodward 1993) enough to explain the continued acceptance of CFS as the correct label for their illness? I suggest two additional factors were important in this decision. First, conflicts over the nature of CFS gave sufferers a choice of understanding the illness in less stigmatizing ways than some people have suggested. This is evident in sufferers' ideas of possible etiology. Second, once sufferers were diagnosed, they were exposed to a world of information that has continued

to reinforce and give coherence to their experience as it has evolved over time. Information about a phenomenon labeled CFS convinced sufferers that they had found the right definition of their problem, even if others doubted its existence.

Attribution Options of a Contested Illness

Most sufferers attributed CFS to physical causes. Others believed a combination of physical and psychosocial factors, or an energy imbalance were responsible. A few said they had no idea. One woman who thought her symptoms were "typical of how a virus works" drew on past illness experiences and literature on the viral etiology of CFS. Other sufferers, influenced by medical practitioners as well lay and professional literature, variously suggested that CFS might be linked to toxic levels of exposure to pesticides, radon gas, or dental amalgams[4]..One sufferer seriously considered removing his old mercury fillings but eventually decided against it. One woman recalled her exposure to pesticides as follows:

> I think my immune system was wiped out by...extreme exposure to the pesticides as a child. For two years...in a military camp where we lived, we children used to run behind the jeep [spraying DDT] every day from June to September. In the late forties there was no knowledge of poison. I

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[4] A few sufferers gave me the following articles on possible effects of pesticides and mercury fillings. These articles do not propose a direct link between dental fillings or pesticides and CFS. Rather they describe symptoms that are thought to arise from exposure to these substances. Many of these symptoms are similar to those experienced by CFS sufferers. Some sufferers who can recall clear concentrated exposure to pesticides believe toxicity is a plausible explanation for their symptoms, while a few have wondered if there is any substance to claims of a connection between dental fillings and CFS.
"The mercury in your mouth" Consumer Reports May 1991 pp 316-19.
Denton, Sandra 1989. "The Mecury Cover-Up" Health Consciousness June: 29-33.
Hanson, Mats. 1983 "Amalgam-Hazards in Your Teeth" Orthomolecular Psychiatry 12 (3): 194-201.
Fauteux, André 1993. "Linked to Chronic Fatigue: Blood Tests for Pesticides Exposure Unavailable to Québec Doctors" Habitabec Montréal 21st May, p.4.
Irwin, June 1991. "Are Pesticides Killing the Boy Next Door?" Family Practice 9th February p.10.

> am sure that my little friends across Canada -if they are not dead from the carcinogen in DDT- are with this illness.

Other sufferers attributed their CFS to iatrogenic effects of antibiotics, anesthesia, or long term use of sedatives. A few women deduced a hormonal connection based on exacerbations around their menstrual cycle. Excessive exercise, sleep disorders, and genetic predisposition were other physical causes that sufferers offered.

No sufferer thought that CFS was a purely psychological disorder. Some had wondered whether CFS was a type of burnout from overwork or resenting their work environments. Others questioned whether CFS was a new term for a nervous breakdown. Still others believed that they were vulnerable to stress related illnesses as a result of remote events such as "being adopted", "a gang rape at age eleven" and losing a parent through death or divorce. But through readings, medical consultations, and support group information, these sufferers eventually rejected a purely psychological explanation in favor of a multifactorial etiology.

Sufferers were well aware of the different explanations for CFS, but none explained CFS in a way that could be construed as unambiguously stigmatizing. That is not to say that physical explanations of illness are necessarily less stigmatizing than psychological causes. One only has to think of AIDS. However the hypothetical physical causes that sufferers proposed, with the possible exception of genetic constitution, were hardly likely to incur stigmatizing labels. On the other hand, there is little doubt that many sufferers understand a psychological attribution as stigmatizing and are relieved when they can reject it.

> When I first got it I was looking for the cause, physical cause...Then I looked at a psychological level and I thought it's probably time to see a mental health professional...so I said to my baseline doctor "do you think this is psychological?" Not in a way like do YOU think, but rather should I be looking at a psychologist? She said " you don't have sore throats and swollen lymph nodes from something that is psychological". I looked at her and I said "thank God". I knew then too that she believed me...

This sufferer was one of a minority who seemed most open to the possibility of a psychological basis of CFS. Yet by juxtaposing relief at the doctor's assessment that her

illness was not psychological with the feeling of being believed, she suggested the negative implications of a psychological diagnosis. Ironically it was the contested nature of the illness that gave both her and her doctor the option of defining CFS as physical.

Confirming Information

After diagnosis, many sufferers intently pursued information about the condition. Some attended professional conferences on CFS in the United States. Others contacted doctors and researchers in various parts of the world, read medical journals and support group literature, and attended lectures by local 'experts'. These sources of information provided continuing referent points as the illness evolved. Not all information was sympathetic to the condition and sufferers. But enough of it was, so that sufferers could discount disconfirming information in favor of that which meshed with their own experience.

The course of illness may be used to illustrate how sufferers' experiences were affirmed by other sources and why they may have continued to accept CFS as the right diagnosis. As noted in the previous chapter, sufferers reported a gradual or precipitous onset of symptoms that often followed a diagnosed or undiagnosed viral illness. Some time after the onset, sufferers entered a period of months or years of severe debilitating symptoms. During this time, occasional relief was short lived. Yet many attempted to "push through" (Woodward 1993). If they woke up feeling well, their first thought was "whatever it was, it's gone". With this in mind, they tried a few activities. But within hours or days at most, symptoms were back and sufferers might be bedridden for several days. One man recalled that about ten months after the onset of illness: "I was an exercise addict...I thought ....if I can physically exercise, I will get better. But everytime I would bike on a good day, I would crash so bad...I couldn't understand it. Then finally reading on it, [I discovered] that exercise was the worst thing you could do".

In fact several sufferers had learnt from support groups that they should have "gone to bed for six months to a year" when the illness first began. This information came too late for most sufferers to act upon it because of the length of time it took for diagnosis and because many doctors would not recommend extended inactivity which has known deleterious effects. A few sufferers discounted suggestions for complete rest and were none the worst for it. They made a point of exercising their bodies and minds regularly arguing that "the trick is to find the balance between the level of exercise that is helpful and that which is harmful". Since many other aspects of the course of their illness conformed to information about CFS, there was no need to relinquish the diagnosis because of a few discrepancies.

Sufferers in this study never again reached the nadir of that early severe period. Most reported improved functioning sometime between one and a half to three years after the onset of symptoms. Some resumed work within this time, but were only able to carry out one or two major activities in a day. For most, improvement was painfully slow. There were no exact timetables. Two and a half years after the onset, one sufferer described a typical day.

> I get up at 10:30, I eat, put some music on, wash my face, brush my hair and then I am too tired. I go back to sleep until 1:00. Then I eat. After that I can stay awake a while and try to read a page or two. Then I go back to sleep until 4:30. Then I get up and walk around. I try to go outside, get fresh air. I have dinner at 6:00. I try to read a bit, do basic things like paperwork. Then I go to sleep at 9:00. [if] a friend calls me and says "tomorrow we are going shopping". I do not know how I will be tomorrow. Sometimes when you wake up, you feel that you can do things but you do not know how long that period is going to be. Maybe half an hour, you are able to do things, normal things...after that it sort of hits you like a wall, a wall of bricks...Let's say she comes and picks me up to go somewhere, just the ride in the car could be enough. You get to the event, and that is it, I am falling asleep.

Once improvement began, the illness followed a remitting and relapsing course. Remissions did not mean that sufferers were symptom free. Rather in remissions there were more good days than bad days and, when present, symptoms were tolerable. Remissions could last several weeks or months. They permitted better functioning and fueled optimism. In the beginning, sufferers even hoped remissions were a sign of cure.

> My husband and I laugh about it and I say it's the big "C", that "C" word-CURED. When I have been feeling really good for a long time and I think I am cured, he laughs. I go and do something, and I say "I guess I'm not cured yet". But it is true, when I am feeling good, I am feeling very good and so I think it has lifted. They also say there can be a spontaneous end to it and so I think, maybe this is it. Now I am kind of cynical about it, it has been almost 6 years. I guess it will not a be spontaneous thing.

But eventually, the return of symptoms underlined the chronic nature of the illness.

Relapses lasted from a few days to a few weeks. Some events reliably worsened symptoms, but exacerbations were often unpredictable. Minor relapses were precipitated by illnesses such as a cold, moderate levels of physical activities, hot or cold weather, emotional stresses and for some women, the days around their menstrual period. Sufferers also reported that death or caregiving burdens of looking after chronically or terminally ill significant others intensified fatigue, depression, irritability, and ability to keep perspective. Financial and family strains increased anxiety.

Relapses also affected mood. During these times, some sufferers reported experiencing from mild depression to despair. With time, some learnt to cope with relapses by positively reframing the situation. They learnt to identify and to take encouragement from early signs of improvement.

> At first, I'm so ill I don't care about it. I just can't raise my head off the pillow, the fevers, I feel delirious, the aching, I can't eat. Then there's a point where my fibromyalgia's killing me. Having to lie around in bed is not good, you need to keep moving. I still don't have an appetite, but I'm fed up, I'm angry and I'm feeling depressed. I have now learned that's a really good sign because I have the energy to feel upset that it's happening and usually that may be anywhere from a week to three weeks, that mid-phase. That is the mid-phase to my getting better again. It's taken many episodes, long episodes to learn that. Now, in that despair moment I think [this is a] good sign, it's happening, I'm not there, I'm just so miserable and I'm so fed up with lying around. But it's a sign that yes, it is going to happen. I think when you're just starting out, you don't know any of these patterns.

Some sufferers wondered whether the return of symptoms were indeed just exacerbations of CFS or whether they were ushering in a new, and possibly worse, condition such as cancer. Reports of such links had circulated among support group members. To date only one study has found an upward trend of brain cancer in CFS sufferers in Nevada. But that trend was consistent with observed increases in brain cancer in North America (Levine et

al. 1994)[5]. However, incomplete information about scientific studies could create concerns that were out of proportion to the known facts.

Despite experiences with a cycle of relapse and remissions, many sufferers persisted in resuming normal activities when they felt well. They were testing whether they had recovered, trying to maintain social relationships or rebelling against the illness' constraints. One man noted "It is the hope that it is finally over...then you start to feel confident and you say 'I am healthy'. So you send out applications to universities and so on. So many plans, so many things and then a week and half later, you are back down again". One woman explained: "sometimes I say 'to hell with it, I will live for the moment and pay for it later'...you just want to break loose. When I was young, I would go to a party and drink too much and know I would have a rotten hangover, but you do it anyway, It's the same thing".

Sufferers who belonged to support groups heard echoes of their own experiences among other members. As well, many saw some widely disseminated videotaped material that detailed the lives of CFS sufferers (or putative sufferers) which they used as points of comparison or affirmation of their own experiences. Several mentioned two videotapes in particular: "Wide- eyed and Legless"[6]. and "Living Hell".[7] The course of illness described

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[5] The study of cancer incidence and CFS sufferers was reported at the Albany conference in 1992, Since many of respondents of this present study had attended the conference, information from various papers became fairly well known. The proceeds however, were not printed until 1994. The study of cancer incidence was conducted by Levine, Paul H., M. Atherton, T. Fears, and R. Hoover. 1994. "An Approach to Studies of Cancer Subsequent to Clusters of Chronic Fatigue Syndrome: Use of Data from the Nevada Clinical Registry". Clinical Infectious Diseases 18 (Suppl. 1) s49-53.

[6] The video "Wide- eyed and Legless" 1993 BBC Production, was shown to me by a sufferer to give me a graphic idea the day to day life of someone who was thought to be a sufferer. It chronicles the increasing debilitation of a woman who eventually died. Her husband suspected that she had CFS.

[7] Copeland, Lennie, producer 1994. "Living Hell" written by Lennie Copeland, Authentic Pictures in association with the CFIDS Foundation of San Fransisco, was shown at a meeting marking International CFS/ME (myalgic encephalomyletis) Awareness day, May 12, 1994, to which I was invited by a support group leader. Some stories were particularly bleak. Informal discussions after the showing revealed that though many sufferers could

by sufferers in the present study is consistent with that found by Woodward (1993). She distinguished between minor and major relapses by duration and severity of symptoms, and documented symptom fluctuations over a day.

In summary, sufferers' accounts show a course of illness in which an acute or gradual onset often followed a viral illness. Subsequently sufferers entered a prolonged period of severe symptoms and disability. A slow recovery, marked by unpredictable relapses, followed until sufferers reached a plateau somewhere below their pre-illness level of functioning. Initially, many refused to enter the sick role, but sooner or later discovered the futility of resistance. The early debilitation and subsequent relapses were sources of depression, anxiety, and frustration. The indefinite duration of the illness clouded expectations for the future.

Sufferers' reports of two physicians' renditions of the course of the illness, show how closely these doctors approximated the highlights of sufferers' experiences. These two doctors had large numbers of CFS sufferers in their practice, including several of this study's respondents. One doctor has spoken about CFS in several local public forums.

> Dr. ____ distinguishes between acute onset *viral* fatigue syndrome and myalgia encephalitis which is acute onset *postviral*,...he is saying for some people it comes on like a ton of bricks and in others, it develops very slowly and gradually. And he said... had it not hit me like a ton of bricks, in all likelihood it would have probably come on very slowly and gradually...he said the first year is often just one downhill ride and then I got a lot worse before I got better...he said a common pattern is the next couple of years ...you're progressing with a few little setbacks...his line is that

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relate to the physical and psychological symptoms, they generally felt they were better off than the people shown in the film, one of whom committed suicide. Some expressed concern about others in their families seeing such a film and being devastated by it. The term myalgic encephalomyelitis or benign myalgic encephalomyelitis (BME) was preferred by the group of sufferers in Toronto interviewed for the present study and it is commonly used in Britain. According to the newsletter Quest August 1, 1994 communication # 7 of the National ME/FM Network, World Health Organization's Dr. J.A. Costa e Silva, Director- Division of Mental Health, issued an update on The World Health Organization's International Statistical Classification of Disease and Related Health Problems (ICD-10) tenth revision, 1992 Vol 1. This update states that the term Benign Myalgic Encepahalomyelitis should be avoided until the status of the condition has been clarified. Encephalomyelitis means inflammation of the brain and spinal cord Taber's Cyclopedic Medical Dictionary 1973, and presently this has not been confirmed in CFS.

> the next couple of years....at the end of it, I can expect to be about eighty percent of what I was before, but I don't think so...I think I'll be better than that. (Italics mine)

> I attended a conference...in April of 1992, given by Dr._____ ,...the renowned guru. He told us..."those of you who have had it for 5 years or more, will probably be affected on a chronic basis for the rest of your life". There was a big moan through the hall. He told us... "I have had patients in my practice who have had it for 12 or 13 years" and everybody moaned. He said "I am telling you that because the biggest mistake that you people make is that you tell yourself that you will be better in a few weeks or months...you try and maintain your old lifestyle and meet your old schedule and you realize that more and more you cannot, and you become more and more frustrated. In addition to the medical and physical problems, you start getting the psychological problems".

While there were minor discrepancies between these doctors' accounts and individual sufferers' experiences, the broad outlines of both are congruous. With affirmation from doctors, from fellow sufferers in support groups, videotapes, and some literature, sufferers were better equipped to deal with disconfirming information. They could now discount negative information on more than their own personal experience. When doctors dismissed the condition, sufferers could counter with the opinions of other medical experts who accepted CFS. When the social historian Edward Shorter[8] cautioned against legitimizing as illnesses conditions that historically reflect social rather than biological factors, sufferers retorted that he had no clinical experience with people with CFS. Sufferers could also counter media reports of the late 1980s and early 1990s which presented a skewed picture of them as passive victims, succumbing to the illness.

> ...the stuff that's in the newspaper, now its becoming better. Before, you were just totally nuts or hysterical...psychologically slanderous articles without much biological information. None of them ever focused too deeply on how hard you struggle to cope with this. They'll say its devastating to your life, but I think it would be beneficial to have a few histories where it showed the person wasn't just lying in bed sleeping twenty two hours a day and saying 'poor me'.

In short, once sufferers received the diagnosis, they were exposed to a plethora of information that paralleled their own experiences. Not all information was confirmatory, nor did the body of information form a template into which sufferers' experiences fit

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[8] Shorter has written a book on the history of fatigue and several articles on the subject. Shorter, E. 1992. From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era. New York: Free Press. According to one insurer interviewed for the present study, Shorter has also appeared in the media talking about CFS. Several sufferers in the present study have attacked his views on CFS.

precisely. But it provided enough matching information that sufferers could comfortably believe they had found the definition that fit their problem.

