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### THE POST-VIRAL FATIGUE SYNDROME

### ABSTRACT

syndrome (myalgic encephalomyelitis) Post-viral fatique is a physically debilitating disorder associated with chronic disabling fatigue. This thesis presents two studies which look at the impact of illness from a personal-psychological and from a family perspective. The first investigates the psychological features of the syndrome. The prevalence of psychiatric disorder in 20 patients with the PVFS Sixty percent satisfied criteria for a current was determined. psychiatric disorder. Diagnoses were of neurotic depression and other neuroses. Only 25 % of a comparatively disabled group of 20 arthritis sufferers received similar diagnoses. Diagnoses did not substantially differ in type from a group of 20 subjects with major depressive disorders, although selected differences in symptom profile and the role of previous life-time psychiatric episodes, suggest that the PVFS cannot be regarded as a variant form of depressive disorder. Α logistic regression analysis achieved a satisfactory separation of the two disorders on the basis of psychiatric symptoms.

The second study investigates 9 school-aged children with mothers suffering from the syndrome, and 9 children with healthy parents. The children in the PVFS group had been exposed to their mother's illness from between 18 months and 14 years. They were found to have significantly more problems in the school environment in comparison to controls, rated as more shy and anxious, less assertive and with more relationship problems with peers. General family orientation was less active with fewer out-of-home family pursuits. Family interactions were somewhat more negative. Child adjustment is discussed in terms of the linkages between family, school and peer-group in the lives of these childen. Investigations into the adaptive potential of such linkages and the permeability of the boundaries between the spheres, raise important questions for ameliorative work in the counselling of PVFS sufferers and their families.

### THE POST-VIRAL FATIGUE SYNDROME

Thesis submitted for the degree of Doctor of Philosophy

Charlotte Anne Procter Trevelyan College

Department of Psychology University of Durham September 1990

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### DECLARATION

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### The Post-Viral Fatigue Syndrome: a psychological perspective

### 1.1 Introduction

The post-viral fatigue syndrome (also termed myalgic encephalomyelitis, chronic fatigue syndrome or the post-viral asthenia syndrome) is a physically debilitating condition characterised by chronic disabling fatigue or lack of energy. It is debilitating primarily on account of this fatigue. The patient experiences prolonged non-recuperative fatigue and mental lassitude following exertion, emotional or physical strain. The fatigue has been described as comparable to that which is experienced by sufferers of multiple sclerosis with severe spinal cord involvement (Behan et al. 1985), and resembles the weakness and loss of stamina of haemodialysis patients. Most prominent is the sense of feeling acutely unwell or constantly under the weather - such as being invaded by an influenza virus, from which there is no rapid recovery. In its severe forms, the extreme lassitude and mental fatigability is also suggestive of the ways in which affective disorders commonly present. Large cross-sectional studies of patients with affective disorders have shown consistently that between 60 and 97 % of cases report fatigue as a prominent feature (Mathew et al. 1982; Morrison, 1980). The fatigue contributes to the severe loss of role function, making it unfeasible for a sufferer to continue employment or to maintain

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The syndrome is also debilitating because of the medley of symptoms presenting in a number of bodily areas. It comprises a set of muscular, cardiovascular, gastrointestinal and supposed "encephalitic" symptoms, assumed to be a consequence of disordered peripheral and central nervous systems. Early descriptions of the syndrome pointed to irritative and transcient paralytic signs, with reports of facial nerve palsies, drop foot and paresis (Ramsay, 1986). The disorder is now seen primarily as one of chronic fatigability. Current reports emphasise the absence of abnormal neurological signs (Behan et al. 1985; Archer, 1987). But the signs of mental fatigue, that is, the reported poor concentration, word-finding difficulties, slips of the tongue and short-term memory impairments, have been regarded as indicative of "functional central nervous system disturbance" (Smith et al. 1986).

Finally, the post-viral fatigue syndrome is debilitating because of the chronic invalidism which occurs in many sufferers. The resulting preoccupation with illness and constant symptomatic vigilence may seriously restrict daily functioning. Such increased sensitivity to bodily signals occurs in situations of relative deprivation of cognitive / sensory stimulation resulting from the isolating and limitating nature of many chronic physical conditions (Penebaker & Brittingham, 1981). In the post-viral fatigue syndrome, it has been reported that the chronic fatigue and somatic presentations may outlast all evidence of viral contagion or organic signs (Ramsay & Rundle, 1979). A group of patients is described in whom the disease process appears to have "burnt itself out", but the secondary effects

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of illness persist often with considerable muscular atrophy and reinforced patterns of illness behaviour. The reports of hypochondriasis and abnormal illness behaviour traits are speculative (Behan & Behan, 1988), but such suggestions have brought attention to potential mechanisms through which chronic disorder can be maintained.

Scientific analyses of the syndrome have been few and because of the paucity of objective clinical signs to explain the perpetual fatigue, mass hysteria has been postulated in epidemic outbreaks (McEvedy & Beard, 1973), and a variety of psychiatric diagnoses have been given in individual cases (eg. Winbow, 1986). Systematic investigation into the disorder has been hampered by the absence of a reliable diagnostic test which has left syndrome identification to the presentation of self-reported symptoms and objective signs. New diagnostic techniques are now becoming available, including viral hybridization techniques for the growth of cultures, and phosphorus nuclear magnetic resonance which has displayed abnormalities in the intracellular acidosis (Arnold et al 1984). of muscles An enterovirus, Coxsackie B, has been isolated in muscle biopsy samples in cerebrospinal fluid, and has been located as a major and aetiological agent (Behan & Behan, 1988; Behan et al. 1985). Mild and transient neurological abnormalities have been found along with atypical lymphocytes and circulating immune complexes.

The syndrome is also associated with depressive symptomatology, varying from mild dysphoria and emotional lability in some, to severe emotional reactions in others, in severity meeting the criteria for major depressive disorders. The episodes of psychological symptoms may fluctuate throughout the course of the physical illness emerging

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in response to periods of severe relapse and improving in periods of Such symptoms may be mild and persistent but may fail to remission. satisfy criteria for a major depressive disorder. Alternatively, an individual may experience depressive episodes of limited duration which do reach a level of severity analogous to a clinical depression. Some of these episodes may be understood to be "reactive", in that they represent an emotional response to the discomfort and restrictions of life-style imposed by the illness. They may be a response to periods of diagnostic uncertainty, which is often prolonged in this disorder because of the technological problems of diagnosis and the lack of medical consensus as to how such symptoms are to be understood. Many still are unconvinced of the validity of a diagnosis of post-viral fatigue. The sufferer may also be reacting to illness management difficulties or perhaps the secondary effects of marital and family problems which may have resulted. In some, it appears that the psychological sequelae is more than a response to disability and the change of life style imposed by the illness. The involvement of the virus in the central and peripheral nervous systems and the brain stem suggests depressive disorders of a more "endogenous" type typical of an organic brain reaction.

It is important to distinguish the depressive symptoms which could be described as a normal depression, which can be understood in terms of a reaction to the losses imposed by the illness, and a depressive response which can be judged as seemingly unrelated to or out of proportion to the severity of the illness and surrounding external events. Of course, it is a difficult decision to state whether an individual is responding inappropriately to his or her situation, but where feelings of worthlessness, hopelessness and impaired thinking

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and judgement are evident and where an individual is capable of expressing their mood as clearly distinguishable from their normal experiences of sadness and misery, and which is less responsive to pleasurable environmental events, then the mood state can be labelled as "abnormal". Similarly, careful investigation is needed to arrive at a conclusion that the collection of psychological symptoms form a pattern which indicates its presentation and course to be comparable to the recognisable syndrome of depression. For the syndrome of depression to be present in cases of post-viral fatigue, an understanding of the presentation of depression in common medical disorders is needed. Where a physical illness presents with symptoms which could also be suggestive of a psychiatric diagnosis (for example, anorexia, weight loss, sleep disturbance or fatigue), separation of organic or psychiatric disorder is bound to be problematic because of this symptom contamination.

The post-viral fatigue syndrome has a physical and a depressive component. In some, the physical side of the illness predominates. The moderate levels of "depression" found on clinical presentation may be accounted for by the somatic presentations of the condition and not as components of a depressive illness per se. In fact, in some PVFS sufferers there is little evidence of dysphoria, and adjustment to the illness is often good. In others, a depressive disorder may mask, accompany or aggravate the physical condition.

The type of psychological symptoms which predominate in PVFS are characteristic of the mixed anxiety and depressive states frequently encountered in primary care, and commonly labelled as the "neuroses" by general practitioners (Goldberg et al. 1987). Patients receiving

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labels are usually those frequent attenders at surgeries such presenting with relatively common somatic complaints in a variety of bodily areas, who fail to respond to usual medication and counselling. They are those attenders who are often regarded by the primary doctors as "difficult" patients and those who will frequently be referred to the psychological professions (Salmon et al. 1988). On clinical presentation, prior to diagnostic confirmation, such are the categories into which PVFS sufferers have often fallen. The self-help literature is replete with accounts of dismissive treatment and condescending attitudes from some doctors, often given alongside "dismissive" diagnoses of neurosis (Francis, 1988; Jeffreys, 1982). A consultant neurologist reports that many patients with the post-viral fatigue syndrome arrive from the offices of other medical practitioners labelled as neurotic neurasthenic or depressed (Behan & Behan, 1982). Because of the vague nature of the presenting symptoms the individuals will frequently see numerous physicians and undergo often without satisfactory diagnostic extensive investigations closure. A consultant physician for infectious diseases comments on the difficulties in identifying the syndrome:

"The patients... came to us in a state of utter despair, their medical supervisors finding themselves baffled by a medley of symptoms which they are unable to place into any recognisable category of disease. Without exception, these patients had been referred for consultant opinion and they were generally seen by neurologists who were equally nonplussed having found no abnormality on physical examination and with extensive laboratory investigations. Many of the patients were finally referred for psychiatric opinion and it is interesting that four psychiatrists to my knowledge referred patients back with a note which in essence said, "I do not know what this patient is suffering from, but the case does not come into my field"" (Ramsay, 1986).

One study presents three case histories where individuals had

undergone eight, nine and eleven years of illness before a diagnosis of post-viral syndrome was arrived at (Keighley and Bell, 1983). The distressing period of diagnostic uncertainty is not exclusive to the post-viral fatigue syndrome. It is a common precursor to recognised diagnoses of multiple sclerosis or carcinoma, for example (Skegg et al. 1988). The professional disbelief held towards the syndrome by many practitioners, who have linked its occurence with hysterical overlay (McEvedy and Beard, 1955; 1970), abnormal illness behaviour and hypochondriasis can in some ways be understood. Behan (1988) reports a "clinging dependency on relatives", exacerbation of abnormal pre-morbid traits and often severe hypochondriasis. These can be secondary psychological complications to the organic illness (Behan, 1988; Kendell, 1967), and in the absence of clinical findings the presentation may appear to reflect the text-book descriptions of mass hysteria, psychogenic and factitious disorders. Disturbances such as "irritable bowel syndrome", "non-restorative sleep syndrome", "fibromyalgia" and "total allergy syndromes" appear to have much in common with the post-viral condition, in the way they present. These conditions, in common with the post-viral fatigue syndrome, have little evidence of organic aetiology and are often contested to be indications of depressive disorders which are being expressed in somatic signs (Kirmayer et al. 1988).

In a study of 100 patients referred to a consultation-liaison service for the evaluation of medically unexplained symptoms, the patient's psychological state was assessed using multiaxial classification according to DSM-III criteria (Slavney et al. 1985). Thirty-seven percent of the group satisfied criteria for somatisation disorders, factitious and psychogenic disorders. 16 % showed evidence of major

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affective disorders and anxiety disorders and a further 8 % adjustment disorders with depressed, anxious or mixed mood states. In 14 % of the patients, a physical condition was being aggravated by psychological factors. Again, the presenting symptoms were of a similar nature to those affecting patients with the post-viral syndrome.

Where fatigue is the overriding symptom presented in PVFS, it can also suggest predominantly "psychological" problems. The Diagnostic Interview Schedule from the National Institute of Health (Robins et 1984) was administered to 100 attenders at a general medical al. fatigue outpatient clinic (Manu, Matthews et al. 1988). The patients complaining of tiredness, lassitude and weariness before were activity, lacking the energy to sustain performance to task completion and experiencing an abnormal degree of exhaustion out of proportion to the activities performed. The attenders had been suffering from chronic fatigue for on average 13 years. The fatigue was attributed to a medical-organic diagnosis in only 5 of the patients and of these, two were considered also to be suffering from a depressive disorder. In 44 of the patients the chronic fatigue was seen to be attributable to a coexisting mood disorder such as major depression, dysthymia or bipolar disorder. Nine had anxiety disorders represented by panic attacks and social phobias and 10 patients were diagnosed as having a somatisation disorder. A more recent study by Wessely and Powell (1989), assesses 47 referrals to the National Hospital for Nervous Diseases, with presentations of chronic unexplained fatigue. Seventy-two percent of them were given psychiatric diagnoses of depression using research diagnostic criteria which had been modified in order to exclude symptoms of fatigue.

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Considering that diagnoses of "depression with conversion symptoms", "hysterical personality" or "hysterical conversion" have been given to patients later correctly diagnosed as suffering from multiple sclerosis (Skegg, 1988), caution is called for in the assessment of patients with physical symptoms who are referred to psychiatric care.

Thus, confused presentations of affective disorders with somatic overlay are not uncommon. The somatic presentation of psychiatric disorder accounts for 35 to 50 % of the misdiagnosed and undetected cases of psychiatric disorders in primary care (Freeling et al. 1985). In a general practice study (Bridges & Goldberg, 1985), in the 17 % of patients who presented their psychological complaints in purely psychological terms, 90 % of psychiatric cases were correctly recognised by G.P.s, using independent self-report and standardised diagnostic interview measures. If a psychiatric disorder was presented secondary to a physical illness, 57 % of cases were identified by G.P.s. If the psychiatric disorder was unrelated to the physical illness, only 23 % of the psychiatric disorders and 16 % of the adjustment disorders were detected. Overall, if cases were presented with somatized symptomatology, 53 % of psychiatric disorders incorrectly diagnosed. Coexisting physical illnesses were were responsible for 95 % of the "missed" cases, or "hidden psychiatric morbidity" (Goldberg, 1980).