The Effects of Illness on Identity

The course of CFS had a profound impact on sufferers' self esteem and identity. Sufferers' pre-illness views of self had highlighted their actual physical, cognitive, and social competence as well as their potential for future personal development and social role occupancy. But symptom severity impaired their performance and interrupted social roles. Brief remissions and frequent relapses militated against recovering ground lost to role interruptions. And the uncertain duration of the illness gradually reduced hopes of realizing dreamed-of futures. As the course of illness gnawed away at their activities, roles, achievements and imagined futures, the possibility of meeting desired social norms receded. Many sufferers began to see themselves as physically and cognitively impaired and they began to face the possibility that they might not enjoy certain social roles.

Changes in Physical and Cognitive Aspects of Self

Having CFS drew sufferers' attention to three aspects of their physical selves- body image, physical functioning and physical health. As their activities declined, many sufferers gained weight. And many had difficulty reconciling their new appearance with their previous body image. They shared societal preoccupation with youthfulness, thinness, and attractiveness as desired cultural norms and their opposites as devalued traits.

> I have put on weight, which doesn't seem like important, but to me it is. I put on at least 20, 25 pounds since I have been ill. Just the whole way I feel about myself is not very good. I see a fat, saggy, old woman now and just three and a half four years ago you should have seen me, I was thin in shape, people never gave me my age. I felt good and didn't feel my age.

Of greater concern to sufferers than body image and appearance was loss of control over their physical functioning. They had gone from being fit and active to being exhausted after taking the dog for a five minute walk. In fact, that could be the day's activity. A few were assessed as being sufficiently debilitated to merit medical exemptions from mundane demands such as bank line-ups. Problems of endurance were compounded by symptom unpredictability. Since they could no longer predict their physical abilities, previously sociable sufferers tended "not to make commitments to things or to people...just live life day to day, because I do not know how I am going to feel on any given day". They could not even commit to special occasions. Despite planning for extra rest a day or two before and after such activities, unexpected exacerbations kept several sufferers from attending major family events such as the funeral of a parent or close grandparent and marriages of close relatives.

Many sufferers also became concerned about their general physical health. Many were plagued by multiple infections, but a few reported they hardly ever had minor infectious illnesses any more. Some felt that CFS had made them more vulnerable to other, more serious, illnesses.

> I also worry about long-term. In this little booklet I was reading last night, they talked about cancer as more prevalent [in CFS sufferers]...I read things like this and I think "oh God, what next?"... because there is so much talk about the immune system, and I worry that mine is...[that] cancer, it is just going to come in and walk right all over me.

In many cases, declining physical capabilities were accompanied by cognitive impairments most notably in memory, concentration and information processing. Sufferers reported forgetting important meetings, not being able to follow the agenda, and not being able to hold their own in social situations because they could not follow the conversation. When they could not avoid social situations, some tried to 'pass'[9] as 'normal' by lying, while inwardly feeling severely stressed.

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[9] Goffman (1963) divided stigmatized conditions into those that are discredited, and those that are discreditable. Discredited conditions are usually visible, while discreditable conditions may be hidden at least most of the time. The

> I have trouble remembering...and I am not as sharp as I should be.... I go along but I feel like I am a bit of a fraud... I am afraid to be found out....I feel very shallow, I cannot get into deep discussions with anybody...I just feel very stupid...If I were at home and not out working, maybe it would not bother me as much. But I am in with people who are very intelligent...Last weekend we were at a dinner party and...I came away from there feeling very bad about myself, very poor self-image. You cannot even sit there and describe it...I do not want to tell people what I have. I guess if it attacked the muscles and it just stayed with the muscles, but when you start talking about a person's brain, like Alzheimer's, it is such a pathetic disease. I do not want people to look at me as if I am not as smart as I should be.

> I don't have a life anymore, my life is this moment. For me it's good, it's a social moment [the interview],...I find I am unable to carry on conversations,...my memory just goes on me, and sometimes I start saying something and I don't know what I am getting at anymore, I forget. I can't always keep focus on what's being said, I lose track ...not being out in the workforce, not being out in the world what do you talk about? This is my reality (spreading her hands to show her small apartment)....Oprah is the highlight of my day. I never used to be a TV watcher...Now I can tell you what's on [like] the TV guide. So if I do find myself in a social context, [for example] a wedding.... I really don't know what to say. I sit there and I am very quiet. I don't, I can't relate to people anymore. I am embarrassed. I am embarrassed to say I am not working. I am embarrassed to say I am sick. So I have started lying in the last year.

Cognitive impairment was clearly incapacitating in social relations. But more than creating embarrassment, cognitive impairment could present a real danger to sufferers and to others. One man recounted almost setting his home on fire, and no longer cooks if he is alone at home. Quite a few voluntarily quit driving a car because they were regularly running red lights. They would see the light, but its meaning would not register. They were not processing the information appropriately.

> I had to stop driving because it happened 3 times in the space of a month that I went right through a red light and right through 2 stop signs, with my wife, daughter and grandson in the car. I said "that's it, car is gone". Once I got off a plane, I was driving [home] and I suddenly became disoriented. I got a mental flash that I was driving the wrong way on the freeway. I slammed on the brakes and the car spun around and went over the side of the road. It took me about 2 minutes to come out of the stupor, and I drove home very slowly. It can hit you at any time. You cannot trust yourself and it is dangerous to others. I imagined what would happen if I had had an accident with them [family] in the car.

Some recalled driving and missing exits they had taken daily for years. Others started from home and turned around to drive back without knowing where they had turned or why.

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person with the discreditable condition may thus 'pass' as normal unless they choose to disclose their problems to others. Thus 'passing' is a strategy that people with a discreditable condition might use to manage social relationships. Some conditions, like epilepsy, may largely be invisible, and thus be considered a discreditable condition. However, even in well controlled epilepsy, seizures may occur unpredictably and reveal the discredited condition (Conrad & Schneider 1983; Scambler 1984)

Some sufferers found themselves not remembering where they were or where they had been. But perhaps the most poignant consequence of impaired cognition was described by a woman who wept as she recounted forgetting her young son in a park, after being distracted by a conversation with a friend. She realized what had happened only when she returned home and her husband asked for their son. Fortunately a family friend found him and brought him home. High level cognitive functioning was a prized characteristic among this well educated sample of CFS sufferers. To regard themselves or be regarded by others as intellectually compromised was a considerable blow to their self images.

Altered Futures: Delayed Dreams, Canceled Options.

The uncertain prognosis of CFS forced sufferers to rethink plans for work and family roles. Those who were students had to put career training on hold. These were dreams delayed. Some hoped they would eventually get back on track, others cautiously resumed a reduced academic load, and still others dared not think about the possibility. Those who had withdrawn from work, had to re-imagine themselves as unemployable for the foreseeable future which was quite frightening for someone say in their twenties. Those who had remained in or returned to the workforce wondered whether they had reached an undesired ceiling in their careers, and whether they could even remain employed if they could not advance. As it was, they were barely treading water to stay at their present levels.

> I think that on a professional level, it probably is a pause of about 5 years...Unfortunately, I have my colleagues. In the pecking order, I have fallen to a weak position because not only was I defined as ill, but I am not producing, even though their production is not impressive. I cannot get in the boxing ring with them. In the mid-range time, I will probably try and do something else. If I had other options, I do not think that I would continue [in this profession].

Dreams of a dynamic career were relinquished slowly, painfully and reluctantly. Some sufferers tempered disappointment at having to lower expectations of themselves, by assigning greater priority to health than to achievement.

Work and career training had been integral to most sufferers' identities. Work was a source of self esteem as well as means to financial independence. It was a blow to have hard fought-for career goals dissipate.

> ...the career aspect. That is devastating. You have a goal in life...I made a decision quite young in life that I would never be financially dependent on any man, a husband, a boyfriend...That I would be able to stand on my own two feet. So I pushed and pushed and went against all the odds, I got a Master's degree. I really felt that the better educated I was, the better the salary, the better I would be able to take care of myself and have a very good life. That was my goal. This illness has taken everything away from me. Not only the self-esteem, but the career. I had plans. I was going to buy myself a home. It was all taken away.

> Financially I have been broke for 4 or 5 years now. That is a bad feeling too. I have had all my freedom and independence taken away. Even if I am able to make choices, I cannot back them up financially now, I cannot commit myself completely. It took a lot away.

Without work, some sufferers felt they that their lives were a waste because they were not contributing to society. Such thoughts fed feelings of discouragement and led some sufferers to contemplate suicide. With respect to occupational roles, the problems sufferers faced were how to remain optimistic for the future, how to make decisions about the present, and how to find alternatives to explore.

Uncertainty about future family roles also led sufferers to question how they saw themselves. Single men and women spoke sadly of the possibility that they would never marry, never have children. How could they think of marriage when they did not know if they could continue to support themselves let alone others? Women, whether single or married, were confronted with both a biological clock for childbearing and questions of whether they would have the energy for childrearing. It was not that partners could not help, and in some cases, paid help was certainly affordable. Rather, much like sufferers who already had children, childless sufferers felt that while they could still be "good" parents, the vagaries of this illness would prevent them from being the parents they wanted to be.

> The one thing that sits very sadly with me is the maternity issue. .....People that are quadriplegic and [have] all sorts of terrible illnesses do [have children], but I also knew that with my husband's really hectic lifestyle, it was bad enough being quite isolated with this myself and yes, you could hire help, but they're not with you twenty four hours a day necessarily. It would have taxed both of us. This illness taxed our marriage tremendously and neither he nor I, much as we would have liked a child, we didn't want to lose ourselves. And what would I do alone with the child [in the

> event of divorce].?..I guess I'm harsh on myself in the sense that there are a lot of mothers that aren't perfect mothers but they still have children. But I never wanted to have to constantly be saying "Mommy'd love to go to that concert, but you know I'm sick" or "Mommy can't this time but I hope to next time" and next time comes around and sure enough, the child is disappointed. That has to have an impact. One mode the counselor presented was "what do I think? Is it more important to have a really strong mother twenty four hours a day who's basically unhappy with her life, but always around for the child, or a mother that isn't very well at all, but spends one hour in the day of quality time with that child?" Well, I think the latter . But it isn't how I want it. I would be very unhappy with that. So you make the choice....I met a lady the other day who had some problems and who had her first child at forty-two so I keep thinking, well all this research is happening. I don't want twelve children.

Despite the glimmer of optimism at the end of the quote above, having children is a canceled option for many women sufferers.

Sufferers found the changes in their physical, cognitive, and social ways of being profoundly unsettling. Several said they did not feel good about themselves. Some described feeling " like I was not a whole person any more", "I might as well be dead", "contrary to what you know you really are", "useless", "spectators", "unable to function normally". Many began to see themselves as sick people, and commented on negative reactions that status elicits in society. One woman felt she was perceived as "weak" because of her illness. Other sufferers believed that "people don't want to be around sick people" or that being sick was associated with social distancing and marital breakdowns. Another regretted that her young children had never known her as a capable person. Her young adolescent son "was astonished when he found out what I had done for a living 'Mom, the dimwit'". These comments suggest the self devaluation that may accompany impaired functioning. Self devaluations were made relative to the larger society, but they did not necessarily depend on overt negative reactions. It was enough that sufferers shared the values of the larger society for them to recognize when they had fallen short (Goffman 1963).

Having CFS meant losing control over their day to day lives and their destinies. Many sufferers lost their credibility, friends and family, self esteem, financial independence, and the chance to achieve their full potential. Many sufferers found it ironic that they should be accused of secondary gains considering the price they had paid in the

magnitude and range of their losses. The task facing sufferers was how to carry on despite undesirable changes in their social identities and unpredictable symptoms of indeterminate duration. Carrying on involved restructuring identities, finding meaning in illness, and managing symptoms.

Restructuring Identities.

Reconstructing identities following chronic illness or disabling injury has been well documented (Bury 1982; Williams 1984; Charmaz 1987; Corbin and Strauss 1987; Yoshida 1993). The identities of CFS sufferers had been closely bound to self images of being physically active, intellectually acute and socially engaged. To regard themselves as limited in all these spheres was a difficult adjustment.

> I was a very active person, super active, super energetic. I worked hard and I played hard... I would ski every week-end. I had a sport for every season, country sports because I am a nature lover, and everything has been taken away.

> I was working two jobs, I was going out socializing, I knew lots of people. I was culturally oriented I liked to go to plays, concerts. I had such a full life... and [now] to go to a movie is a production.

Sufferers' attempts to "push through" in the early period of illness, or to break through during remissions, may have been not only acts of frustration, or testing to see if they were cured, but testing to see whether their old selves had returned. The importance and attachment to their pre-illness self was unmistakable. All sufferers made a point of letting me know they had not always been the way I was seeing them now.

Work and Restructured Identities

One quarter of the sample of sufferers continued to work, thereby maintaining an activity that was important to their self esteem and identity. These sufferers identified two factors that were critical for them to continue working- a strong work ethic that made them feel guilty when they did not work and a work structure that allowed considerable

flexibility. Instrumental help at home was also important in some cases, as it allowed sufferers to focus their energies on work as their main activity.

Being independent entrepreneurs or free lance workers put workers in a structure that allowed considerable control over the amount and pace of their work. With that control however, came the responsibility for the consequences to their incomes. Sufferers who worked part time also enjoyed structural flexibility. Some did "on call" work for a single employer, but could refuse assignments. Others registered for casual, contract work with several institutions and were able to play one institution off against another without losing their position in each. For example, they could tell one institution they were unavailable because they were working for another, knowing this would probably not be verified. In fact they were buying time to recuperate from exacerbations. But they lived with a certain amount of anxiety about being discovered. Some sufferers were allowed to pool vacation times and leaves of absence to obtain necessary respite. A few refused promotions or asked for demotions because they feared that with their illness they could not meet the demands of a higher level job.

It may seem intuitively obvious that symptom severity, and therefore impairment, would also be an important factor in sufferers' ability to work. This element was not explored with these sufferers. But a study of the quality of life of CFS patients found no difference in levels of impairment, as measured by the Sickness Impact Profile[10] scale, between sufferers who worked and those who did not (Schweitzer et al. 1995).

Sufferers paid a high price for preserving that part of their identities derived from work. They were exhausted at the end of a regular work day. They could hardly wait for the weekend to recuperate.

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[10]The Sickness Impact Profile measures sickness related dysfunction in twelve categories-alertness, recreation and pastimes, home management, social interaction, work, sleep and rest, ambulation, body care and movement, emotional behavior, mobility, communication and eating.

> Monday to Thursday, I'll come home and put a chicken in the oven or something like that, the rest of the time its junk food. I can manage for the week but on Thursday and Friday I am totally whacked out. That's when I have to make something quick for supper, order pizza whatever and lay down on the couch. Normally I am on the couch anyway at 7 o'clock, but on Thursday and Friday I really hurt...after 7 o'clock I am a vegetable. I really push myself. If its a Friday night and I get home really tired and drained, I might take the kids out to a movie.

> I didn't go out on dates, I haven't been to a party because when the time came to go, I couldn't go because I was just too tired. You don't teach until three o'clock. You go home and work for another four hours. You have to correct, you have to prepare. So by the time Saturday came, it was all I could do to psych myself up to wash my hair and have a shower, to get clothes to the dry cleaner...to do the shopping, to do everything I have to do. So I'd say from the seventies on, the past twenty years, I have had no social life at all.

Not only was there a physical and social price of working, but the rewards of immense effort would probably be limited. Sufferers had to scale back expectations of how far they could advance.

Many of those who did not resume work professed an equally strong work ethic. They were different from working sufferers in their access to flexible work structures. Without such structures to support their efforts, these sufferers expressed a pervasive concern that while they might get a job, they could not keep it. Some had tried unsuccessfully to obtain or do part time work. Others had lost their jobs to downsizing while on sick leave. The dilemma for these sufferers, and for others who had considered changing jobs before they became ill, was how to reconcile symptom unpredictability with prospective employers' presumed expectations. Sufferers could not guarantee that they would be reliably present on the job, produce predictably, or do sustained work. They lacked confidence in their ability to do precision work accurately. They worried about explaining extended work absences on their curriculum vitae. If they were truthful, they feared they would not be hired. If they lied and needed frequent time off, what excuses could they give?