General practice studies of depression suggest that the classic descriptions of depressive disorders in psychiatric texts are not appropriate for clinicians who see illnesses in their earlier stages and in their milder forms (Goldberg et al 1987). The supposed "typical" symptoms fulfilling criteria for the syndrome of depression

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are depressed mood, guilt and suicidal intent. There is expected to be a "point of rarity" between the depressive symptoms and those associated with an anxiety state (Kendell, 1975). However, the mixed states of anxiety and depression override this separation and depressive illness without a depressed mood is not uncommon.

An investigation into the depressive symptoms presenting to general practitioners found that 3 % of women and 7 % of men with the syndrome of major depression paradoxically suffered no from dysphoria (depressed mood). Eighty-seven percent of men and women with a depressive syndrome showed somatic symptoms of anxiety and the most frequent symptom in women after depressed mood was "fatiguability and loss of energy", present in some 84 % of women and 80 % of men with the syndrome of depression. It appears that over three-quarters of patients with affective disorders will generally suffer from at least one somatic complaint (Martin, 1987). To some, it is regarded as a "coping mechanism", as a defence, or where primary-gain is expected from the focus on the somatic rather than the emotional features of an illness (Katon et al 1982). The consultation process tends to induce an expectation of presenting somatic symptoms, and there may be primary-gain from a focus on the somatic rather than the emotional features of an illness, where connotations of guilt, self-blame or malingering are evoked. The resistance by many sufferers to discuss emotional issues and psychological difficulties has also been described in these terms. The psychiatric diagnosis is regarded as a denial of the reality of distress and illness - regarded as a dismissive diagnosis given with little sympathy or understanding (Ramsay, 1986).

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The term "alexithymia" is used to describe the inability of some patients to describe their feelings and emotions verbally (Sifneos et al. 1977). Presenting a depression without presenting cognitive and emotional symptoms, does appear to be relatively common. Only 10 % of overall psychiatric disorders, and 17 % of new psychiatric presentations presented with predominantly psychological symptoms (Goldberg, 1972). This perhaps tells us about patients' expectations of the medical consultation process, and the information which they regard as 'useful' for their G.P.s. It can explain the wide discrepancies which are reported in diagnostic decision making and the variations in prevalence rates found between practices (Schulberg et al. 1985). Patients attribute different meanings to their malaise and clinicians interpret symptoms using different diagnostic paradigms. Essentially, there is no clear distinction in the presentation of problems with a psychological basis and problems with an organic basis. Instead, there is a "grey area" into which many consultations may fall:

 Those in which primary psychiatric or adjustment disorders present with somatic symptoms.

2. Those in which accompanying psychiatric or adjustment disorders are secondary to a physical illness. In these, a) the psychiatric disorder may coexist but be unrelated to the physical illness, thereby deserving a separate diagnosis; or b) the psychiatric disorder may represent a response to the physical illness, and is thereby secondary to it; or c) the organic illness is an aetiological agent in the development of the psychiatric disorder, via central nervous system, or endocrine effects.

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3. Those in which an organic disorder presents, perhaps as yet undetected or in the early clinical stages, but with a somatic overlay, which may mask a physical illness or foster secondary illness behaviour outlasting the course of the physical illness. Lipowski (1986) describes:

"Somatization may coexist with any physical illness and initially mask it. Numerous studies have documented an association between physical and psychiatric disorders. Some chronic diseases, such as multiple sclerosis or systemic lupus erythematosus ... can in their initial stages give rise to vague and changing symptoms that may both foster and be masked by somatisation. The postviral asthenia syndrome (PVFS), whose cardinal symptoms include fatigue, malaise, muscle aches and pains, and depression, has often been misdiagnosed as a somatoform disorder.... It follows that a patient with somatisation may actually suffer from both a psychiatric and an organic disorder and hence deserves careful medical assessment." (Lipowski, 1986)

PVFS sufferers are not unlike the common sufferers of depressive disorders and it is therefore not surprising that the problem has often been identified as a "psychological" one. Because of the difficulties of diagnosing this disorder, the real psychological features of the illness have largely been ignored. With insensitive questioning, the patient tends to deny any abnormalities of mood or mental having frequently encountered hostile and functioning, unhelpful responses from doctors who believe that the presence of these symptoms will rule out the possibility of organic aetiology. For many of these patients, a "psychological" explanation for their condition represents a refutation of the "genuine" nature of their illness (David and Wessely, 1988; Jeffrey, 1982). The hostility expressed by many and the severe resentment at being given a psychiatric diagnosis (Behan, 1988) stems from a misguided stance of many investigators into this condition. They have often stressed the

"good pre-morbid personalities" of their patients as confirmation of an organic aetiology (Fegan, Behan and Bell, 1983) and have dismissed the possible interplay between psychological and physical influences on health.

The following quotation is typical of the stance which has been taken by those who acknowledge the "organic" nature of the condition, with its fundamental misunderstandings of the role of psychological factors in any disease process:

"It should be possible to make the correct diagnosis, however, based on the history of a good pre-morbid personality with an entirely satisfactory work record. The absence of any family history of psychiatric illnesses, or any psychiatric stress factors, failure to benefit from psychotropic drugs and the severe resentment at being labelled with a psychiatric diagnosis, also helps to indicate the true syndrome" (Behan et al. 1988).

Firstly, "pre-morbid personality" neither confirms nor refutes an organic aetiology. It is likely that a pre-illness experience of depression indicates a psychological vulnerability which may predispose towards a depressive response to an ensuing viral infection (Imboden et al. 1961) but it certainly does not rule out the organic explanation for the syndrome.

Secondly, physical and psychiatric illnesses tend to occur together more frequently than by chance. Evidence from a variety of sources emphasises that a patient who presents with a physical illness is more likely than a healthy person to be also suffering from a psychiatric illness. Research from a general practice setting has shown that those patients with psychiatric illnesses have a higher consultation rate for physical illnesses than psychiatrically well patients

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(Eastwood & Trevelyan, 1972). A third of those presenting with physical illnesses also show evidence of an accompanying psychiatric disorder, half receiving diagnoses of "psychosomatic disorders" and the rest being given psychiatric diagnoses at some time during the year (Shepherd et al. 1966). This significant overlap of physical and psychiatric problems is also evident in general hospital studies (Shepherd et al. 1960; Maguire et al. 1974; Moffic and Paykel, 1975). What is more, a work record disturbed by absence through illness does not rule out a PVFS diagnosis where past illness may suggest immunological deficiencies or even an early start of the syndrome itself. The research suggests that certain individuals are prone to suffering from a number of separate complaints, and perhaps that one type of problem induces vulnerability for another.

Thirdly, there is evidence that a family history of psychiatric illness can predispose to general medical ill health (Rutter, 1966). In Rutter's study, a parental psychiatric condition was associated with an increased incidence of psychological and physical problems in the children. Just as incidences of both psychiatric and general medical problems tend to cluster in certain individuals, who display perhaps a greater vulnerability to ill health or a lower generalised tolerance, so does illness of both types tend to cluster in certain family units. Whilst poor mental and physical health in a parent can predispose to behavioural and emotional maladjustments in a child at the time of the parental disorder, such an individual is also at increased risk for ill health later in life. Additionally, early experiences of stress have been shown to lower an individual's immunocompetence (Perez & Farrant, 1987).