> ...this is not a good time for a job even if I were perfectly well. I phoned every agency and I told my story to a few of them...there is no way that anyone would hire me because of this illness, This is going to be a big problem...I can make an application...and lie... it would take me in good health not missing one day, one year to retrain... and then,...I have to be in perfect health , because the employer, which I understand, you cannot say "excuse me, like I have to go and lie down". This is out of the question. So now I am on welfare, I am finding it so hard and its such a big strain...

Sufferers on disability benefits were afraid to apply for jobs with new employers. If hired, they would forfeit existing payments without the guarantee they would qualify for group benefits[11] with a new employer. In that case, if the new job did not pan out sufferers feared they would be left without a source of income.

While the restructuring task for those working was to reconcile themselves to lowered expectations, for those who were not working it was a question of justifying to themselves and others why they were not. The nature of the illness, a poor economic climate, and structural constraints set by work environments and insurers were obvious reasons that they could point to. Beyond these factors, some sufferers questioned the harms of a work ethic taken so far that it had become unhealthy. They began to repudiate the very values which they had embraced so completely.

> This North American rat race is pathetic. ...You look at life very differently. I don't know why people are not more sick in North America. I am not averse to hard work. I was overindustrious, an overachiever, I did too much. Many people who have this disease are like that.

Others tried to find meaningful new activities. One person did volunteer work in prisons, another in hospitals, and several became members or organizers of support groups[12].

Meaningful New Activities: Support Groups

Two sufferers briefly recounted the start of support groups in Toronto and Montreal. The Toronto group began first in January 1987. Advertisements about the meeting brought in an estimated several hundred people. After some discussion, a decision

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[11] People automatically qualify for group benefits if they are working with a company the first time a new group disability benefits plan comes into effect. However, people who join a company after the group disability benefits contract has been in effect, may be subjected to health screening to determine their eligibility.

[12] Thirty two of the total sample of forty two sufferers had been in or were still members of support groups. Six of these were sufferers recruited through physicians' offices as part of a larger study by Kirmayer and Robbins (1995). The remaining twenty six were recruited through support groups and CFS associations.

was made to break up into smaller geographically bound groups that could meet in sufferers' homes or in church basements.

The Montreal group was begun in 1990 by a sufferer who had moved here from Toronto in 1988. For a while, she thought she was the only person with the illness in the province of Québec. To break the isolation she was experiencing, and believing she had benefited from a brief experience with CFS support groups before moving to Montreal, she decided to find out whether there were other sufferers.

> I announced it on the TV and in the newspaper. The first meeting was at my house. There were 33 of us [sufferers] and 2 doctors. They came not to instruct us but to learn from us...[After a] time, there were 105 people. So we rented a hall...There were several physicians and all of us started talking about perhaps starting an association because we would have more credibility. One thing followed another and now we have about 35 support groups in the province and we are an official association with a charitable tax number. I was on TV many times and in the newspaper. There was an article in the paper that they took from an American paper and it said "if you have any of these symptoms, call this number". And they gave my number and people called me.

The Toronto group had split along geographic lines. The Montreal group split as numbers grew, first along linguistic, and eventually along smaller geographic, lines. The founder of the Montreal group observed that the support group has provided her with a renewed sense of importance.

> Sometimes I reminisce about what could be, but I do not dwell on it like I used to. When I accepted the illness, that is when I decided to do something positive. ...I decided to start the association...I still like some kind of intellectual stimulus and I needed to do that. I needed to feel that I was good for something, because when you lose everything with this illness, your self-esteem goes. You feel that you are good for nothing, a lot of people get very suicidal and I was at one point, at the very beginning. This made me feel important and I have contact with other people. If you are in the house all day long, you cannot get out into the workforce and you cannot be as social as you were before. I am not a hermit, I need that physical contact. Whether it is on the telephone, you are still having some kind of contact. It was very isolating for me for many years...

The feeling of usefulness, of contribution to others, and sense of purpose is not surprising. Support group leaders become resources for information, referrals, and emotional support. They organize meetings and social activities and collaborate with other leaders to stage larger events such as lectures to mark May 12th, International CFS Awareness Day. One support group leader described his role as follows:

> ...basically most support groups have monthly meetings. But in our group's case, it has not been monthly because I did not feel that I was qualified or gifted for that kind of work, social work. I

found it difficult and for many months, I myself was not feeling well enough to attend the meetings. Under those conditions, I felt that it was wrong to call a meeting and not show up. So we met every 4, 5 or 6 months. Now we try to meet more often.

What usually happens at these meetings?

Basically, it would be a question of giving people information, if they have questions medical or others, such as "where can I find a doctor who understands this illness, who shall I see?" Questions about how to diagnose an illness, how to know whether it is Chronic Fatigue or something else, which people want to know before they see a doctor. There are the obvious questions like "how long will it last, is there a cure?". Questions about what medications to take, what can be done in terms of diet...Another group of questions are about dealing with the disease from an emotional point of view, or how to manage energies. Mostly, the support group is there in order to answer questions. You might also say it is there in order to give emotional, moral support to people-that is what most people will tell you. However, after having worked at it for many years, I can tell you that answering questions is more important. Once you are able to answer peoples' questions, they are a lot less agitated or worried. Moral support becomes secondary once you have answered basic questions. People have worries such as "am I going crazy?". Once you can answer that by saying "no, this is an illness, it is a disease and it is not psychological" -as far as we know at the moment- I do tell people that. Once you tell them these things and say that it is not fatal, it has been my experience that that is much more important than anything else you do in groups.

The helping role was not vested in leaders. To the extent that they could, each member of the group tried to provide encouragement, hope, and practical advice. They performed this role in meetings or by telephone.

Some support groups, associations, and individuals have taken more political action. In 1993, A Task Force of the Board of M.E. (Myalgic Encephalomyelitis) Ontario produced an ambitious paper: "Catalyst for Change: Discussion Papers on Some of the Challenges and Opportunities for M. E., Ontario (The term myalgic encephalomyelitis is the name by which CFS is known in Britain, and it is the term preferred by sufferers in Ontario). The paper focused on educating the public, physicians, insurers, lawyers, and government on the problems of people suffering from CFS. It provided a clear succinct synopsis of the difficulties that sufferers face when they apply for disability insurance. The Task Force's brief highlighted some issues in sufferers' experiences with doctors and insurers that are consistent with findings of the present study.

The Task Force proposed a number of initiatives to disseminate information on CFS and to develop resources for sufferers. If realized, many of these proposals would enhance the credibility of sufferers and the legitimacy of CFS. For example, the Task Force recommended the establishment of clinics devoted to CFS, funding for CFS research, and

special clinical days for continuing medical education on CFS. Moreover, the report suggested distributing general information on CFS to libraries, physicians' offices, clinics, and pharmacies. These are all venues that may confer legitimacy on information found within their walls.

In 1993, another organization- The ME/FM (fibromyalgia) Action Network was established in Ottawa. In June 1993, the network was incorporated as a non profit organization and applied for charitable status which was approved in 1994. In 1995, the network received a grant of $35,000 from the federal government to fund its various projects. It is currently investigating possibilities for becoming self sufficient.

The network acts as a clearing house for national and international information on CFS, a referral center for sufferers seeking doctors, lawyers, and help with insurance matters, and an action group that tackles issues of concern to sufferers. In three short years, it has been involved in a broad range of activities on behalf of its members. For example, the network closely followed definitions and classifications of CFS. It published the 1992 International Statistical Classification of Disease and Related Health Problems (ICD-10) diagnostic classification of ME (CFS), noting that it was the first time that the illness had appeared in this World Health Organization publication. It followed the progress of proposed revisions to the 1988 case definition of CFS by writing to the Center for Disease Control (CDC) in Atlanta for updates on their discussions. It urged sufferers to write to the CDC to try to influence the new case definition. It reprinted the criteria of the new case definition shortly after it was published in the December 1994 issue of the medical journal Annals of Internal Medicine. In 1995, it informed the Laboratory Center for Disease Control in Canada (LCDC) of the new CDC case definition, and asked for its position on the matter.

The ME/FM Action Network, also set its sights on insurance issues. Besides reporting regularly on cases that could impact the status of other CFS sufferers applying for or presently receiving benefits, it appointed someone with experience in disability cases as

its National Director of Insurance Matters. In addition, the network launched an Insurance Survey, which they eventually handed over to an outside firm to collect and analyze the data. The study is still in progress. Its intent was to collect information on such matters as the number of outstanding insurance cases, the names of companies involved, cases pending trial, cases settled and so on. The network also contacted several provincial Superintendents of Financial Institutions as well as their federal counterpart to clarify their role with respect to insurance companies, and their positions, if any, on CFS cases. A related issue that the network pursued was CFS sufferers' eligibility for the disability tax credit. In a series of newsletters, the network provided tips to sufferers on how to claim the credit and lobbied governments, with some success, to consider sufferers as eligible for the credit.

The network set up a national referral network of lawyers and doctors, publishing new additions from various parts of the country as they came on board. They monitored the media and wrote letters correcting inaccurate information when necessary. They publicized political actions such as a petition to the House of Commons for recognition of CFS and research funding, that garnered over 14,000 signatures. For several months in advance, they encouraged activities for International CFS Awareness Day on May 12th. They kept members apprised of upcoming popular and academic conferences, books, videos, and articles of interest. They announced a new academic journal devoted to CFS - Journal of Chronic Fatigue Syndrome. Their brief announcements of research studies included reports on the status of a treatment study using the drug Ampligen and the work of Australian researchers (Dunstan and Roberts 1994) who claimed they had found a diagnostic marker for CFS. These investigators are reportedly awaiting patents before publishing papers on their findings[13].

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[13] News of the findings of diagnostic markers for CFS first appeared in the ME/FM Action Network newsletter Quest 1994 communication #7, 1st Aug. , p.2. Reasons for the delay in publishing findings appeared in the following newsletter-Quest 1994 communication #8 Oct. , p. 3.

The network has also acted as a conduit for researchers seeking subjects for various projects. It has publicized the plight of a medical doctor who was being brought before the disciplinary committee of the Ontario College of Physicians and Surgeons allegedly for malpractice while he claimed that it was because he was practicing complementary as well as mainstream medicine.

The network publicizes its activity through a newsletter, Quest which it publishes six times per year. The newsletter has taken the stance that sufferers should be under the care of a medical doctor and that doctors should be consulted before undertaking treatments for example. It carries a disclaimer noting that it is a clearing house for information and that it is not dispensing medical advice or supporting any specific medical hypothesis about the illness.

The newsletter also acts as a source of encouragement to sufferers through the president's letter that appears in each issue, brief notations of upbeat publications about or by sufferers, and a humor section- "Welcome to our World!". In their April 1994 issue, for example, "Welcome to our World!" carried the following:

NUMBNESS- reprieve from pain

PALPITATIONS- a chance to feel like you've exercised.

In 1994, the newsletter added a logo of a stylized half of a maple leaf and a flock of Canada geese flying in the "V" formation. The president's letter in the February 1994 issue of Quest explained the symbolism: "When the Canada Geese fly South for the winter, they fly in the "V" formation. As each bird flaps its Wings, it creates and Uplift for the bird immediately following. By flying in "V" formation, the whole flock adds at least 71% greater flying range, than if each bird flew on its own" (Neilson 1994:1)[14].

Individual support group members have also taken political action. One sufferer sent a letter to the Prime Minister and organized a march on Parliament hill in 1994.

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[14]The president credited "The Goose Story" to the publisher of the Orilla ME Support Group, Janice Winchester.

Another support group member became involved in an organization aimed at helping homebound people in general, inspired by her experience with CFS.

The above examples show how sufferers who were support group members or leaders of various CFS organizations could incorporate helping and activist roles into their identities. Many were well educated, highly articulate, and politically sophisticated. Support groups and associations gave them a channel to express their grievances, help others, and regain some sense of control by participating in activities for their own benefit. Knowing that so many others shared their plight softened the impact of dismissive and disparaging comments. Information from support groups and other sources reinforced sufferers' definitions legitimizing CFS.

For many sufferers, support groups were both a lifeline and a means of rebuilding identities. But a minority of sufferers regarded support groups unfavorably. These sufferers believed that support groups encourage people to revel in the sick role identity.

> I tend to think that the more you are involved with a support group, the more you dwell on it. And the more you dwell on it, the less you deal with it, the more it becomes something that mushrooms. Instead of learning to adapt to it and to accept it and to work around it, you tend to become totally focused on it. I don't think that's healthy at all.

Others eschewed support groups because they did not want to relate to people who assumed the identity of passive victim.

> "I thought they were going to commit mass suicide...They were at a different level in the way they thought about it. For them, it was "I have this sickness and that is it, I am going to die and I don't want to know about anything, I don't care". Maybe they were worse off than I was. I said "I can't get to that level". Maybe I will feel that way in a year from now, but not now.

Still others simply did not find it an appealing prospect to talk about their experiences or listen to those of others.

On the one hand, illness forced sufferers to think about their identities in terms of what they could do, on the other it forced them to dig deep and think about who they were.

Some began to explore creative aspects of self that could be expressed in less physically demanding activities such as art, music, or indoor gardening.

> ...now I am exploring another facet of living, and that's the art world...I am much more art based than science based...Now I'm painting, That was more for the serenity that it gives me. And yet... the feedback you get [from others] is "serenity, that would be hell for me"...I'm not good but I'm working on it. I can certainly see my progress. Now I am beginning to think, maybe the world of science wasn't so good for me.

Others focused on the spiritual dimension of self that in some cases had been long neglected or shaken by being ill. Becoming more spiritual helped sufferers to find meaning in illness, to cope, and to see themselves as "more caring", "more tolerant" and "a better person".

> I really factored out in my mind that....I may not have a high paying job, whatever. It does not matter. As long as we stay stable and healthy, the ultimate goal is to survive... we live and work to accomplish things, such as having a house, a car and then we die. When you cannot do that ... you have to have something else. If this sickness has stopped me from having everything that we as a society want to have, then I am a failure, I have failed at everything, so I am miserable. What I focus on is what Jesus Christ said is *important*. You change your attitude from 'me' to 'you'- giving instead of taking. Then I said "there is a reason for all this, if this is happening, God must have a reason for it". Maybe He is helping me to sharpen a tool and if it is not in this lifetime, it will be in another lifetime, I had my chance, that is all. I really believe that and that feels good, so nothing is in vain. You are not suffering for nothing.

> I studied reincarnation and that sort of thing well before I became ill. It was much easier for me than for many with this illness, to accept the point of view that illnesses may or may not be a karma. They can be the automatic result of actions in a previous life, which require correction from the point of view of your mentality or your behavior in this lifetime, like an action/reaction. Also, I know that we get illnesses because our souls are aware subconsciously that we want to make more progress in life, from a spiritual point of view than we make by being stuck in a certain routine. These illnesses break up our previous patterns of behavior and career etc. This knowledge helps me to deal with the illness much more effectively than other people.

Becoming more spiritual was not only about organized belief systems. To many sufferers, it meant taking stock and affirming their values beyond societal definitions of the good life. It was not a repudiation of the work ethic and other societal values as others had done. Rather, it meant putting into perspective work, relationships, achievement, consumerism, coveted lifestyles, the place of health, and the "right" body image.

> Just looking out my window and seeing all the trees, going up north...these are things that were not really important to me, but they are now...I can recognize good in people and when I do, I do not let them go

> I haven't looked at it as a negative thing. The first year, I didn't know where I was headed and I never seemed to be getting better and it was difficult...but now coming out of it, it's like this whole new world and this whole new perspective and feeling...that life is worth living. ...before I got sick...there was a certain amount of situational fatigue in my life.... This feeling of every day is like another, and drudgery. I don't think I was cut out to be the full-time homemaker that I became and I think I put a lot of pressure and unrealistic expectations on myself. It's interesting that that was the way my life was before I got ill...It's been about finding meaning in my life again, getting sick. I really, really believe that.

Coming to terms with changing identities has been far from easy. For many sufferers, it remains an ongoing process. It has been especially difficult for those sufferers who have neither been able to find meaningful substitutes for lost roles or to find meaning in illness.

> The uncertainty, very, very difficult, the suffering also. You combine those two, the lack of understanding of what's going on, not having the knowledge of when it will end or how it will end, combined with the suffering. Suffering is made easier by understanding precisely what it means. If you've broken your arm, it hurts but you understand. When you are suffering, [and] you don't know why and you don't know when it will end, it compounds, it reduces your ability to deal courageously with the suffering. You cannot grin and bear it and grit your teeth and tough it out because you don't know when you are supposed to tough it out until.

Developing creative aspects of themselves, valuing contemplation over activity, critiquing societal values, and helping others have gone some way to restoring some sufferers' self images. Rebuilding shattered identities helped sufferers to sustain the will to carry on despite illness.

Managing the Course of CFS

In more practical terms, to restructure their lives and identities with some degree of satisfaction, sufferers had to find ways to manage symptoms and maintain improvements. One commonly used approach to managing symptoms was to lead healthier lifestyles. This entailed reducing stress, adopting healthier diets, making decisions about exercise, and assuring greater balance in their lives. Several sufferers enrolled in transcendental meditation (TM) courses. Others tried to minimize sources of stress, by avoiding doubting friends, relatives, and casual acquaintances and, as been mentioned already, pacing and spacing activities. A related strategy was to evaluate social relationships and activities and become more ruthless in making choices and setting priorities. Several sufferers kept

journals to track their progress and discern patterns of exacerbation and remissions, so that they could take the steps necessary to keep symptoms in check.

Healthier lifestyles also entailed changes to diets. Some sufferers tried dietary systems such as macrobiotics, diets purporting to control yeast infections that some think are responsible for CFS, and the Swank diet reportedly helpful for people with multiple sclerosis. Others took various supplements, including intravenous vitamin therapy, vitamin B12, vitamin C, carrot juice, malt, and amino acids. No one claimed diets were a cure, but many thought they helped alleviate fatigue and food sensitivities. A few flatly rejected any benefits from diets. One man who had tried juices and colonics stated" "I think the diet makes you more tired. You spend more time juicing than anything else. I was putting four to five pounds of carrots a day in the juicer. I was spending all kinds of money, nothing was working...Go out and eat a pizza and a beer, you'll feel better".

The second strategy for symptom management was the pursuit of mainstream and alternative treatments. Among the medically prescribed drugs that sufferers tried were analgesics, antidepressants, sedatives for anxiety or sleep difficulties, antibiotics for infections, anti inflammatory drugs, muscle relaxants, steroids and licorice[15]. Any given treatment had its proponents and detractors, but comments about antidepressants and antibiotics were particularly common. Several sufferers found low doses of antidepressants helpful for pain relief and sleep problems. They hastened to assure me that these doses were below therapeutic levels recommended for depression. Many regarded antibiotics as iatrogenic causes of CFS.

Alternative treatments included: garlic, evening primrose oil, ecchinacea, ginseng, seeds of blessing, herbal mixtures, homeopathic, and naturopathic remedies. Hands on treatment included massage therapy, faith healing, and lesser known modalities such as

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15 Reports of using licorice as a treatment for CFS has generated both interest and critiques. The treatment was proposed by Baschetti, R. 1995. "Chronic Fatigue Syndrome and Liquorice" New Zealand Medical Journal 108 (998) : 156-7.

reiki, shiatsu, zero balancing, and craniosacral therapy. A few sufferers were treated with hypnosis, color therapy, primal screaming and exotic machines. To date there are no reliable treatments for CFS. Sufferers continue to search or to wait, hoping to hear of a breakthrough.

This chapter and the previous chapter have shown that the lives of CFS sufferers were profoundly altered by the course of the illness and the social reactions it has provoked. Societal reactions show how a medically unexplained illness can become a stigma. But sufferers' own reactions to changes in their social and personal identities show how a chronic illness can lead to negative self labeling. Sufferers are thus doubly stigmatized. What should not be lost sight of is how hard most sufferers have worked to overcome stigma from both sources.

Summary and Conclusions

The foregoing account shows that sufferers defined their problems as illness when alternative explanations no longer seemed plausible. It often took increasingly debilitating symptoms examined against the psychosocial contexts of their lives, their coping abilities and commitments to social roles, to convince sufferers they were ill. Many resisted entering the sick role for several weeks, months or even years. They were less resistant to the diagnosis of CFS once it was made. The question was why were sufferers willing to accept a contested diagnosis when, in many cases, they had been without a diagnosis for years? Perhaps the diagnosis did help these sufferers to proceed with their lives, as Woodward (1993) found in an Australian sample of people with CFS. But I propose that sufferers accepted a diagnosis of CFS for two additional reasons. The diagnosis of CFS was less stigmatizing than the label of malingering or being told it was all in their heads, because the very conflict around whether it is a physical or psychological illness meant that sufferers could opt for an etiology that was not stigmatizing. Thus, they could believe that viruses,

toxins, iatrogenic effects of drugs, and other physical factors were likely causes of the illness. A second reason why sufferers accepted, and continued to accept, the diagnosis was that they received repeated confirmation of their experiences through some lay and medical literature, sympathetic doctors, and the accounts of fellow sufferers.

Sufferers' struggles to describe the symptom of fatigue provide some insight into why others are not convinced of the reality of the condition. People with chronic pain face similar difficulties articulating their experiences (Hilbert, 1984; Ewan, 1991). Hilbert (1984) suggests that chronic pain sufferers cannot adequately convey their experiences to others because pain is commonly understood as acute and short lived. This understanding of pain is grounded in both experience and language, and therefore culture. However, most people have not experienced chronic pain. And current concepts and language fail both chronic pain sufferers in their attempts to articulate their experience and listeners who attempt to apprehend the phenomenon. The result is that the direct experiences of chronic pain sufferers have no resonance with others. Unable to understand the experience of chronic pain, others are not convinced of its reality and legitimacy. Hilbert (1984) suggests chronic pain sufferers are in continual danger of "falling out of culture" and becoming non members of society because they claim to have an experience for which others have no referents, either directly or through language concepts.

The parallels with fatigue are striking. Most people have experienced short term fatigue that is relieved by food or rest or both. Some people have also experienced longer term fatigue with known illness or injury. But continuing fatigue without an identified cause is less easily understood. I suggest that it is not only lack of experience or inadequacies in language that make it difficult for others to apprehend chronic fatigue. What is also missing are words or concepts that would make fatigue understandable by connecting it to a physical or objective entity. Chronic fatigue of CFS does not link the sensation to measurable or visible elements such as low hemoglobin levels, blocked coronary arteries that reduce oxygen to the heart, or restricted lung expansion from

respiratory disease. Descriptions of chronic fatigue remain a language of metaphors and analogies that require an act of faith for others to accept. Despite lacunae in language and medical findings, many CFS sufferers eventually found a measure of legitimation by having their direct experiences externally reinforced by fellow sufferers and by some doctors. And some have worked towards the legitimation of CFS through collective action.

With time, the course of illness eroded sufferers' views of themselves. Their accounts were replete with themes of loss: of opportunities, independence, spontaneity, self esteem, self image, valued roles, physical and mental capabilities and productivity. Those who worked, had to settle for being less than they believed they could be. Those who did not, were plagued by the feeling that they were less than they should be. The social world of sufferers became vastly constricted. They felt cheated of years of their lives and feared they would lose more in the future. They railed against being less than they could be or wanted to be. They resented having to revise and redirect their life goals. They regretted missing events and time with people that could never be recaptured. The losses that they chronicled seem to vastly outweigh any possible gains that may have been obtained from intentionally malingering. These losses should give pause to people who believe that CFS sufferers are malingers, since the malingerer must be able to both dupe others and to gain more by feigning illness than she or he would lose.

The losses linked to symptom duration, severity, and unpredictability contributed to sufferers' views of self as diminished relative to characteristics valued in society. Negative self labeling independent of actual instances of discrimination or devaluation is known as felt stigma as opposed to enacted stigma (Scambler 1984). In his study of people with epilepsy, Scambler (1984) found that felt stigma exacted a considerable toll. Not only did felt stigma influence people to lower career aspirations for fear that promotions would increase the risk of exposure, but it became "a profound and lasting, if intermittent, source of unease, self doubt and disruption in people's lives" (Scambler 1984: 217-218). He identified two components of felt stigma for people with epilepsy. The first is the shame

associated with having a condition that sufferers themselves perceived as stigmatizing and the second is the fear of enacted stigma. In a subsequent report (Scambler & Hopkins 1990) found that felt stigma was pervasive. Some CFS sufferers in this study were embarrassed at having CFS which they perceived as a stigmatizing condition -"a pathetic disease", a disease of "yuppies" an illness with a "stupid name". Most sufferers however experienced felt stigma because the disabling effects of the illness foreclosed avenues of achievement and functioning in valued social roles. Like people with epilepsy, CFS sufferers also feared enacted stigma especially in the workforce. The previous chapter presented examples of sufferers' fears of enacted stigma from doctors, insurers and family and friends.

As conventional social markers of success receded from their grasp, sufferers had to re-define themselves. Their pre-illness views of self emphasized what they did, as they listed past and present roles, achievements, activities, and what they had expected to do in the future. After CFS, sufferers had to find out who they were- what they were made of. Several focused on developing neglected or unexplored spiritual or artistic aspects of self. Several undertook a lengthy and often painful inner journey to discover their values, priorities, and strengths. Health, relationships, and the natural environment, took on a new salience. For some, discovering meaning in illness helped to make indeterminate suffering bearable. One major readjustment that all sufferers had to make was to reduce the space that physical activities played in definitions of self and to recognize that adapted or sedentary activities could provide a sense of achievement and social contacts. Another was to accept that future work and family roles that they had envisioned were no longer possible. A third was to find ways to redirect their remaining abilities into meaningful activities. Through support groups some had the opportunity to care for and about other sufferers and engage in social activism. These activities were important avenues in reconstructing less stigmatizing or non stigmatizing identities. Social activism publicly challenged the

stigmatized status assigned to CFS, while supporting others gave sufferers the opportunity to make socially useful contributions.

Yoshida (1993) has proposed a process and outcome model of identity reconstruction for people with spinal cord injury that has relevance to CFS sufferers. In her pendular model of self, the disabled person does not follow a unidirectional path to identity reconstruction but moves back and forth between pre disabled and disabled self, at different times, and in different situations. The arc described by the pendulum begins from the former self, moves through a middle self where disabled and normal parts of identity overlap to a disabled identity as the total self. Using this model, most CFS sufferers in this study would have reached a middle self, where former and chronically ill identities overlap. None consider themselves totally unchanged, and few see themselves predominantly as CFS sufferers. They have returned to some level of normalcy and incorporated or adapted former aspects of self into their new identities. They have used their intelligence to adapt their work to new realities, to cope with the physical debilitation and social stigma, or to politicize their plight. At the end of the interviews, sufferers seemed to be in all stages of coming to terms with changed identities that they did not desire. They miss their old selves, their old lives. But at least some sufferers have come to realize that a changed identity does not have to be negative.

CHAPTER 8

STIGMA AND LEGITIMATION IN CHRONIC FATIGUE SYNDROME: THE ROLE OF SOCIAL LOCATION

Despite the lack of conclusive biomedical evidence or medical consensus on the reality and nature of CFS, people in crucial social roles have staked out positions that stigmatize or legitimize the illness and its sufferers. And sufferers have maintained the conviction that CFS is largely or completely caused by physical factors. By studying both stigmatization and legitimation of CFS across four groups of social actors, this study has contributed to a better understanding of reactions to an illness whose status remains ambiguous. The findings showed the processes by which doctors, insurers, and significant others stigmatized and legitimized CFS, structural elements of their social locations that influenced these processes, and the costs to sufferers and others. CFS was found to be stigmatized as a psychological disorder or malingering as many others have noted. Further sources of stigma associated with CFS that have not been identified previously were its duration and attendant disability. The study also showed that believing in sufferers' credibility was central to believing in the reality of an illness that is not objectively verifiable. Since the illness is both stigmatized and legitimized, two processes seemed important to examine- how sufferers' credibility was assessed on the one hand and how stigmatizing or legitimizing definitions were chosen on the other. By simultaneously studying stigmatization and legitimation it was possible to identify how shifts occurred between the two positions.

Insurers' and significant others' perspectives on CFS are also new contributions to the literature on this illness. Previous data on how family members were affected or reacted were known only from sufferers' perspectives and the one published study of the impact of

CFS on insurers (Lloyd & Pender 1992) estimated only the economic costs. The present study details broader effects on insurers and shows how difficult it was for significant others to bear the emotional burdens of being close to someone with this illness.

The comparisons allowed by the study design led to the identification of common elements in the social locations of doctors, insurers and significant others that influenced their views about CFS and the impact of the illness, which in turn contributed to reactions to sufferers. Social location refers to the position of doctors and insurers in the medical and disability compensation systems respectively and the position of significant others in sufferers' social network. The elements of social location identified as important to stigmatizing and legitimizing CFS included goals, world views, relationship with sufferers, the vantage points afforded by these relationships, and options to manage the impact of the illness. The data do not suggest that social location is deterministic but rather that it conditions views and reactions in ways that make stigmatization or legitimation more likely.

The study also found that sufferers maintained their illness convictions in the face of widespread controversy and disbelief through both individual and social factors. On a personal level, persistent or recurrent severe somatic symptoms, functional deterioration, and self evaluations led sufferers to conclude they were sick. At a social level, these beliefs were sustained by intermittent reinforcement from supportive doctors, support group members, and selected medical literature.

These findings are presented with certain caveats. First, although together clinicians, insurers, and significant others manifested a wide range of stigmatizing and legitimizing reactions, the samples of clinicians and significant others were biased positively towards sufferers. No clinician who outrightly dismissed CFS agreed to take part in the study and the significant others who sufferers suggested were known to be at least sympathetic to the notion that CFS is a real illness. The insurers were a more varied group but several conceded that some CFS claims seemed to be genuine cases of illness and disability. Insurers stressed that their views about CFS were personal and did not

necessarily reflect that of their companies. But there were enough similarities across the sixteen people from eight private insurance companies to discern the patterns described. Second, views about CFS were quite unstable within and across groups. Thus, the views presented here represent the time period of the data collection from the fall of 1993 to late 1994. Finally, the findings rely on a cross sectional design and interviews that require retrospective data. However, the findings on sufferers' illness experiences are quite consistent with those of Woodward's (1993) dissertation on the natural history of CFS which used a longitudinal design. Her findings on doctors also overlap with those of this study. The findings on insurers and significant others require further study to establish their reliability.

With these caveats in mind, this final chapter draws together the strands of four different perspectives on chronic fatigue syndrome- those of doctors and insurers, and those of sufferers and their significant others. It summarizes, sufferers' experiences with stigma, the ways in which CFS was stigmatized and legitimized, and the costs of each position. It also shows how views about CFS and the impact of the illness could be traced back to common elements in the respondents' social locations on the one hand, and forward to their reactions to sufferers on the other.

Stigmatizing CFS

Most sufferers believed that CFS was a physical illness, but some accepted a possible role for psychological factors. The majority considered psychological distress a consequence rather than a cause of the illness. To their dismay however, sufferers found doctors, insurers, and significant others who considered the illness 'imaginary', 'all in their heads' or a 'psychological disorder'. Some were dismissed from the practice of doctors. Others felt harassed and disbelieved when insurers denied or terminated benefits, made what seemed to be excessive requests for independent medical examinations, or instituted

surveillance. They felt rejected and misunderstood by family members or close friends who distanced themselves or not so subtly suggested they should return to work.

Disparagement and rejection by others created a number of difficulties for sufferers. Dismissals by doctors before a diagnosis was made could leave them wondering whether they could or should take on the sick role. Without a diagnosis, they had no framework for organizing their lives and deciding how to manage their symptoms (Woodward 1993). Many reacted by initiating an extensive search for validation among mainstream and alternative care practitioners. Receiving a diagnosis confirmed their perceptions that something was wrong, but sufferers were often dismayed to discover they had a stigmatized illness that has no reliable treatments.

Denial or termination of benefits had not only practical consequences, these actions were a blow to sufferers' self esteem. They signaled the disbelief of insurers and spelled a shift from self sufficiency to dependency on family or even greater downward mobility to social assistance. Many sufferers felt that fighting these decisions depleted energy that should have been conserved to aid recuperation. Rejection by family and friends left sufferers to face an uncertain future with diminished resources for social support.

Sufferers felt betrayed by reactions of disbelief from their regular doctors with whom they had previously had a good relationship, from insurance companies to which they or their employers had paid contributions in good faith, or from close friends and family members whose support they had taken for granted. Repeated experiences of not being believed took their toll on sufferers' self esteem and self image.