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Holmes and Rahe (1967) demonstrated the increased incidence of illness onset following periods of high life-change density. They postulated that a failure of adaptation could promote alterations in immune functioning inducing vulnerability to viral attack. A series of studies conducted by Schmale and Iker (1966) related a period of significant life events and a feeling of "giving up", to the development of cervical malignancy. Psychosocial distress was also related to a later manifestation of rheumatoid arthritis (Meyerowitz et al. 1968). Various studies have also demonstrated the role of negative life-events and stressors in the onset of infectious diseases (see Dorian & Garfinkel for a review, 1987).

Stress factors are known to play an important part in the onset of physical illness. They have been implicated in the PVFS (Steincamp, 1989). The disorder is linked to an immunological deficiency. Abnormal lymphocyte production has been found with the suppression of the helper-cells which would normally fight infection (Ramsay 1986). It may be that the virus itself is responsible for the malfunctioning of the immune system, and by adapting can evade detection by the host immune system (Behan et al. 1988). Many patients have reported a stressful episode in their lives prior to acute onset (Salit et al. 1987). Bereavement, occupational and marital stress have all been identified as responsible for reduced immune responsiveness resulting in an increased susceptibility to infection, malignant carcinomas and other diseases. The close interdependent relationships between the immune system, the CNS and neuro-endocrine system, supported by the work on stress (Farrant & Perez, 1987), indicate that the existence of "psychiatric stress factors" does not rule against the organic nature of a presenting illness. It is of course, notoriously difficult to

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establish that stress produces vulnerability to disease, and largely findings have been extrapolated from correlational designs using retrospective patient reports. Future research must address the specific association between falls in immunocompetence and the development of illness.

A poor response to anti-depressant medication is no proof that a disorder is not primarily a psychological one. Whilst a certain degree of caution must be exercised in the use of psychotropic medication in the medically ill, good responses to anti-depressants have been reported for cases of post-viral fatigue (Salit, 1987; Smith, 1986). In one anti-depressant trial for the medically ill 40 % of patients with cancer, diabetes and epilepsy responded favourably (Popkin et al. 1985). Finally, the patient's reluctance to accept a psychiatric label and to report a depressed mood in many cases, is likely to reflect the attitude which many have encountered from sceptical practitioners. Depression without dysphoria may occur in depressive disorders, but depressed mood has been reported in almost all case reports of PVFS. Whilst most patients are eager to state that their depression is a reasonable response to a feeling of chronic ill health they would no doubt feel safer about admitting to the more inexplicable feelings of hopelessness and despair if they had no fear of being dismissed by their general practitioners as not suffering from a "true syndrome".

### 1.2 Psychiatric disturbance in the Post-Viral Fatigue Syndrome

A 1954 text of clinical psychiatry (Slater and Roth) makes out a case for "post-infectious neuromyasthenia". In terms of its clinical presentation, with the muscular and neurological involvement, it

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appears to resemble what today is referred to as post-viral fatigue. In this text, it is regarded as a presenting case of depression. It is said to benefit from anti-depressant medication and occasionally electro-therapy in creating a psychological state conducive to recovery. Slater and Roth regard it as a disorder in which the underlying and initiating infection gives way to a depressive disorder with hypochondriacal symptoms long after the infectious agent has been controlled.

Whether or not the post-viral fatigue syndrome can be regarded as an infection-induced depressive disorder, there is clear evidence in it of depression-like symptomatology. The early literature reports on epidemic outbreaks of systemic illnesses resembling poliomyelitis. Psychological symptoms are widely reported ranging from mild depression and anxiety symptoms to severe behavioural abnormalities (Kendell 1975). The symptom reports are based upon first-person accounts, psychiatric pre-diagnostic speculations or check-lists of presenting self-complaints. None of the epidemic studies report on symptoms collected from standardised and valid measurement techniques.

Emotional disturbances have been reported with a tendency to tearfulness, euphoria, anxiety with physiological accompaniments and irritability. Symptoms of a suspected organic basis have included reports of hysterical behaviour and transient personality changes, with the development of phobias and delusions. An inability to concentrate is frequently reported along with short-term memory difficulties, transient speech problems including chronic anomia and a feeling of mental "confusion" with problems in decision making. There is often a significant change in sleeping patterns with reports of

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hypersomnia and of insomnia.

The psychological symptoms have been reported to persist even after recovery from the myalgia. In Iceland, "neurotic and functional" symptoms were still evident six years after the initial epidemic (Sigurdson & Gudmundson, 1956). Two years after the 1954 epidemic in Alaska, about 19 % of those affected still displayed "significant emotional instability", and 13 % were reported to be "tense with concentration difficulties" (Peszke & Mason, 1969). All of the 8 patients re-examined 16 months after the New York epidemic showed signs of depression (White & Burtch, 1954). Following the epidemic at the Royal Free hospital in London (1955), cases of severe depression requiring certification and suicidal attempts were reported (Kendell, 1967).

Reports of an epidemic in Ayrshire between 1980 and 1983 (Fegan et 1983; Keighley & Bell, 1983) present results from the clinical al. investigation of 22 suspected cases of post-viral fatigue syndrome. 82 % of these had elevated neutralising antibody titres to Coxsackie в. They all presented psychological symptoms. One 48 year old woman was described as having a "chronic and severely debilitating emotional illness of agitated depression" 16 months after an acute presentation. Four years later, when the full diagnostic status of the condition was confirmed (past infection with Coxsackie B), the patient was still described as suffering from "acute anxiety... and depression with fits of crying, dizziness and faintness". A second woman of 52 years whose medical history can be traced back 15 years, presented with "agitation and depression, and frank suicidal thoughts". The "emotional lability" was described as intermittant with the feelings

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of tiredness and physical exhaustion. Evidence of past infection with Coxsackie B was also confirmed. A 41 year old man presented with a recent onset of myalgia and fatigue. He described "curious feelings of panic at work with no specific provocation; increased anxiety and irritability, sleep disturbance with early morning wakening" (diagnosed Coxsackie B).

The occurrence of these symptoms are also frequently reported in the endemic cases of this disorder. The medical investigation of some 500 endemic cases found an 80 % prevalence of psychiatric symptoms (Behan et al. 1988). Depression and anxiety with hypochondriacal introspection is reported, accompanying a clinging dependency on relatives. The disturbances of sleep patterns are reported to resemble those encountered in narcolepsy, with hypersomnolence and reversed sleeping pattern in many.

There are considerable difficulties in making sense of the psychological problems laid out in these medical studies. They do not utilise standardised criteria for the assessment of depressive symptoms, and whilst most reports mention some degree of depression it is not clear if this represents a symptom of dysphoria or whether it suggests depression because of the comparable organic medical The report of a patient who claims feelings of being symptoms. low-spirited may correspond to a "normal depression", that is, an understandable reaction to the changes imposed by ill health. However, to suppose that a patient is displaying an "abnormal mood" state, requires a conceptual leap. A patient may descibe feelings of worthlessness, hopelessness with impairment of thought and judgement and may describe mood as clearly distinguishable from mere dejection

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or misery. The patient would appear to be expressing more than just a normal response or adjustment to illness. In order to justify the diagnosis of a major depressive syndrome, we must understand the symptom configuration, the course of the depression and its reactivity to the presentations of the illness and to external events. In order to match a syndrome of depression the model of depression presented among psychiatric inpatients may not be appropriate. Of more relevance are the affective disorders which are commonly encountered in general practice settings. Among these groups syndrome identification is equally problematic.

Of considerable importance is the finding that most symptoms which correspond to a depressive syndrome are transient and will often not be present on re-examination (Hankin et al. 1982). In terms of a medical condition which involves fatigue, pain and somatization, the depressive symptoms may mirror the cyclical or fluctuating course of the illness, being exacerbated by physical discomfort and feelings of being unwell.

The selection of subjects for study is also a crucial determining factor in the presentation of psychological symptoms. Clinical populations may largely reflect high reporting levels of depressive symptoms; it seems that individuals with mental health problems are more likely to use general health care facilities (Hankin et al. 1982). However it has been suggested that sufferers of PVFS are often reluctant to admit to feelings of depression and anxiety because of the fear of being castigated as malingerers or of inventing an illness for secondary gain (Behan et al 1988). The aversion often found towards a psychological explanation for their illness can be

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understood in terms of the dismissive treatment which many have experienced from a succession of specialists, and the long struggle which is often undergone before a correct diagnosis is arrived at (Ramsay 1986; Straus et al. 1985). It is likely, however, that a great deal of relief will be experienced by many who may be articulating these feelings for the first time.

methodological problem An additional arises because of the heterogeneity of subjects which make up the post-viral groups. Whilst the syndrome is still in the early stages of diagnostic definition and where clinical abnormalities are often difficult to trace, it is to be expected that the populations being studied are often not comparable. The initial criteria for selection in one group of studies was a presentation of "chronic unexplained illness" involving more than one body system which in different circumstances might have been understood to be the presentation of a "functional illness" (Keighley & Bell, 1983). Other studies have begun with selection by means of a presentation of "chronic fatigue" (Holmes et al. 1988; Poteliakhoff 1981; Straus et al. 1985). Investigations of patients referred with medically unexplained symptoms recurring or persisting for prolonged periods often present a picture which is similar to the clinical presentation of the post-viral syndrome. In one study, of 44 patients referred with illnesses with a definable onset for which no cause had 39 were found to be sereologically been found, positive for Epstein-Barr viral antibodies with evidence of active infection for at least one year (Jones et al. 1985). It is already well accepted in the literature that infectious mononucleosis, including the medical Epstein-Barr virus is often followed by prolonged states of fatigue, anxiety and depression (Cadie et al. 1976; Straus et al. 1985). The

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resulting clinical picture is in effect post-viral but is perhaps distinct from the post-viral syndrome initiated by the enteroviruses. The Epstein-Barr syndrome is analogous to PVFS but has been excluded in many of the reports.

Subject selection has done little to distinguish the acute and the chronic stages of the illness; those for which there is evidence of persistent infection with the initiating virus and those where antibody titres point only to past contagion. It is likely that the post-infection stages are clinically distinct from the persisting infectious condition. Patients have also been included when although they present a similar clinical picture, no sereological evidence has been found (Taerk et al. 1987). Whilst this does not rule out the true syndrome, it does present some methodological problems. Where the existence of self-help group may allow patient self-diagnosis, care must be taken to avoid the inclusion of subjects for whom no medical available. Where examination of opinion is psychological symptomatology is underway, perhaps there is also a need for the separation of those who show evidence of a pre-illness history of affective problems and those without such a history. Since it is possible that an individual's response to an illness may influence its course and outcome, the examination of pre-illness coping responses and depressive episodes may be of some importance.

There have only been a few mentions of the post-viral sequelae in the psychological literature. An early report presents two isolated case histories of young women who developed the syndrome after the Royal Free epidemic in 1955 (Kendell, 1967). It appears that the case histories were compiled from medical notes and speculation. It is

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said that the two women had shown evidence of a predisposition to "neurotic breakdown", one having had "an unhappy home background and a long history of ill-health", the other a history of nocturnal enuresis up to the age of 9 years. Both were said to be "quiet and reserved, with few friends and little drive". The sequelae of depression were said to be accompanied by "histrionic, attention-seeking behaviour, hysterical fits and frequent suicide attempts", or with "a striking restlessness and inability to concentrate" with "frequent aggressive and self-destructive outbursts". The accounts are vivid and extensive but lack comprehensive psychiatric exploration. However, the report raises the aetiological dilemmas of the possibility of viral damage to mechanisms subserving emotional and behavioural control, or that the psychiatric symptomatolgy represented the reactions of a "neurotically vulnerable" individual to a long term and distressing condition. Because of the extreme and widespread nature of the emotional changes and accompanying epileptic features in one, a strong case is made out for cerebral damage as the cause of these symptoms.

Α of three cases of post-viral syndrome referred for report psychiatric opinion comes from the Runwell Hospital in Essex (Winbow, 1986). Psychiatric treatment was seen to be of no particular value because of the presence of atypical symptoms. Whilst virological and immunological studies confirmed persistent contagion with the enterovirus, Coxsackie B, two had been referred described as suffering from a "phobic anxiety state" and one from an "endogenous depression with early morning wakening and a classic diurnal variation of mood with the depression being worse in the morning". All three had proved to be unresponsive to anti-depressant medication. The diagnoses were made independently of the presence of the virological and

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immunological features and it is unclear if such diagnoses would have been made if the psychological symptoms were considered to be part of or an exacerbation of a post-viral syndrome.

The first attempt to classify the psychological symptoms accompanying the post-viral syndrome according to standardised diagnostic criteria was a study by Taerk and colleagues in Toronto (Salit et al. 1987; Taerk et al. 1987). Using a group of 24 subjects with a suspected post-viral fatigue syndrome, 16 were found to meet the diagnostic criteria for a present major depression (67 %), whereas, of 24 matched non-clinical volunteers, 29 % met the diagnostic criteria for a major depression. Overall, 71 % of the post-viral group had a life-time prevalence rate of affective disorder in comparison to 38 % of the control group.

The researchers administered the National Institute of Mental Health Diagnostic Interview Schedule, which corresponds to DSM-III diagnoses (Robins et al. 1984). The differences in life-time prevalence rates between the two groups holds only for major depression. No group differences were found for dysthymic disorder, anxiety disorders (phobias, agoraphobia, panic and obsessive compulsive disorders) or substance abuse. The numbers of subjects are however too small for this to be taken as a conclusive finding. Similarly, it is likely that the small sample size may be contributing to a rather elevated prevalence of depressive disorders in the post-viral group.

An important point to come out of this study is that whilst 54 % of the post-viral group had experienced one or more episodes of an affective disorder following the onset of the fatigue syndrome, a

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significant 50 % of the group showed evidence of at least one episode before developing the post-viral syndrome. Only 17 % of the comparison group had had a major depressive episode within 12 months of the interview, and 12 % at least one episode over a year ago. This leads to the speculation that the development of chronicity following an acute viral illness may be related to a "psychological vulnerability" in individuals who have a history of affective problems. This vulnerability could be understood in terms of an individual's "threshold of tolerance" to distress. Alternatively, theories of illness clustering or immunological deficiencies resulting from affective illnesses could explain this finding. Taerk describes a process of "psycho-maintenance", whereby a psychological vulnerability to, or the pre-existence of a depressive disorder, can predispose an individual to long term illness after a viral infection.