But it was not only overtly stigmatizing reactions that made sufferers feel diminished. The mere possibility of encountering these reactions provoked a sense of shame. Sufferers were also embarrassed to have a suspect illness which in some cases they themselves had discredited in the past. Many also devalued themselves not only because they had the illness but because they had become chronically disabled- unable to participate in activities, fulfill roles, and meet their own and society's expectations. The insidious and

corrosive act of self labeling independent of others' overt negative reactions is known as felt stigma (Scambler & Hopkins 1990). Several sufferers became despondent and contemplated or attempted suicide. Sufferers paid the costs of stigmatization with tainted social identities, impaired mental health, and loss of social ties. And society paid the costs in sufferers' extensive health care use and need for social assistance.

To deal with felt and enacted stigma, sufferers employed the classic strategies described by Goffman(1963). Some concealed the illness and tried to pass as normal. Others used the strategy of covering in which they disclosed the problem but continued to behave as normally as possible so that CFS appeared to have a smaller place in their lives than it actually did. These strategies may reduce opportunities for enacted stigma but they also rob sufferers of potential sources of support (Ware 1992). A few sufferers recognized that concealment perpetuates the stigma associated with the illness. They publicly acknowledged having CFS and actively lobbied for its legitimation. Some sufferers who had previously characterized the illness as non existent or trivial used another strategy. They reframed their notions of CFS so that it became an illness that was real, physical and serious. This strategy has also been observed by Reid et al (1992) who studied people with repetition strain injury (RSI). When they became afflicted with a condition they had previously discounted, they began to view RSI as a work related illness or an illness of hard workers (Reid et al. 1992: 610). Like RSI, CFS shows the classic dilemma of those who now bear a mark that they had once stigmatized.

Doctors, insurers, and significant others who believed that CFS was a psychological disorder pointed to the absence of specific laboratory findings, personal and societal stresses affecting sufferers, and their coping abilities. Their various social locations provided differential access to the details of sufferers' lives. Doctors and family members knew most about sufferers' coping behaviors and about their personal and family stresses, sometimes going well back into the past. Insurers on the other hand usually knew about only more recent personal stresses, but they also considered the illness in light of the larger

context of contemporary socio-economic pressures. Doctors and insurers formed their opinions about the nature of the illness on the basis of direct or indirect experiences with groups of sufferers, while family and friends generally knew only one sufferer.

No clinician in this study suggested that sufferers were malingering. Some insurers and significant others, suspected malingering because of sufferers' sick role behaviors and appearance and because the possibility of secondary gains was present. These significant others and insurers had seen sufferers who seemed to revel in the sick role or to behave in ways that were inconsistent with being sick. In particular, some sufferers seemed to function normally in all but their occupational roles. Some seemed to use the sick role for monetary gains or the control of others. Sufferers' well-looking appearance also aroused doubts about their claims of illness.

Psychological disorders may evoke negative reactions because their onset and course are thought to be within the control of those afflicted (Weiner et al. 1988). Having such a disorder is therefore seen as a sign of weak will. For CFS sufferers to be told they had a psychological disorder when they believed they had a physical illness not only assaulted their character, it discredited their perceptions, interpretations, and self evaluations. Repeated discounting of this sort delegitimates sufferers' experiences (Ware 1992). Although stigmatizing, psychological explanations still leave CFS in the realm of illness and thus allow some measure of legitimacy. But a charge of malingering makes no such concession. It uncompromisingly shifts the discourse from illness to motive. Sufferers are not weak, they are disreputable. The proper response is not to grant sick role exemptions but to withhold legitimacy and deny undeserved rewards such as compensation and sympathy.

To the extent that stigma has been discussed implicitly or explicitly in studies of CFS sufferers' illness experiences, the focus has been on negative characterizations of its origins (Woodward 1993; Ware 1992; Wheeler 1992). But the current study showed that it was not just the belief that CFS was a guise for malingering or a psychological disorder

that provoked negative reactions. Sufferers' claims about the illness' duration and severity created doubts even in the minds of some who believed and supported them. Similar reports from people with RSI have been interpreted as the result of "compassion fatigue" (Ewan et al 1992: 18). Arguably, if CFS had been considered a short-lived form of malingering, psychological disturbance, or even a genuine physical illness, it would hardly have generated more than a passing interest. It would certainly not have created acrimonious debates and serious personal and social consequences. The chronic debilitation associated with CFS is an important source of the stigma attached to the condition. Being disabled lowers one's social currency.

Legitimizing CFS

To put in context the ways in which doctors, insurers, and significant others legitimized CFS requires a preliminary discussion of what it means to legitimize an illness. Social process and paradigm shift models have been proposed as two related ways of understanding how illnesses become legitimized. These approaches have been used to study conditions as diverse as miner's nystagmus (Figlio 1982) RSI (Willis 1994), cancer (Brown 1992) and CFS (Woodward et al. 1995). These studies emphasize two aspects of legitimacy -official recognition and widespread acceptance but they also question the official grounds for legitimation. Figlio (1982), and Willis (1994) drawing on Figlio's framework, focused on the socio-political processes involved in achieving official recognition for the illnesses known as miners' nystagmus and RSI respectively. Both conditions remain controversial but were eventually granted partial legitimacy in the form of compensation. Legitimation can be considered only partial because compensation came at the price of shifting RSI and miners' nystagmus from a model of malingering to one of psychosomatic disorders. As Willis (1994) points out the psychosomatic paradigm

originally intended to reverse Cartesian dualistic thinking and re-unite mind and body is not completely legitimate; it has come to mean 'all in the mind".

Woodward and colleagues (1995) emphasized the notion of legitimacy as widespread acceptance. They combined models of paradigm shift, social process, and social movements to show that CFS is in transition toward legitimation. From Kuhn, they take the notion that normal sciences like medicine are dominated by particular models that do not change until anomalous information which challenges their explanatory power has become widely accepted. From Willis they draw on three processes in the legitimation of RSI -1) a [new] cluster of symptoms appeared 2) medicine and other actors responded and 3) negotiations about the meaning of symptoms ensued. Using the notion of paradigm shifts and social processes to show the position of CFS in its course towards legitimation, they present the following argument. CFS presents current medical models with an anomaly. But it is becoming more widely accepted as a distinct category as refinements to its definition show that it cannot be subsumed under existing illnesses. Responses in the form of research studies by a range of professionals, many of which show sufferers in a sympathetic light, add weight to efforts to legitimize the illness. Finally among the legitimizing meanings of CFS being currently negotiated are suggestions to consider it a work issue and their own proposal that it becomes a public health issue because of its incidence and social costs.

The social movement model that Woodward and colleagues (1995) describe relates to the legitimation of Alzheimer's disease. It details the claimsmakers- caregivers, scientists and advocates; the basis of the claims- scientific research findings; and the 'social movement' which brought the claims to public attention- the media and politicians. They suggest that CFS support groups might perform a similar function. Although such groups cannot be said to constitute a true social movement, they have gone a long way toward publicizing the illness, lobbying for legitimation, and more importantly they have ensured that the medical profession is not the only source of useful information thus diluting

medical power. They concede that a major stumbling block to the legitimation of CFS is the lack of adequate biomedical findings. Their arguments on the legitimation of CFS implicitly assume that the illness is physical.

While this analysis offers some interesting insights on where CFS stands in its transition to legitimacy, it also raises certain problems. The case definition that distinguishes CFS from other illnesses emerged in three overlapping but not identical forms in the United States (Holmes et al 1988); Britain (Sharpe et al. 1991) and Australia (Lloyd et al. 1990). And in Canada one CFS association is calling for a Canadian definition to be developed. Recently, an international group of clinicians and researchers have revised the American (CDC) guidelines (Fukuda et al. 1994) but some researchers continue to defend the adequacy of the original case definition (Komaroff 1996). Moreover, the revised definition eliminated the few physical signs from the inclusion criteria "because...their presence had been unreliably documented in the past" (Fukuda et al. 1994: 957). These signs- low grade fevers, palpable or tender lymph nodes and sore throats without exudates- are used by many sufferers as evidence that they are not depressed. Excising these signs might weaken that argument. Thus, new definitions may not only represent refinements as Woodward and colleagues suggest but a decided shift toward considering CFS a psychiatric or psychosomatic disorder. Either characterization would be a Pyrrhic victory for many sufferers. Moreover, sufferers in the present study believed that many more symptoms are characteristic of CFS than those included in the 1988 CDC case definition. As long as the definition of CFS is perceived to be on shifting ground, the claim to be a distinct entity may not be accepted with confidence. The legitimacy that derives from being recognized as a distinct and separate illness remains elusive.

In addition, other conditions have commanded considerable attention in the past but later disappeared. Neurasthenia comes to mind. And there is nothing to say that researchers now interested in CFS will continue to study the condition. In a time of dwindling research funds, the illness is not a priority. Although its personal and social costs are considerable,

as this and other studies have shown, it is not life threatening and it has an image problem. Despite a lack of proof, illnesses like RSI and miner's nystagmus could be intuitively linked to physical factors, while to many CFS seems to be merely a matter of poor coping with current societal stresses.

By comparison with the above studies, Brown's (1992) focus is on the need to rethink the accepted grounds for legitimation. His study found that "lay epidemiologists" efforts to legitimize claims of a link between industrial pollution and cancer cases in Woburn, Massachusetts were initially dismissed because their data did not meet the traditional scientific burden of proof (Brown 1992). However, by persisting they eventually succeeded in having their concerns placed on various public health and research agendas. Brown (1992) suggests that this case may lead epidemiologists to re-evaluate how they think about issues such as low base rates of illnesses. Cumulative data from other small samples may well produce more anomalies to existing models allowing a paradigm shift to occur (Brown 1992:279).

The present study showed that negotiating meanings involved deciding whether CFS was real as opposed to malingering and whether it was a distinct category. It also showed the substitutes for traditional proof of a legitimate illness, concrete ways in which CFS was recognized, and sufferers' efforts to bring about official recognition.

The first step in legitimizing CFS was deciding that the symptoms represented an illness as opposed to malingering or normal responses to life stresses. These decisions did not rest on the fact CFS was officially recognized in various disease classifications. Like the data from Brown's (1992) lay epidemiologists, CFS did not meet the traditional burden of scientific proof that would guarantee its widespread acceptance as an illness. Across the three groups, sufferers' credibility became a proxy for scientific proof.

Respondents in all groups agreed that credible sufferers showed appropriate sick role behaviors and little or no evidence of secondary gains. For clinicians and significant others this meant that sufferers were reluctant to enter the sick role and eager to leave it. For

insurers it meant that if placed under surveillance, these claimants' behaviors were consistent with their accounts. Some insurers were impressed with the consistency of claimants' sick role behavior over time, reasoning that they could not keep up the pretense that malingering entails over such long periods. People from each group used additional elements to assess sufferers' credibility. Doctors used their clinical experiences and sufferers' epidemiological profile. Sufferers' credibility was enhanced if their symptoms fit illnesses with which clinicians were familiar, such as post viral fatigue. And their relatively young age, previous good health and occupational successes, suggested they would not have remained ill for protracted periods unless something was terribly wrong. Insurers by comparison were more inclined to grant credibility if claimants did not consult self-styled CFS experts. And sometimes unusual elements of a claimant's account had a ring of authenticity that lent credibility. Significant others considered sufferers' character, signs of physical distress, and marked changes in their levels of functioning in deciding on their credibility. A few acknowledged that believing sufferers was an act of faith.

The second element of legitimation involved believing that CFS was a new illness worthy of its own label. This is in line with Woodward and colleagues (1995) notion of a separate category. In all groups there were some who believed that CFS was probably a form of mental disorder, most likely depression. However, some clinicians became convinced that CFS was a new illness after hearing strikingly similar and distinctive accounts from several patients or from discussions with colleagues who had more experience with CFS. Unlike some doctors who found similarities in sufferers' accounts compelling evidence of a distinct illness, some insurers interpreted this phenomenon as evidence only of widespread media and support group publicity about CFS. They were more likely to accept CFS as a new category on the advice of their medical advisors.

The majority of significant others regarded or came to regard CFS as a physical condition distinct from depression. This belief was more likely when CFS followed a physical illness or when sufferers were evaluated as unlikely to be depressed because of

their personalities or lack of undue stress at the onset of illness. Some significant others discounted depression only after learning more about CFS, after standard therapy for depression failed to improve sufferers' symptoms, or after retrospectively interpreting signs as suggestive of a physical condition. Their social location gave them a window on sufferers' lives that grounded their evaluations in close observations and experiences with sufferers over time and in many different circumstances.

In this sample of doctors, insurers, and significant others there was no consensus on whether CFS was a real new illness. Nevertheless, there were many concrete expressions of legitimation among all groups. Doctors diagnosed the illness and kept sufferers in their practice, insurers paid benefits to some sufferers for at least a period of time, and most significant others acknowledged that sufferers were sick and in need of relief from their usual social roles. Such legitimation in microcosm can be helpful to sufferers (Woodward et al. 1995).

The discussion above and the findings of this study suggest that official recognition, widespread acceptance, and concrete expressions of legitimation are all important. But they are not enough to ensure that an illness will not be stigmatized. One only has to look at examples such as mental disorders and AIDS. Full legitimation without stigmatization requires that no moral judgment is attached to illness. For sufferers, full legitimation would mean acceptance of CFS as a real, chronically debilitating, physical illness without attaching blame for its onset and duration. They wanted more than the spotty and cautious recognition from official agencies that seemed almost random. They wanted doctors to give the diagnosis if warranted and acknowledge patients' needs for medical care. They wanted insurers to accept properly documented claims, to drop their adversarial stance, and to stop demanding excessive proof of continued eligibility for compensation. And they wanted friends and family to stop judging them. These actions would validate their perceptions and experiences. They could seek medical services and disability income without being made to feel they were undeserving, and they would not

have to defend their withdrawal from social roles to family and friends. In short, they could become legitimately sick without being subjected to moral judgments.

Costs and Benefits of Legitimation and Stigmatization

While legitimating CFS clearly benefitted sufferers, it had its costs. The time involved in managing CFS cases represented income foregone for clinicians who work in a system of payment that is volume driven and fee regulated. Clinicians also had to cope with the challenges of CFS. They found diagnosis lengthy, difficult, and fraught with fears of misdiagnoses or missed diagnoses. So much so that some clinicians continued to monitor the accuracy of their diagnosis years after giving it. In addition, they had to be mindful of sufferers' sensitivity to any imputation of a psychological disorder when making psychiatric referrals or explaining current etiological hypotheses. To avoid offending patients, some worked out low key approaches to any discussions involving psychological issues. Others avoided the subject even if they personally believed CFS was a psychiatric disorder. Several were reluctant to label the illness as part of their explanations for fear of "medicalizing" the problem, depressing patients, or setting in motion a self-fulfilling prophecy suggested by the name. Woodward (1993) also found a reluctance to label CFS and for similar reasons among her sample of Australian doctors. She argues that doctors would hardly have withheld a diagnosis had the illness not been controversial. The present study suggested there was some truth to the notion that doctors' discomfort rather than patient protection was behind the reluctance to label.

Clinicians' greatest difficulty however arose when their treatment goals were not met. When treatment failed, as it inevitably did, some clinicians were tempted to blame it on patients' lack of will or to reframe the illness as being psychological rather than physical. Implying that CFS patients were weak-willed deflected threats to doctors' identities as

healers. It also showed how the duration of CFS could become a catalyst for shifting from legitimizing to stigmatizing definitions of the condition.

These clinicians could have followed the practice of some of their colleagues and labeled complaints of CFS patients pejoratively, dismissed these patients from their practice, dumped them by referrals or refused new patients suspected of the illness. Or they could learn to treat the patient, not the disease as they chose to do. Treating these patients over the long haul entailed: learning and planning for patient demands, accepting the limitations of treatment, managing their own feelings of insecurity and frustration, putting in context the comments of skeptical colleagues, and finding value in what they could offer. These clinicians provided symptomatic treatment, evaluations of alternative therapies, and support. Most offered supportive therapy because they recognized its value for patients even though this mode of treatment gave them little personal satisfaction. By continuing to treat CFS patients they conveyed the message that these people were worthy of medical attention and commitment, and in so doing provided a measure of legitimacy to sufferers.

By accepting CFS claims as legitimate insurers were faced with financial costs and procedural changes. The most obvious financial costs were disability payments. Data from just two private insurance companies of a possible one hundred and fifty showed that CFS disability payments costs more than $6,000,000 annually. With the average age of claimants being just over forty and considering that many of these contracts run until age sixty five, future costs are potentially enormous. Some insurers incurred additional costs in routine surveillance, increased independent medical examinations, and litigation that were involved in the disposition of these claims.