A consideration of the selection of subjects in this study is of considerable importance. The first criterion for selection was the presentation of subjective weakness and exhaustion which must have been present for three months or more. The duration of the symptoms is important in distinguishing a self-limiting aftermath of an illness from the chronic fatigue syndrome. It is also important because post-viral "symptoms" can be detected within 24 hours of an infection with a Coxsackie virus in 28 % of those affected, and in 65 % within a month of the acute illness (Calder et al. 1987). However, there is no agreed upon time scale in deciding when the normal response to viral contagion extends to an abnormal sequelae. Taerk selects subjects whose illness dates back to an "apparent" acute infective episode. Serological investigation indicated that 7 had had past infection with Epstein-Barr virus, other infections included giarclia lamblia,

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cytomegalovirus and herpes-zoster viruses. However, 12 patients showed no evidence of viral infection.

Viral isolation is frequently unsuccessful because of the often prolonged period since the acute phase. The average duration of symptoms in this study is 18 months. Specific antiviral antibody titres, as used in Taerk's study, can suggest which viruses were involved, but more sophisticated techniques for detecting latent or or persistent viruses in tissues are now becoming available, providing better diagnostic potential for this syndrome (Behan et al 1988; Ramsay 1986). There is always a possibility that without diagnostic clarity alternative diagnoses and perhaps somatised depressive disorders may be considered which clinically resemble the post-viral syndrome. However, in view of the clinical descriptions of these patients (Salit et al 1987), we can be fairly certain that they represent "probable" cases of post-viral syndrome. It may have been informative, however, if the group without evidence of viral infection had been compared to the "definite" cases in terms of life-time psychological difficulties.

Taerk uses the Beck Depression Inventory (Beck, 1978) to measure the current self-reported depressive symptoms. Whilst this is not comparable to a DSM-III diagnosis it does suggest a point-prevalence level which complements the pre and post onset life-time prevalence rates. 67 % of the post-viral group, alongside 17 % of the non-clinical group reported that they were currently experiencing symptoms of depression (from mild depression to a severe rating, a score on the BDI of +9). The BDI has not been standardised for use with medical patients and one third of the items of the total score

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are made up of vegetative components. Whilst such symptoms make up the criteria for a major depressive disorder in most psychiatric patients, their reporting is likely to be seriously affected by the presence of a medical illness, providing substantial scores for a subscale of depression even in the absence of psychological symptoms. A raised point-threshold may provide a more accurate presentation of the current depressive symptoms.

Three of the group (13 %) score between 16 and 19 on the scale; five (21 %) score between 20 and 30, and an additional 3 subjects (13 %) score between 30 and 63. These scores are elevated enough to be considered as significant markers of depressive symptomatoly, and none of the non-clinical group scored in these categories. It is probable that the diagnostic interview will also produce some false-positive cases of depressed post-viral patients. Sixty-three percent of the symptoms making up the diagnosis are vegetative and physiological items (Kathol & Petty, 1981). If depression does occur it is likely to contribute to these physiological symptoms and it will aggravate the medical symptoms, but the contaminating effect of the depression and the post-viral syndrome will be difficult to disentangle.

Taerk administered the Dexamethazone Suppression Test (DST) to 15 of the 24 patients. Only one was classified as an abnormal responder. The abnormal response suggests a disregulation of the hypothalamic-pituitary-adrenal axis resulting in hypersecretions of cortisol. The DST is regarded as a laboratory test for the diagnosis of melancholic or 'endogenous' depression (Carrol et al. 1981). Its application to mild to moderate depressions in the community is

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however controversial. The abnormal response has been found to occur in only 14 % of depressed outpatients (Rabkin et al. 1983). The DST is expected to predict a favourable response to anti-depressant medication, however, recent research shows this not to be the case (Myers, 1988). It seem likely that abnormal plasma cortisol control may be just one symptom of depression and thus has little predictive value. The existence of prior episodes of depressive disorders in 50 % of Taerk's post-viral group does present the possibility that the current depressive episodes he has described may correspond to major depressive illnesses as opposed to emotional distress alone.

In what follows I will be discussing the common presentation of depression in terms of somatised disorders. This will help to understand the diagnostic difficulties presented in post-viral fatigue and to recognise the common plight of sufferers of major depression and this syndrome. By presenting the picture of depressive disorders in somatic and vegetative terms, I hope to stress this similarity and to call for the acceptance of a psychological approach to this illness whilst not disallowing the genuine nature of suffering endured or disclaiming an organic explanation for the disorder. A careful exploration of the syndrome of major depression in terms of its psychological versus its vegetative symptoms aims to clarify the difficulties in the assessment of depression in individuals where general medical i11 health is also contributing to somatic symptomatology. Finally, I will consider some explanations for the existence of depression in medical conditions and come to some conclusions about the psychological component in the post-viral syndrome.

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# 1.3 <u>Somatisation and diagnostic uncertainty: the organic/psychological</u> grey area

SOMATISATION is a process in which distress is perceived or reported in terms of bodily dysfunctions. On an experiential level discomfort is felt in cardiovascular, respiratory, musculoskeletal and gastrointestinal systems. The distinction between an autonomic mediation of affective problems and the symptoms of genuine organic disturbances is problematic, especially where depression and anxiety can aggravate organic symptoms or where secondary somatisation can develop in the long term sequelae of a chronic medical illness. On the cognitive level, somatisation represents the attribution of autonomic responses as signifying serious physical illness where pathology may or may not be present. On a behavioural level it is displayed in terms of an "abnormal illness behaviour" in which an medical consultations and requests individual makes frequent repetitive investigative procedures and no physiological evidence for disorder is found. Whether it coexists with a genuine organic illness or signifies a psychiatric or adjustment disorder, persistent somatisation can result in long-term disability.

DSM-III identifies the criteria for a "somatisation disorder" which is distinct from the criteria for a "somatised depressive illness". Its foundations are problematic if we conceive of some degree of diagnostic uncertainty in most medical explorations. For a "somatisation disorder" to be identified, non- specific symptoms must have been reported in various body systems for a prolonged period of time. The first criterion of somatisation is frequent consulting

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behaviour for somatic manifestations of psychiatric illness with none of the more obvious "psychological" symptoms such as feelings of dysphoria, loss of interest or hopelessness. These will often be the patients who frequently return to their general practitioners with multiple unexplained symptoms where often no understandable organic explanation can be given for their distress. In the course of diagnostic exploration they are referred to several practitioners and more often than not tests come back negative and the patients fail to fall into categories recognisable to the specialists. A diagnosis of somatisation disorder will usually foreclose medical investigation after a prolonged period of diagnostic uncertainty. Such foreclosure is worrying considering that diagnoses of somatisation disorder or depression with somatic presentation have frequently been reported prior to the discovery of underlying multiple sclerosis, carcinomas, myasthenia gravis and Cushing's disease (Marsden, 1986). Whilst for the patient, the lack of some medical explanation for their discomfort causes extreme anxiety, the overly hasty labelling of a problem in terms of a somatisation disorder may place an undiagnosed patient in a potentially dangerous situation. It appears that often the misapplication of psychiatric labels to medically ill patients in the early periods of diagnosis can reduce their chances for improvement and may result in a worsening of their physical health (Hall et al. 1978). The plethora of invasive investigations during a period of diagnostic enquiry may also prove damaging to a patient, both physically and through the reinforcement of the idea of serious illness in anxious patients.