Insurers' usual cost containment procedures of underwriting, adjudication, and rehabilitation were inadequate to deal with CFS claims. Underwriting could not screen out CFS claimants as high risks, since risk factors for the illness are unknown. Ironically, before becoming ill most CFS claimants closely fit the profile of clients that insurers pursue- relatively young, affluent, productive, and healthy workers. Cost containment at

adjudication fared little better since traditional ways of evaluating disability could not reliably estimate claimants' degree of disability nor could they distinguish the normal course of CFS from intentional malingering. As to rehabilitation efforts, these came belatedly and with no clear guidance on how to achieve positive outcomes.

As a result of these limitations in their usual procedures, insurers have instituted some changes to the way they deal with CFS claims. Some insurers have become more cautious in granting policies if the preliminary medical data show suspicious symptom clusters even without a diagnosis. Many companies have instituted more stringent adjudication measures. These include more use of surveillance, more frequent evaluations of claimants by independent medical examiners (IMEs) and the requirement that sufferers meet the CDC criteria although these research criteria were never meant for medico-legal use. From an insurer's perspective these measures made good business sense. From sufferers' perspectives, surveillance was as good as an accusation of fraud and IMEs were almost unanimously condemned for shabby treatment and insinuations of malingering.

Significant others who believed sufferers were faced with practical responsibilities and emotional burdens. On a practical level some had to assume new household and financial responsibilities as sufferers became too debilitated. Emotionally, some became resentful toward sufferers who could no longer meet their expectations for mutual support, affection, and shared activities. Some were subjected to disparaging remarks about sufferers by less sympathetic family members and friends. Several feared that sufferers would commit suicide. They were distressed by witnessing sufferers' physical, emotional and social deterioration, negative changes in their personalities, and sometimes by troubling discrepancies between their behaviors and claims of disability. Parents of sufferers found it the most difficult to cope. They had to think of how to be supportive without undermining the independence of their ill adult children, how to deal with their own sense of helplessness, and how to come to terms with their children's unfulfilled promise.

Some significant others grew tired of the prolonged additional responsibilities of being close to a CFS sufferer and pulled away. Others circumscribed the limits of their support to prevent or contain resentment towards sufferers and to preserve the relationship. But most continued to offer practical and emotional support even at great costs to themselves. They have taken the responsibility for maintaining the relationship, learned about the illness, accommodated for the unpredictability of symptoms, and defended sufferers from others' hostility and denigration. They have tried to encourage social integration mindful that their efforts could be construed as doubting sufferers' disability. Their responses show their strong affective bonds with sufferers and the value placed on the relationship. By continuing to provide support and to believe sufferers, significant others legitimated sufferers' complaints.

While legitimizing CFS has obvious costs to others, stigmatization may also have unintended consequences. Clinicians who stigmatize CFS earn a reputation among CFS sufferers as being uncaring and biased which may or may not matter to them. More importantly, their reactions contribute to sufferers' "doctor shopping" which is costly to the publicly funded Canadian health care system. Similarly, insurers who reject CFS claims may be faced with some additional costs for independent medical examiners, surveillance, and litigation to counter contested claims. More significant is the fact that denial or termination of benefits shifts costs to families or to the public sector for those sufferers who must turn to social assistance. Finally family members and friends who distance themselves from sufferers may not only rupture that relationship but they may unintentionally alienate others who support sufferers.

Social Location and Reactions to CFS

The preceding discussion showed that CFS was stigmatized by viewing it as psychological, malingering, or chronically disabling and it was legitimized by considering

it as a real physical condition. The discussion also showed that stigmatizing and legitimizing CFS had consequences not only for sufferers but for doctors, insurers, significant others, and the public sector. The findings of this study further suggested that common elements in the social locations of different actors made it more likely that they would stigmatize or legitimize the condition. These elements mediated views about the illness and its impact which in turn influenced reactions to sufferers. Some elements were implicated more in perspectives on the illness and others more in its consequences.

Views about the reality and nature of CFS seemed to be more clearly influenced by world views, relationships with sufferers, and the vantage points for observing sufferers that different social locations afforded. The data suggest that clinicians were inclined to believe that CFS was real as opposed to malingering not only because of sufferers' credibility but also because they used what Dodier (1994) terms a frame of solicitude and because of fears of missed diagnosis. The frame of solicitude refers to an approach to unverifiable complaints in which doctors admit that they cannot be sure of what patients are experiencing. They are therefore willing to give patients the benefit of the doubt and commit to helping them. The potentially high costs of missed diagnoses are thought to create such a strong and pervasive fear in medicine that doctors operate on the decision rule: when in doubt find illness (Scheff 1966).

Insurers on the other hand, were more likely to find malingering as many did, at least with initial CFS claims. These claims did not fit insurers' conceptions of disability, but they did fit those world views of insurers that cast suspicion on claims and claimants. For example, insurers generally expect an objectively verifiable illness or injury to explain disability which clearly puts CFS claimants at a disadvantage. They also expect unverifiable claims to rise in times of recession which occurred with CFS. And they believe that having insurance is an important incentive for some people to file disability claims. They argue that during recessions downsizing, shrinking job mobility options, and increased productivity expectations of the remaining workforce make disability compensation an attractive income

alternative to stressful paid work or to social assistance. These world views on claimants, claims, and disability virtually assured that insurers would challenge the reality of CFS. Nagi (1969) suggests that in contrast to doctors, insurers operate on the decision rule: when in doubt deny benefits (p.162).

Family and friends' belief in the reality of CFS may be tied more to consequences for their relationship with sufferers. In considering the evidence of social location on the labeling of mental disorders, Link et al (1987) suggested that spouses' reluctance to label their mates as mentally ill may be explained by the negative consequences to the relationship. In that case, recognizing mental illness may be harmful because of the associated stigma and because of the decisions that may have to be taken. In this case, refusing to recognize the presence of an illness is likely to harm the relationship because it denies sufferers' credibility. Family and friends who wanted to preserve the relationship with CFS sufferers had little choice but to acknowledge illness. This is not to imply that they did not believe in the illness or believe sufferers, but given their social location, to do otherwise would have likely caused considerable damage, as some significant others indicated.

Views about the nature of the illness were heavily dominated by a biomedical perspective. While no respondent claimed that he or she knew the causes of CFS, most were willing to share their personal hypotheses. These views were highly unstable both across and within groups, changing with experiences with sufferers and with new ideas from the professional and lay literature.

Clinicians variously considered the causes of CFS to be physical, psychological, heterogeneous (either physical or psychological) or psychosomatic. These views reflected the range of models found in the medical literature and the type of patients seen. Since the medical literature on the etiology of CFS remains inconclusive, I suggest that clinicians gave greater weight to literature that confirmed their clinical impressions. Insurers leaned more towards psychiatric or psychosomatic explanations for CFS. This is not unexpected

since some contracts may still carry exclusionary clauses for these conditions, and some of these conditions are treatable therefore reducing time on benefits. But recent health data showing ominous trends in the rise of nervous and mental disorders, relapsing patterns, and high costs probably made insurers reluctant to recognize CFS under the psychiatric rubric. The implications for profits in view of concerns about growth in this area of claims were sobering.

By comparison with doctors and insurers, significant others believed in physical, psychological, and psychosomatic causes of CFS. A small number suggested the possibility that CFS was caused by damage to the etheric body or by an energy imbalance. These etiologies lie outside of Western biomedical models and show the encroachment of Eastern ideas into the discourse on CFS. The appearance of these unorthodox views of illness only in sufferers' social networks is probably not accidental, but rather a function of social location. It is unlikely that biomedicine would accept views that challenge its scientific base and its criteria for defining illness, nor would these views find resonance in conservative institutions such as insurance companies.

Views about the reality and nature of CFS were also influenced by the type of relationship that people in different systems have with sufferers. These relationships differ with respect to their defining characteristic, duration, frequency, and the contexts of interactions with sufferers. The therapeutic relationship between clinician and patient includes both technical expertise and an affective component (Ben Sira 1980). It may be new or long standing, but it is episodic. It involves seeing patients both in times of sickness and wellness, for example for periodic health check-ups. Seeing patients in various contexts and over varying periods of time helped clinicians to form opinions about the credibility and mental health of patients which were brought to bear when these patients presented with an unverifiable complaint.

In contrast, the insurer-client relationship is defined more by a business contract. The relationship may be cordial before and after a claim. But it can become frankly

adversarial. The seeds of such a conflictual relationship lie in some of the world views of insurers already mentioned. While the clinician-patient relationship may also take on adversarial overtones, it is less a part of the ethos of a therapeutic relationship. This is not to ignore the practice of defensive medicine[1] occasioned by "suit-prone" patients (Ritchey 1979). Usually in group policies, insurers and clients had never had direct contact until a claim was filed. Even then, contact was often limited to letters and telephone calls in which the claim was the specific focus. Visits from rehabilitation personnel tended to be minimal, if at all, because of high case-loads. This distant relationship around a single issue meant that insurers had the least opportunity for direct contact with clients in a variety of contexts. This distance may give a certain degree of objectivity in assessing a claim. However, claims are not only about objectivity and especially not in the case of CFS. Insurers did make judgments of claimants credibility and yet they had the narrowest base on which to do so. One could also argue that they had a vested interest in not finding CFS sufferers credible.

In comparison with clinicians and insurers, the defining feature of the relationship between significant others and sufferers is an affective bond. Significant others occupy the social location of the "wise" (Goffman 1963) those people who are in close and continuing contact with the discredited or discreditable. It puts them in a unique position to make observations at close quarters, over time, and in many different situations. They have the most comprehensive information on sufferers, but they may be the least objective. As I have suggested earlier they may also have a vested interest in believing sufferers, since to

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[1] The practice of defensive medicine entails exhaustive tests to eliminate missed diagnoses and misdiagnosis to the extent that this is possible. Defensive medicine may also include assessments of patients' likelihood of bringing malpractice suits. In much the same way that insurers might assess clients who are likely to bring claims, and to screen them out at underwriting if possible, doctors may also refuse to accept "suit-prone" patients. The profile of suit-prone patients includes vague complaints, a previous history of suits, and "doctor-shopping" (Ritchey 1979). In the event that something goes wrong, doctors' affective demeanor with patients may offer them more protection from lawsuits than their technical expertise.

do otherwise may put the relationship at risk. But their vantage point does not guarantee that they will believe sufferers. They may have seen behaviors, attitudes, and ways of coping that raise doubts about sufferers' credibility. And old conflicts in their shared histories may bias them towards negative evaluations of sufferers. In assessing credibility, the relationship with sufferers may be important, not only because of vested interests, but because of the type of information that can be gathered in different relationships.

In sum, views about the reality of CFS were founded not on biological evidence but on social judgments about the credibility of sufferers. Elements of social locations such as world views, sources of information, vantage points, and relationship with sufferers combined to shape these judgments. The social locations of doctors and significant others were more conducive to believing sufferers than that of insurers.

The number of proposed etiologies and their instability were a testament to the fact that no one position has gained more legitimacy than another. However, some etiologies were clearly stigmatizing while others legitimized sufferers' complaints. The clearest legitimation came from viewing the illness as physical while psychological imputations suggested moral weakness. What this range of views offered was the opportunity for different actors, including sufferers, to choose among options. It meant that sufferers could choose at least one physicians whose views of the illness were consistent with their own. They could choose to maintain a relationship with friends and family members who were sympathetic, but for better or worse, they were stuck with their insurance companies.

The impact of CFS on doctors, insurers, and significant others was closely tied to certain professional, institutional, and personal goals, their relationships with sufferers, and the strategies available for managing the impact. The primary goal of doctors is to heal or, failing that, to restore function to the extent possible. When the intractability of CFS threatened these goals, several clinicians were tempted to blame patients for not recovering or to shift from thinking of the illness as physical to thinking of it as psychological. Faced with an illness without identifiable disease, doctors can either alter treatment or manipulate

the doctor-patient relationship, sometimes in ways that are damaging. For the most part however, these clinicians avoided stigmatizing patients because they also operated from a solicitous frame and an ethos of doing no harm which helped them to take into account the patients' feelings and to manage their own frustrations.

In contrast to clinicians, insurers' main goal is profit. Functional or healthy clients are important to the extent that such clients protect profit margins. Chronic fatigue syndrome threatened insurers' profit margins because routine cost containment measures were inadequate, and because of characteristics of the illness and claimants. Originally claimants were from the higher socioeconomic classes and qualified for high monthly benefits. The later socioeconomic spread among claimants was of little help due to the duration of claims. Insurers had financial, procedural, and legal options to manage the impact of CFS claims. They have used these options to both accept and reject claims. On the one hand, early acceptance rested on mistaken assumptions about the numbers and length of CFS claims, and an emphasis on limitations in functioning rather than the cause of these limitations. Later acceptance came on the advice of medical consultants and the hope that the CDC criteria would discriminate true from false claims and drastically reduce the numbers. On the other hand, early and later rejections came from taking a hard line on the need for objective evidence to support disability claims. These differences show that elements, such as views about disability though common across the industry, are multifaceted and may be interpreted in different ways. It also shows that social locations are not closed systems but are open to influences from the outside.

The goal of significant others is to maintain a close relationship with sufferers. The foundations of these relationships included affective ties, mutual obligations for instrumental and emotional support, and shared activities. Sufferers' debilitation meant they could not keep up their end of the relationship. In some cases, significant others became resentful and increasingly distant from sufferers. But most found new ways of sharing

activities and accepted that they would have to take on additional responsibilities to protect sufferers' mental and physical health and to preserve the relationship.

By focusing on multiple groups simultaneously, the present study identified five common elements of social locations-goals, world views, vantage points, options for managing effects, and relationships-that conditioned reactions to CFS and its sufferers. It suggests that social location influenced but did not predetermine a uniform response. People in these different locations belonged to many systems and were not immune to the influence of ideas from outside the contexts I have emphasized here. Moreover, different elements of social locations were not monolithic. And elements act in combination, muting or enhancing each others' effects.

Implications for research

Many questions about CFS and those affected by the illness remain to be answered. The findings of this study suggests various avenues for future research on sufferers' illness experiences and societal reactions to CFS. One such area relates to the differences between sufferers who work and those who do not. Do working sufferers form a specific subgroup of people with CFS? This study found that working sufferers continue to experience many severe symptoms- a finding consistent with studies by Schweitzer et al. (1995) and Woodward (1993). In Woodward's (1993) sample, sufferers who continued to work felt they had no choice. But the present study suggests that several other critical variables may be involved. These include: structural features of the workplace, especially flexibility, work skills that can be parlayed into part-time or independent contract work, social supports that allow sufferers to concentrate their energies on occupational pursuits, and the strength of negative attitudes towards social assistance. Working sufferers may also have different coping skills and follow therapeutic regimens that are different from those of sufferers who do not work. This clearly seems to be a fruitful area for further exploration.

A second area for more study involves the relationship between CFS claims and insurers' responses. The small data set available for analysis in this study showed a decline in claims in 1993 that could not be properly interpreted since that was the last year for which data was available. Did this trend continue? Was it related to the number of claims or the number of rejections? What role did insurers' adoption of the 1988 CDC criteria play in the pattern of claims and companies' responses? How have insurers responded to the changes to the CDC criteria that were made in 1994? Have claimants changed their symptom descriptions to reflect the 1994 criteria in their benefit applications? How have insurers' rehabilitation efforts developed and with what results? Finally, the finding that parents of sufferers seemed to have had the greatest difficulty coping opens up a broader area of what the parenting role is with regards to adult children and what are the special difficulties of parenting an adult child who becomes sick.

Conclusion

Paradoxically, by exploring a largely hidden illness through CFS sufferers' experiences and societal reactions, this study has uncovered beliefs about what constitutes legitimate illness and when the sick role may be legitimately adopted. It has shown that although both stigma and legitimation in CFS rest on contested grounds, they carry personal and social costs that are little known and probably underestimated. It has also surfaced variables in social location that run as undercurrents in response to less ambiguous illnesses but which may have had a greater impact in reactions to CFS.

APPENDIX A

LETTER TO INSURERS

Dear _____

I am a Ph.D student in medical sociology at McGill University. I would like to request your cooperation in my dissertation study of the social and personal consequences of chronic fatigue syndrome (CFS). A broad understanding of the impact of this condition requires data not only from the perspective of patients, but also from family members, doctors and insurers. While there is considerable literature on CFS from the medical perspective and some information from patient accounts, very little is known of how the condition affects the disability compensation system in terms of dollars, the adjudicating process, or decisions concerning policies.