A study of 11 cases of patients with persisting illness and fatigue were investigated by researchers from departments of immunology and

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allergy, virology, dermatology, microbiology and pathology and psychiatry (Straus et al. 1985). Six patients were considered by the psychiatrist to have a somatisation disorder, one was given a diagnosis of "anxiety neurosis" and another a diagnosis of depression. These 11 patients all showed evidence of prior infection with the Epstein-Barr virus and clinical presentation clearly suggests a post-viral fatigue condition. In the face of relatively unimpressive and non-specific clinical findings which may delay the identification of viral infection (Behan et al. 1986), it is somewhat understandable that diagnoses of somatisation have been made in these cases.

The second criterion for a somatisation disorder is that there is no obvious organic reasons for the symptoms, or that the reported symptoms are out of proportion to the presumed organic pathology. With psychological treatment it would be expected that physical symptoms would abate or at least revert to a level which is consistent with the organic pathology. The use of a diagnosis of somatisation disorder where organic evidence is minimal is problematic if it is used as a means of understanding a medical problem that seems to defy "hysteria", now replaced by classification. diagnosis of Α classifications of "abnomal illness behaviour" and "psychosomatic" complaints, has often been used for the same reasons: it makes a disorder which is seemingly unexplicable, make sense. The "hysteria debate" is one which has plagued the research into PVFS since 1955 (McEvedy & Beard, 1955; 1970). As Marsden asserts (Marsden, 1986): " there can be little doubt that the term 'hysterical' is often applied as a diagnosis to something that the physician does not understand. It is used as a cloak for ignorance".

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The presumed aetiology or "understandability" of a condition is rarely acknowledged to be an influential determinant in the application of a diagnostic label. In primary care, it does appear to be of some importance in the labelling of a depressive disorder (Blacker, 1987). G.P.s have been reported to describe a depressive condition as "endogenous" if they can see no external reason for the distress, but an "adjustment disorder" or "understandable distress" if they can (Blacker & Clare, 1986).

The difficulty lies in that the clinical findings of PVFS are nonspecific and unimpressive. The degree of disability often seems out of proportion to the objective extent of the illness (Straus et al. 1985), and although the idea of "mass hysteria" is now seriously contended (it cannot apply in sporadic endemic cases), some degree of "hysterical or functional overlay" is accepted (Ramsay, 1985). "Intense introspection and hypochondriasis" (Behan, 1988), hysterical behaviour and transient personality changes have been reported (Kendell, 1967). Whilst Kendell believes that these personality changes indicate neural involvement in areas subserving emotional and behavioural control, it is the belief of David, Wessely and Pelosi (1988) that the "histrionic" or "manipulative" behaviour is a product of the often acrimonious doctor-patient relationship, whereby, "in a desperate search for recognition patients may resort to what one such sufferer called 'unacceptable patterns of behaviour'... This is a manifestation of the patient's need for an acceptable diagnosis, often equalled by the pressure on the doctor to provide one".

#### 1.4 The presentation of depression in primary-care patients

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Over the last 30 years, there has been a gradual increase in the diagnoses of affective disorders by general practitioners (Burton & Freeling, 1986). The rate of new diagnoses increased from 1.4 to 31.4 per 1000 cases between 1956 and 1971 (Royal College of General Practitioners Research Unit, 1976). This is seen as increased awareness on the part of the practitioners rather than a change in incidence. That doctors miss some 30 - 50 % of psychiatric problems (Goldberg et al. 1987; Freeling et al. 1985) must have some serious consequences to the patients. The failure to recognise and treat a depressive disorder which accompanies an organic condition can cause aggravation of the physical symptoms, result in increased consultations through a lowering of the pain-threshold (Bridges & 1987), may interfere Goldberg, and with the necessary treatment-compliance behaviour. Altered compliance with conditions such as insulin-dependent diabetes or chronic renal failure can in themselves become life-threatening.

The predisposition of the G.P. to respond primarily to the physical symptoms of a depressive disorder can result in the reinforcement of somatising consultative behaviour, encouraging a patient to express a psychological problem in somatic terms. Goldberg (1976) believes that the failure to probe for mental symptoms can often be a conscious decision on the behalf of the physician.

Firstly, how do depressed patients present to their G.P.s? In two general practice studies, of those diagnosed as suffering from psychiatric disorders by independent means, only 10 % overall (Goldberg et al. 1979) and only 17 % of new illness (Bridges & Goldberg 1985) presented with depressed mood, crying or feeling down

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in spirits. In another G.P. study, three-quarters of all patients with low mood complained of more than one somatic symptom, 32 % complained of two symptoms and 17 % reported four or more somatic symptoms. Headaches were the presenting symptom in 30 % of these cases and general weakness / debility was reported in 28 %. Other common somatic symptoms were non-specific pain, abdominal pain, dizziness, dyspnoea, nausea and sweating (Martin 1987).

These somatic symptoms can be related to depression or anxiety symptoms. They are often associated with disorders of borderline classification, perhaps confused with medical problems of a physical nature.

"They suffer minor disorders of mood whose features are not pronounced enough or perhaps not numerous enough for diagnostic patterns to emerge, which change from day to day, which are partly but not entirely related to the mishaps of life, and in which feelings of depression, anxiety and a host of other emotions and somatic symptoms weave tantalizingly in and out with a choreographic complexity that defies nosological precision" (Harris 1986).

It is the appearance of more global disturbances in functioning, such as changes in sleep and appetitive patterns, increased fatigue and changes in sexual interest that may represent more severe manifestations of depression (Goldberg et al. 1987). Whilst the non-specific somatic/autonomic ailments may be presented because of increased bodily focus resulting from some degree of anxiety and dysphoria, the global disturbances suggest that a depressive disorder of some clinical severity is in evidence.

Mathew (1981) has described the vegetative and autonomic symptoms

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associated with affective disorders. In a study comparing drug-free psychiatric patients with anxiety and matched controls, the patients with psychiatric difficulties showed significantly higher symptom counts on general bodily and specific physical symptoms than the controls. Depression as measured on the Beck Depression Inventory was the factor most highly predictive of the symptoms. The number of physical symptoms was not however related to the severity of the underlying depression. All patients displayed high symptom scores regardless of severity. It seems probable that many of the symptoms on Mathew's check-list are stress-related and are indicative of an inpatient population irrespective of diagnostic classification. Many of the symptoms are anxiety-related, corresponding to the autonomic symptoms associated with panic attacks and phobic behaviour.

There appears to be a relationship between the number of typical somatic symptoms in affective disorders and age (Pollit & Young, 1971). Global sleep disturbances and early morning awakening, symptoms commonly associated with more severe depression, have prevalence rates which increase with age, whereas diurnal variation and feeling worse in the mornings shows a uniform decrease with age. These age relationships apply to people suffering from depression and from psychiatrically "well" populations (Abe & Suzuki, 1985; Casper et al. 1985), suggesting a continuous distribution of symptoms in the community.

The degree of somatic disturbance is also related to the severity of the psychiatric condition. Studies have unveiled a hierarchical incidence of specific somatic symptoms occurring at different thresholds of severity. The specific pattern of somatic symptoms can

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also provide the distinguishing characteristics of different diagnostic subtypes. That specific symptoms may distinguish categories of affective disorders suggests a discontinuous model of psychiatric syndromes with "zones of rarity" (Kendell, 1975) between subtypes. Support for the discontinuous model of syndrome subtypes has been provided by factor-analytic and cluster-analysis studies, but symptom-specific evidence still falls in favour of a dimensional approach (Gilbert, 1984; Goldberg et al. 1987).