I am interested in describing how disability claims are handled for a condition that is not clear cut, how CFS is understood by the company (or the industry as a whole), and the impact it has had on insurers. To conduct such a study, I would require some statistical information, and the opportunity to do short interviews with persons who deal with claims, at different stages of the adjudication process. Relevant statistical information includes (but is not limited to) trends such as increases or decreases in CFS claims, duration of payments, and overall costs broken down by gender, age, occupation and marital status. The interview which lasts about 40 minutes consists of questions about the role of different persons who deal with claims, their understanding of CFS, and how they think the condition is viewed generally.

My study is bound by McGill University Ethics Committee's rules for dealing with human subjects and/or handling confidential information about them. Therefore, all information will be held in strictest confidence. Reports on the study will aggregate results and will not contain any information that could identify a specific individual. No information will identify the company. As a nurse and a former faculty member of McGill's School of Nursing for 10 years, until my return to school for doctoral studies, I am well aware and have always been respectful of the need for confidentiality with students and patients.

I would very much appreciate the opportunity to interview someone in your company and any statistical information that you might be willing to share with me. If you require more information, I will be happy to provide it. I hope you will not mind if I call you later this month to see whether an interview may be arranged sometime in (month). Thank you for any consideration that you may give to this project.

Yours sincerely,

Marcia Beaulieu
Ph.D. Student
McGill University
Department of Sociology.

McGill

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McGill University
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Département de sociologie
Université McGill
Pavillon Stephen Leacock
855, rue Sherbrooke ouest
Montréal, QC. Canada H3A 2T7

Tel.: (514) 398-6868
Fax: (514) 398-7476

Dear

This letter is to introduce Marcia Beaulieu, a doctoral student in this department who is currently engaged in a research project on chronic fatigue syndrome. Marcia Beaulieu trained as a nurse and taught for several years in the school of nursing at McGill, before entering our Ph.D. program.

Ms. Beaulieu is working with a number of colleagues at McGill on a research project funded by the Fonds de la recherche en santé du Québec. The project is designed to develop diagnostic and assessment instruments for patients with a variety of chronic medical conditions, including chronic fatigue syndrome.

To gather data for her thesis Ms. Beaulieu is interviewing both doctors and patients to elicit information on how the rather diffuse symptoms associated with chronic fatigue syndrome are classified and interpreted. Insurance companies also, of course, both play an important part in the classification of illnesses and are a repository of experience on the classification decisions of doctors. It would greatly assist her work were she able to interview some officials within insurance companies, like _____ on their experience with, and methods for dealing with, chronic fatigue syndrome claims.

I am writing, therefore, to ask you to be kind enough to cooperate with Ms. Beaulieu in her work. Sources of information will not be identified in her thesis or in any subsequent publications. At the same time, the work promises to generate information of both academic interest and practical utility.

If you have any questions, feel free to call me at 398-6846.

Yours sincerely,

Michael R. Smith
Professor and Chair

APPENDIX A

LETTER TO DOCTORS

Dear Dr._____

I am writing to introduce a research colleague, Ms. Marcia Beaulieu, and to request your help with an important research project on chronic fatigue syndrome. Ms. Beaulieu is an RN who was formerly on faculty at the McGill School of Nursing and who is currently a Ph.D. student in the Department of Sociology. She is working with us on an FRSQ funded research project to develop diagnostic and assessment instruments for patients with a variety of chronic medical conditions including chronic fatigue syndrome. For her doctoral research, Ms. Beaulieu is studying the variety of ways that doctors explain chronic fatigue syndrome to their patients and the factors that influence their ideas about the condition. This research will clarify some of the dilemmas faced by patients and physicians in managing conditions like chronic fatigue.

Your participation will ensure a broadly representative sample of professional opinion and experience with patients with chronic fatigue syndrome. It would involve a brief interview of about 15 minutes with Ms. Beaulieu. She will contact you to arrange this at your convenience. The interview is completely confidential and no information identifying either you or your patients will appear in publications or presentations of the data. We think that you will find the interview and discussion interesting and look forward to sharing the results of this research with you. If you have any questions you may contact me at 340-7549.

Thank you in advance for your help with this project.

Sincerely,

Laurence J. Kirmayer, MD, FRCPC
Associate Professor & Director
Division of Social & Transcultural Psychiatry

APPENDIX B

Standard Telephone Call to Patients

Ms/ Mr. _____ My name is Marcia Beaulieu.

I am a nurse. I am doing a Ph.D study of chronic fatigue syndrome. (Support group/ association leader's name) suggested that I call you

Is this a good time to talk to you? I would like to take a few minutes to explain the project to you and to give you an opportunity to ask any questions you may wish before deciding whether you would like to participate.

My study is concerned with the impact of CFS on patients, their families or someone close to them, their doctors and their insurers. I plan to interview individuals from all four groups to see how different people see the condition and how it affects them.

For the patient interviews I am basically asking questions about symptoms, experiences with seeking medical help and whether you have had experiences with disability compensation.

There is also a short questionnaire that I will ask patients to fill out. It concerns
how you think your illness has affected others,
generally how you think others view persons with CFS and
how CFS may have interfered with your daily activities.

Because one of the purposes of the study is to describe the impact of CFS on persons close to the patient I will also ask patients for permission to contact a family member or someone close to them. I would like to interview these people to ask about their ideas of CFS and how they may have been affected by being close to someone with CFS.

Of course any information that you give will be held in strictest confidence.
The interview should last about an hour.
Would you be interested in participating?

Arrange to meet.

APPENDIX C

INFORMATION FOR SUPPORT GROUP

THE IMPACT OF CHRONIC FATIGUE SYNDROME

I am a graduate student in medical sociology at McGill University. I am conducting a study on the impact of chronic fatigue syndrome (CFS) on patients, their families, doctors and insurers as part of my Ph.D. thesis research. A broad understanding of the impact of this condition requires data not only from patients, but also from family members, doctors and insurers. If CFS has had a significant impact on your life I would very much like to talk with you about your experiences. If you are willing would you please call Marcia Beaulieu at 737-0603.

If you agree to participate:

1. You will be asked to answer questions about your experiences with medical help seeking and questions about experiences with disability compensation if applicable.

2. You will also be asked for permission to contact a member of your family or household to request an interview about their ideas of CFS and how they may have been affected by your symptoms

3. This interview will last about an hour.

The information you provide will contribute to our knowledge of the personal and social impact of this condition.

All information will be held in strictest confidence. Your individual identity will be removed from all records following the collection of data. In this manner, information regarding your participation will be kept confidential. Findings will be reported in a general way and if quotations are used they will be anonymous.

Your decision about whether of not to participate in this study will in no way affect your future relations with McGill University. If you decide to participate please call Marcia Beaulieu at 737-0603. Please leave your name and a short message if I am not there when you call. If you decide to participate you are free to withdraw consent and discontinue your participation at any time.
Thank you for attention. I hope you will help me with this study.

Marcia Beaulieu, Ph.D. Student
McGill University
Department of Sociology

APPENDIX D

DOCTOR'S CONSENT FORM

THE IMPACT OF CHRONIC FATIGUE SYNDROME STUDY

You are invited to participate in a study of how chronic fatigue syndrome affects patients, their families, physicians, and the disability insurance system. The study is being conducted as part of the Ph.D. thesis research of Ms. Marcia Beaulieu at McGill University. The information obtained will help us to learn more about the personal and social impact of this condition.

If you agree to participate:

1. You will be asked to describe generally your role and experiences with CFS patients, your explanations for the condition, and the factors that influence your ideas about the condition. The interview will last about 15 minutes.

2. All information will be held in strictest confidence. Your individual identity will be removed from all records following the collection of data. In this manner, information regarding your participation will be kept confidential. If you have any questions, please ask. You may also contact Marcia Beaulieu at 737-0603, Professor Prudence Rains, Department of Sociology at 398-6843, or Dr. Laurence Kirmayer at 340-7549.

Your decision about whether or not to participate in this study, will in no way affect your present or future relations with the University. If you decide to participate now, you are free to withdraw consent and discontinue participation at any time.

Your signature below indicates that you have been given a copy of this consent form, have read and understood all of the points above, and willingly give your consent to participate in this study.

Date: _____ Participant _____

Witness _____

I agree that all or part of this interview may be taped. _____

APPENDIX D

FAMILY CONSENT FORM

THE IMPACT OF CHRONIC FATIGUE SYNDROME STUDY

You are invited to participate in a study of how chronic fatigue syndrome affects patients, their families, physicians, and the disability insurance system. The study is being conducted as part of the Ph.D. thesis research of Ms. Marcia Beaulieu at McGill University. The information obtained will help us to learn more about the personal and social impact of this condition.

If you agree to participate:

1. You will be asked to describe generally your role and experiences with a CFS patient, your beliefs about the condition and treatments that may be helpful, and how you think others might react to someone with the condition. The interview will last about 40 minutes.

2. All information will be held in strictest confidence. Your individual identity will be removed from all records following the collection of data. In this manner, information regarding your participation will be kept confidential. If you have any questions, please ask. You may also contact Marcia Beaulieu at 737-0603 or Professor Prudence Rains, Department of Sociology at 398-6843.

Your decision about whether or not to participate in this study, will in no way affect your present or future relations with the University. If you decide to participate now, you are free to withdraw consent and discontinue participation at any time.

Your signature below indicates that you have been given a copy of this consent form, have read and understood all of the points above, and willingly give your consent to participate in this study.

Date: _____ Participant _____

Witness _____

I agree that all or part of this interview may be taped. _____

APPENDIX D

INSURER'S CONSENT FORM

THE IMPACT OF CHRONIC FATIGUE SYNDROME STUDY

You are invited to participate in a study of how chronic fatigue syndrome affects patients, their families, physicians, and the disability insurance system. The study is being conducted as part of the Ph.D. thesis research of Ms. Marcia Beaulieu at McGill University. The information obtained will help us to learn more about the personal and social impact of this condition.

If you agree to participate:

1. You will be asked to describe generally your role and experiences with CFS patients, your beliefs about the condition, and how you think others might react to someone with the condition. The interview will last about 40 minutes.

2. All information will be held in strictest confidence. Your individual identity will be removed from all records following the collection of data. In this manner, information regarding your participation will be kept confidential. If you have any questions, please ask. You may also contact Marcia Beaulieu at 737-0603 or Professor Prudence Rains, Department of Sociology at 398-6843 or Prof. Michael Smith at 398-6846.

Your decision about whether or not to participate in this study, will in no way affect your present or future relations with the University. If you decide to participate now, you are free to withdraw consent and discontinue participation at any time.

Your signature below indicates that you have been given a copy of this consent form, have read and understood all of the points above, and willingly give your consent to participate in this study.

Date: _____ Participant _____

Witness _____

I agree that all or part of this interview may be taped. _____

APPENDIX D

PATIENT'S CONSENT FORM

THE IMPACT OF CHRONIC FATIGUE SYNDROME STUDY

You are invited to participate in a study of how chronic fatigue syndrome affects patients, their families, physicians, and the disability insurance system. The study is being conducted as part of the Ph.D. thesis research of Ms. Marcia Beaulieu at McGill University. The information obtained will help us to learn more about the personal and social impact of this condition.

If you agree to participate:

1. You will be asked to answer questions about your current and past symptoms, your experiences with seeking medical help and how your symptoms affect you. You will also be asked questions about your experiences with seeking disability compensation if this is applicable to your situation. The interview will last about forty minutes.

2. All information will be held in strictest confidence. Your individual identity will be removed from all records following the collection of data. In this manner, information regarding your participation will be kept confidential. If you have any questions, please ask. You may also contact Marcia Beaulieu at 737-0603 or Professor Prudence Rains Department of Sociology at 398-6843

Your decision about whether or not to participate in this study, will in no way affect your present or future relations with the University. If you decide to participate now, you are free to withdraw consent and discontinue participation at any time.

Your signature below indicates that you have been given a copy of this consent form, have read and understood all of the points above, and willingly give your consent to participate in this study.

Date: _____ Participant _____

Witness _____

I agree that all or part of this interview may be taped. _____

APPENDIX D

PATIENTS' CONSENT TO FAMILY CONTACT

THE IMPACT OF CHRONIC FATIGUE SYNDROME STUDY

You are invited to participate in a study of how chronic fatigue syndrome affects patients, their families, physicians, and the disability insurance system. The study is being conducted as part of the Ph.D. thesis research of Ms. Marcia Beaulieu at McGill University. The information obtained will help us to learn more about the personal and social impact of this condition.

If you agree that a member of your family or someone you live with may be contacted to request their participation in the study of impact on families or significant others:

1. Such persons will be asked to answer questions about their views of your illness and treatments that may be helpful. They will also be asked how they think others might react to someone with your condition and whether your condition has affected them.

2. All information will be held in strictest confidence. Their individual identity will be removed from all records following the collection of data. In this manner, information regarding their participation will be kept confidential. If you have any questions, please ask. You may also contact Marcia Beaulieu at 737-0603 or Professor Prudence Rains, Department of Sociology at 398-6843.

Your decision about whether or not to consent to having a family member contacted will in no way affect your present or future relations with the University. If you agree that the contact can be made now, you are free to withdraw that consent at any time.

Your signature below indicates that you have been given a copy of this consent form, have read and understood all of the points above, and willingly consent that a family member or significant other may be contacted to request their participation in this study.

Date: _____ Participant _____

Witness _____

APPENDIX E

PATIENT INTERVIEW SCHEDULE

A1. How old are you?

A2. In what country were you born ?

A3. (IF NOT CANADA) In what year did you come to Canada

A3. To what ethnic or cultural group do you belong?

A4. What language or languages did you speak at home when you were growing up?

A5. Are you presently married?

A6 (IF NO)
Are you widowed, separated, divorced, or have you never married?

("LIVING WITH SOMEONE AS THOUGH MARRIED" = MARRIED)

A7. How many children, if any, have you had?

A8. What is your religion?

Jewish	1
Roman Catholic	2
Protestant	3
Muslim	4
None	5
Other _____	6

A9 How many years of schooling have you completed? (CIRCLE ONE NUMBER
OR FILL IN IF > 20)

0, 1, 2, 3, 4, 5, 6, 7 8,9,10,11 12, 13 14, 15, 16,17,18, 19, 20+

ELEMENTARY HIGH SCHOOL COLLEGE UNIVERSITY

A10 Are you presently working at a job for pay? IF NO GO TO A14

A11. At what job are you presently working?

A12. In what kind of business, industry or service do you work?

A13. How many hours do you work per week?

A14. Which of the following best describes your situation:

Unemployed but looking for work	1	Unemployed, because of illness or disability	2
Retired	3	Student	4
Housewife	5	Other_____	6

A15. (IF UNEMPLOYED, RETIRED OR DISABLED) What was your usual job?

A16. In what kind of business, industry or service did you work?

A17. Just roughly, what was your total household income in 1992 before tax deductions? Would you show me a letter on this card which corresponds to your income category?

(SHOW CARD A) _____(Letter)

A.	Under $3,000	F.	$20,000 - $29,999	K.	$70,000 - $79,999
B.	$3,000 - $5,999	G.	$30,000 - $39,999	L.	$80,000 - $99,999
C.	$6,000 - $8,999	H.	$40,000 - $49,999	M.	$100,000 - $119,999
D.	$9,000 - $11,999	I.	$50,000 - $59,999	N.	$120,000 - $139,999
E.	$12,000 - $19,999	J.	$60,000 - $69,999	O.	$140,000 +

B. Now I'm going to ask you some questions about the problems that led you to seek help from Dr._____,what you think might have caused your problems and who you have seen in the past for these problems?

B1. First, what are the main problems or conditions for which you sought help from Dr.____?

B2. How long have you had problems like SX? SX =SYMPTOMS

B3. Are you bothered by problems like (SX) all the time or do they come and go at different times?

B4. What is it about your (SX) that is most troubling to you?

B5. PEOPLE OFTEN HAVE MANY DIFFERENT WAYS OF EXPLAINING HEALTH PROBLEMS LIKE YOURS.

What are your ideas about what started your health problems? That is, what do you think caused your SX?

B6. You have said that you believe your (SX) are caused by_____
What is it that made you believe that this is (these are) the cause(s)

B7. Has your thinking about what caused your symptoms been influenced by information from other people, radio, television, newspapers or magazines?

FATIGUE

C. LOOKING AT CARD B please tell me on how many separate days in the last month you have been:

CARD B			
0 days None	1-6 days Occasionally	7-14 days Often	more than 14 days Very Often

C1. feeling tired out, fatigued or lacking enough energy to do the things you normally do

0 1-6 7-14 14+

(If none, skip DIS probe)

MD.....OTHER.....PROBE: 1 2 3 4 5

(PROBE REFERS TO THE Diagnostic Interview Schedule Probe to explore if people consulted a doctor or others, what diagnosis and/or explanations if any they were given for symptoms)

C2. When your fatigue first started, did it come on suddenly (that is, over a few hours or a few days)?

NO..... 1
YES..... 2

C3. Has (Did) your (current) tiredness or fatigue lasted for at least 6 months?

NO..... 1
YES..... 2

C4. Is (Was) your (current) fatigue so bad that it has limited your activities to less than half of what you could normally do before?

NO..... 1
YES..... 2

C5. Is (Was) your (current) fatigue present at least half of the time?

NO..... 1
YES..... 2

C6. Do (Did) you have other symptoms that you think are (were) related to your chronic fatigue?

(IF C3 = YES GO TO C8)

C7. When was the (first/last) time you were bothered by persistent tiredness or fatigue?

ONSET: 1 2 3 4 5 6
AGE ONSET: __/__
MOST RECENT: 1 2 3 4 5 6
AGE AT MOST RECENT EPISODE: __/__

1=within the last two weeks
2=2 weeks to less than one month ago
3=1 month to less than 6 month ago
4= 6 months to less than 1 year ago
5= in the last 12 months, not sure when
6=more than 1 year ago

(IF REC = 6 GO TO C9)

LQOKING AT THIS CARD, CAN YOU TELL ME:

CARD C

not at all	somewhat	quite a lot	completely
1	2	3	4

C8. In the last 12 months how much has fatigue interfered with your life or activities? Wouldyou say not at all, somewhat, quite a lot, or completely? 1 2 3 4

C9. How important is (was) stress in causing your fatigue? 1 2 3 4

C10. How important are (were) personal or emotional problems in causing your fatigue? 1 2 3 4

C11. How important is (was) physical illness or injury in causing your fatigue? (e.g. problems with your immune system, prior infections, injury, dietary deficiencies, problems with your glands, hormones or blood sugar)? 1 2 3 4

C12. To what extent do (did) you feel that people are (were) not taking your fatigue seriously enough? 1 2 3 4

C13. To what extent do (did) you feel ashamed or embarrassed because of your fatigue? 1 2 3 4

C14. To what extent do (did) you feel personally responsible for causing your fatigue? 1 2 3 4

C15. Which of the following professionals have you talked (did you talk) to about your fatigue?

General Practitioner.....1
Medical Specialist.....2
Mental Health Professional.....3
Chiropractor.....4
Homeopath.....5
Acupuncturist.....6
Herbalist.....7
Other.....8

C16. How many separate health professionals have you seen for your fatigue?

C17. Which of these health professionals did you see because you were referred to them by other health professionals?

C18. Which of these health professionals did you consult on your own initiative (that is, you were not referred to them?

D. Now I am going to list a number of people or sources of help whom you may have used for personal or health problems. Please tell me if you have used any of these sources of help.

PROBES: HP= HEALTH PROFESSIONALS

Column 1: Have you ever made use of HP for any health or personal problems?

Column 2: (IF YES) Have you ever made use of HP for your current (SYMPTOMS)?

Column 3: (IF YES) Did you find HP helpful?

Column 4: (IF USED) How well do you feel people there understood your problems? Would you say not at all, somewhat, well, very well?

(SHOW CARD WITH OPTIONS)

not at all	somewhat	well	very well
1	2	3	4

	EVER	CURRENT	HELP	UNDERSTOOD not some well very
D1. Self care or help from others at home	Y N	Y N	Y.... N.....	1 2 3 4
D2. Friends/family outside home	Y..... N	Y..... N	Y..... N.....	1 2 3 4
D3. An overnight stay in hospital	Y N	Y N	Y..... N.....	1 2 3 4
D4. Hospital emergency room	Y N	Y N	Y..... N.....	1 2 3 4
D5. Expert in fatigue or a fatigue clinic	Y N	Y N	Y..... N.....	1 2 3 4
D6. Rheumatologist or a rheumatology clinic	Y..... N	Y..... N	Y..... N.....	1 2 3 4
D7. Infectious disease physician or infectious disease clinic	Y..... N	Y..... N	Y... N.....	1 2 3 4
D8. Gastroenterologist or Gastroenterology clinic	Y..... N	Y..... N	Y.. N.....	1 2 3 4

	EVER	CURRENT	HELP	UNDERSTOOD not	some	well	very
D9.First general practitioner, family practitioner or general internist	Y / N	Y / N	Y / N	1	2	3	4
D10. Second general practitioner, family practitioner or general internist	Y / N	Y / N	Y / N	1	2	3	4
D11. Third general practitioner, family practitioner or general internist	Y / N	Y / N	Y / N	1	2	3	4
D12. Clinical ecologist or allergist	Y / N	Y / N	Y / N	1	2	3	4
D13. Physiotherapist or occupational therapists	Y / N	Y / N	Y / N	1	2	3	4
D14. Acupuncturist	Y / N	Y / N	Y / N	1	2	3	4
D15. Chiropractor	Y / N	Y / N	Y / N	1	2	3	4
D16. Homeopathic medicine or practitioner	Y / N	Y / N	Y / N	1	2	3	4
D17. Faith healer or healing church	Y / N	Y / N	Y / N	1	2	3	4
D18. Meditation, prayer or religious devotion other than faith healing	Y / N	Y / N	Y / N	1	2	3	4
D19. Nutritionist	Y / N	Y / N	Y / N	1	2	3	4
D20. Psychiatrist, psycholoDist, social worker or counselor	Y / N	Y / N	Y / N	1	2	3	4
D21. Have you (ever) gotten help from anyone else that I haven't mentioned?	Y / N	Y / N	Y / N	1	2	3	4
D22. Anyone else?	Y / N	Y / N	Y / N	1	2	3	4

D23. You've said that (LIST UP TO 4 HP) understood your health problems very well. Why did you get the feeling that HP understood your problems?

D24. You've said that (LIST UP TO 4 HP) did not understand your health problems at all. Why did you get that feeling that HP did not understand your problems?

D25. Have any of the professionals you visited told you or left you with the impression that your health problems were somehow not real ?

D26. Have any of the professionals you visited told you or left you with the impression that your health problems were due to psycholoDical or emotional troubles?

D27. Have any of the professionals you visited told you or left you with the impression that you were primarily to blame for your health problems?

FIRST HELP SEEKING

D28. After your (SX__) began, who was the first person you consulted for help other than friends or family? (SX REFERS TO SYMPTOMS IDENTIFIED IN B1)

D29. When did you first get help there for your (SX__)?

D30. How many times did you go there for your (SX__)?

D31. Over how many months or years did you go there for your (SX__)?

D32. What did this person whom you first went to for help call your (SX__)? What name did he (or she) use?

D33. To what extent were you satisfied with the help you received there? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

very satisfied somewhat satisfied somewhat dissatisfied very dissatisfied

If doctor mentioned stress, what is patient's view of the role of stress?

If doctor did several diagnostic tests, what did patient interpret this to mean?

MOST IMPORTANT HELP SEEKING

D34. Of all the sources of help you consulted for your (SX__) which one of them do you consider the most important?

D35. When did you first get help there for your (SX__)?

D36. How many times did you go there for your (SX__)?

D37. Over how many months or years did you go there for your (SX__)?

D38. What is it about this source of help that made it the most important to you?

D39. What did this person whom you went to for help call your problems? What name did he (or she) use?

D40. To what extent were you satisfied with the help you received there? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

very satisfied	somewhat satisfied	somewhat dissatisfied	very dissatisfied
1	2	3	4

D41. What is the name of the first doctor to whom you went for your symptoms of CFS?

D42 What is the name of the doctor you considered most important ?

D43. What is the name of the doctor who first diagnosed your symptoms?

D44. What is the name of the mental health professional you consulted?

E. Next, I'll ask about the kinds of treatment (TX) you may have been offered for your current (SX__). Please tell me whether you were offered these.

PROBES:

Were you given (TX) for your (SX__)?

Did you find (TX) helpful?

TREATMENT	TRIED	HELPFUL
E1. pain killers	YES _____ NO	YES NO
E2. antibiotics	YES _____ NO	YES NO
E3. steroids	YES _____ NO	YES NO
E4. anti-inflammatory medication	YES _____ NO	YES NO
E5. muscle relaxants.....	YES _____ NO	YES NO
E6. dietary advice.....	YES _____ NO	YES NO

E7. exercise..... YES_____YES NO
NO

E8. sleeping pills..... YES_____YES NO

E9. heat or cold treatments..... YES_____YES NO
NO

E10. electrical stimulation..... YES_____YES NO
NO

E11. relaxation training or stress management....YES_____YES NO
NO

E12. tranquilizers..... YES_____YES NO
NO

E13. psychotherapy..... YES_____YES NO
NO

E14. antacids..... YES_____YES NO
NO

E15. antidepressants..... YES_____YES NO
NO

E16. acupuncture..... YES_____YES NO
NO

E17. any other treatments?..... YES_____YES NO
NO

E18. any other treatments?..... YES_____YES NO
NO

Now I am going to ask you some questions about experiences that you may have had with disability compensation?

F1. Are you a member of any type of salary insurance plan?

IF YES is that a Group Benefits plan?

or Individual Salary Insurance

F2. What is the name of the company with which you are insured?

F3.
Are you presently receiving disability compensation for your CFS?

F4. Did you ever receive disability compensation for your CFS?

F4. Begininning with when you first decided to apply for disability benefits Can you describe your experience with the disability insurance system?

PFOBES: Înformation requested
period granted disability compensation?
What happens (ed) if runs out_
did the insurers explore rehabilitation possibilities?
IF YES: What happened?
claim been reviewed
reason for the review?
contested?
IF YES: reason for contesting the claim?

F5 What are your overall perceptions of how the insurance company has treated your claim?

F6. Did any of the people that you dealt with told you or made you feel that your symptoms were somehow not real?

F7. Did any of the people that you dealt with told you or made you feel that your health problems were due to psychological or emotional troubles?

F8. Did any of the people that you dealt with told you or made you feel that you were primarily to blame for your health problem?

F9. Did any of the people that you dealt with told you or made you feel that you were not motivated to get well?

F11. To what extent are you satisfied with the way that your disability claims have been handled? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

F12. What was it about the way your claims were handled that made you satisfied?

F13. What was it about the way your claims were handled that made you dissatisfied?

A26. SEX MALE 1
FEMALE 2

DATE OF BIRTH

SUBJECT REFERRED BY

LOCATION OF INTERVIEW

DATE(S) OF INTERVIEW

TIME TAKEN (MINS)

APPENDIX F

INTERVIEW SCHEDULE FOR FAMILY/SIGNIFICANT OTHER

A 1: What is your relationship to _____?

To the best of your knowledge:

B 2: How long has _____ been bothered by fatigue?

B 3: Is _____bothered by fatigue all the time or does it come and go?

PROBE: extended periods where _____feels better

B 4: When _____ fatigue started, did it come on suddenly, that is, over a few hours or a few days?

C 5: What is it about _____ condition that has been of most concern to you?

C 6: Can you describe how you have been affected by _____ having CFS?

PROBE: for changes in roles and relationships/
feelings/
ways of dealing with the situation/
interference with activities/
involvement with help seeking

C 7: Is there anything else about _____problem that has affected you?

C 8: When you first heard that _____had CFS what were your ideas about the causes of this problem?.

C 9: What is it that made you believe that this was (these were) the cause(s)?

C 10: Has your thinking about what causes CFS been influenced by information from other people, radio, television, newspapers or magazines?

C 11: Has your thinking about what caused CFS now changed from what you first thought ?

C 12: IF YES: What do you now think causes _____ CFS?

C 13: What is it that has made you change your ideas about the causes of CFS?

I am going to ask you to look at this card and tell me

not at all	somewhat	quite a lot	completely
1	2	3	4

C 14: How important do you think stress is (was) in causing his/her fatigue? 1 2 3 4

C 15: How important do you think personal or emotional problems are (were) in causing his/her fatigue? 1 2 3 4

C 16: How important is (was) physical illness or injury in causing his/her fatigue? (e.g. problems with the immune system, prior infections, injury, dietary deficiencies, problems with the glands, hormones or blood sugar)? 1 2 3 4

C 17: How responsible do you think your family member/ roommate is for causing his/ her illness.....1 2 3 4

C 18: In the last 12 months how much has the fatigue of your family member/ roommate interfered with your life or activities? Would you say not at all, somewhat, quite a lot, or completely?

People often have their own ideas about treatments that may be helpful for different illnesses and conditions. Which of the following treatments do you think might be helpful for CFS?

TREATMENT	HELPFUL
D 1: pain killers	YES NO
D 2: antibiotics	YES NO
D 3: steroids	YES NO
D 4: anti-inflammatory medication	YES NO
D 5: muscle relaxants.....	YES NO
D 6: dietary advice.....	YES NO

D 7: exercise..... YES
NO

D 8: sleeping pills..... YES
NO

D 9: heat or cold treatments..... YES
NO

D 10: rest..... YES
NO

D 11: relaxation training or stress management YES
NO

D 12: tranquilizers..... YES
NO

D 13: psychotherapy..... YES
NO

D 14: antidepressants..... YES
NO

D 15: acupuncture..... YES
NO

D 16: any other treatments?.....

I am going to ask you a few questions about yourself now:

A 2: How old are you?

A 3: How many years of schooling have you completed?

0, 1, 2, 3, 4, 5, 6, 7 8,9,10,11 12, 13 14, 15, 16,17,18, 19, 20+

ELEMENTARY HIGH SCHOOL COLLEGE UNIVERSITY

A 4: Are you presently working at a job for pay?

A 5: MALE
FEMALE

APPENDIX G

INSURERS' INTERVIEW SCHEDULE

1. In general terms, can you tell me about your work in dealing with disability claims?

   PROBE FOR : Definition of disability
   Basis of payment, percent of salary
   Indexing, policy specific payments

2. A claim for CFS comes into your company, can you describe how it is adjudicated?

   PROBE FOR: Use of independent medical examiners (IMEs)
   Types of doctors consulted, reasons for choice
   Outcomes- rejection, acceptance, conditions,
   Bases for decisions

3. Has your way of dealing with CFS claims changed over time? If yes, in what ways?

   PROBE FOR: Type of information sought
   Use of the CDC criteria
   Greater/lesser use of IMEs
   Changes in decisions/recommendations

4. What accounts for these changes?

5. Is there a typical CFS claimant? Can you describe this person?

6. Have you dealt with a CFS claim that was very different from others? Can you tell me about that?

7. What happens to people's benefits if they begin to improve and return to work and then relapse?

8. If a person with a history of CFS applies for a policy, what response is your company likely to give?

9. When did our company first begin to receive CFS disability claims?

   What is the longest claim that you have had?
   What is the shortest claim?
   On average, how long do you expect CFS to last?
   What name(s) do you use for the condition?
   How is it differentiated from stress?

10. Now I would like to ask you about your ideas of CFS:

    What do you think causes the condition?
    In your view, how important is stress in causing the condition?
    How about personal and emotional problems?
    How motivated are claimants to get well?

11. Has your thinking about CFS changed from what you first thought? If yes, in what ways?

12. How long have you been working in the disability insurance business?

13. Over what period of time have you been working with CFS claims?

14. Roughly, how many claims have you dealt with?

15. What is your job title or classification?

MALE
FEMALE

APPENDIX H

CLINICIAN'S INTERVIEW

1. What is your approach in dealing with patients who present with symptoms that could be diagnosed as CFS?

2. How do you explain CFS to patients with the condition? PROBE FOR: attributions

3. Has your thinking about CFS changed over time?

   If yes, in what ways?
   What accounts for these changes?

4. There are many different names for this condition, what name do you use?

5. In your experience, what is the course of the illness like?

6. Since CFS has no specific treatments, how do you manage patients with this illness?

7. Do you schedule regular follow ups? How often would that be?

8. What do find most challenging about caring for these patients?
   How do you deal with these challenges?

9. What is your position on patients trying alternative therapies? Joining support groups?

10. In your experience, is there a typical CFS patient? Have you cared for patients who were atypical in some way?

11. What do you find most striking about these patients?

Background:

   What is your area of specialty?

   How long have you been in practice?

   When did you first start seeing CFS patients?

   Roughly, how many CFS patients have you seen?

MALE
FEMALE

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