The Newcastle scales which were designed to distinguish metabolic depressive disorders ("endogenous"), from depression which is "reactive" to environmental events (Carney et al. 1965; 1968) show strong positive correlations with measures of depressive disorder according to patient self-report (Beck Depression Inventory), and clinical interview (Hamilton and Present State Examination). The variance common to them all was based upon severity (Ashton, 1988).

Casper et al. (1985) attempted to find distinguishing symptomatic evidence to support the "endogenous/reactive", "unipolar/bipolar" and "agitated/retarded" depressive subtypes. From a factor analytic study, appetite loss was the only symptom which satisfactorily differentiated those classified according to the unipolar/bipolar distinction. No support was found for the endogenous/reactive distinction bringing into question the validity of this subtype. It was found that the somatic symptoms common to depression were present in most subtypes of depression according to Research Diagnostic Criteria, and were not indicative of disorders which could by other criteria be classified as "endogenous". Instead, the classic symptoms of global sleep disturbance, loss of libido, early morning awakening, poor appetite

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and weight loss occurred in a hierarchy, with a close relationship to severity and not to diagnostic subtypes. This hierarchical view of psychiatric symptomatology has received widespread support (Foulds & Bedford, 1975; de Jong et al. 1985; Morey 1985; Sturt, 1981).

An improvement in the understanding of depression has resulted from the application of a latent trait approach to the issue of subtype classification. Unlike the traditional factor analytic approach which identifies discrete clusters of responses, latent trait analysis rests upon the proviso that there exists a hierarchical relationship between symptoms. It views dysfunction as a dimensional, or continuous variable.

The latent trait model when applied to a diagnostic tool such as a depression inventory identifies an underlying trait and relates each symptom to that trait. Each symptom is explained in terms of:

a) Its "threshold" level, that is, its correspondence to a degree of illness severity. Thus the presence of a symptom such as "early awakening", which occurs fairly high up in the hierarchy, will suggest a more severe depressive disorder than the presence of a dysphoric mood, which will occur also in the milder disorders.

b) Its ability to "discriminate" among subjects on the basis of the underlying illness. Thus it shows which symptoms in their presence most specifically relate to the presence of illness. Diagnostic classification according to key symptoms is also the basis of other diagnostic schemas, for example the index of definition from the Present State Examination (Wing, Cooper, Sartorius, 1980). The studies by Goldberg and colleagues (Goldberg et al 1987; Grayson et al 1987) have assessed the common psychiatric disorders which are encountered in general practice settings. Using the GHQ-28 as a screen and the Psychiatric Assessment Schedule (derived from the Present State Examination), which incorporates four diagnostic systems (Surtees et al.1983), they have enriched our understanding of the symptoms of depression which indicated "caseness" at different levels of severity. Diagnostic disagreement among primary care doctors (Grayson et al. 1987), using schemas derived from the study of psychiatric inpatient populations points to the need for in depth symptom profile research to take place among general practice populations. The results from this research suggests that the high symptom thresholds utilized in general practice diagnoses seriously underestimate the extent of psychiatric morbidity.

The following vegetative symptoms of depressive disorders taken from their research show increasing threshold levels:

Subjective anergia Loss of libido Loss of appetite Weight loss due to poor appetite Early awakening Retardation (slow / underactive) Diurnal variation, mornings worse.

Thus, the symptoms at the start of the list occur with frequency in primary care settings, and are associated with milder levels of depression. These earlier symptoms may or may not occur with increasing illness severity, but the symptoms later on in the list will only be found in patients with increasingly severe depressions. The list has a potential use in the application of depressive diagnostic schemes to the medically ill, where organic symptoms manifested by the physical disease process may contaminate traditional measures of depression.

Whilst loss of libido, loss of appetite and early awakening were clearly associated with the dimension of depression as opposed to that for anxiety, the symptoms of subjective anergia and weight loss do not provide much differentiation on the factor loadings for depression and those for anxiety. These two symptoms appear to be common to the two as opposed to the specific subtype categories. Increased appetite and weight gain, now included in some diagnostic assessments of depression (DSM-III) appear to have little connection to psychiatric diagnoses or illness severity. In another study (Casper et al. 1985), diurnal variation of mood with mornings the worst was found to relate not to a dimension of illness severity, or to a specific depressive diagnosis. It is suggested that this symptom reflects "the temporal coordination of the mood cycle", but the implications of this finding are not clear. On Goldberg's latent trait analysis the symptom shows a low slope, which points to its weak discriminatory power; thus it is weakly related to the severity of the underlying illness. With the three other vegetative symptoms, weight loss, early awakening and underactivity, it however represents the most severe manifestations of depression.

Another method of uncovering those "key" symptoms which are suggestive of a level of illness severity or subtype is in an analysis of treatment reponse. A study by Winokur et al. (1985), confirms some of the findings of the Goldberg research group. In terms of the patient response to a treatment programme of ECT, it was those patients with

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symptoms of marked retardation, loss of energy, appetitive and sleep disturbances and distinct diurnal variation who showed the most marked improvements. These symptoms correspond to the symptoms which emerged from the latent trait analysis as being indicative of increasingly severe depressions.

A study by Clark et al. (1983) found poor discriminatory power in many of the vegetative symptoms in psychiatric patients, after controlling for the level of illness severity. Fatigue appeared to be the one vegetative symptom which did discriminate well between levels of disorder.

### 1.5 The presentation of depression in the medically ill

Having considered the role which vegetative symptoms play in depressive disorders from primary care and inpatient settings, we can turn to an investigation of depressive symptomatology in the medically ill.

Medical patients who are classified as not depressed according to self report and interview diagnostic measures very frequently have vegetative symptoms. From work with a variety of medical inpatients (Stewart et al. 1965; Schwab et al. 1967; Kathol & Petty 1981), they frequently show somatic preoccupation (80 %), retardation (76 %), fatigue (66 %), decreased sleep (63 %), decreased appetite (31 %), loss of weight (28 %) and loss of libido (18 %). Considering the frequency with which these symptoms occur in a non-depressed medical group, somatic and vegetative symptoms would not be expected to be good indicators of depression in the medically ill. However, amongst the medical patients who were reported to be suffering from a degree of depression of some clinical severity, there were significant increases in some of the vegetative components suggesting that they were being affected by the presence of depression.

The frequency with which a fall in appetite occurred in the medical-depressed group showed a 43 % increase on the frequency in the medical non-depressed group. Retardation occurred about 25 % more frequently in the depressed as opposed to the non-depressed medical patients. Decreased sleep, decreased weight, fatigue and somatic preoccupation all occurred about 20 % more frequently in the depressed of the medical patients. A loss of libido showed a 14 % increase in frequency. It appears that changes in sleep, appetite and weight patterns and levels of reported fatigue are also functions of the severity and life-threatening nature of the medical condition.

Latent trait analysis similarly shows that these vegetative symptoms do not discriminate well between the depressed and non-depressed medical patients (Clark, 1983). Clark suggests that perhaps these symptoms represent a second latent trait but that they are of no validity in the assessment of the severity of depressive illnesses in medical or in psychiatric groups. The fact that the above studies showed remarkable increases in the frequency of these symptoms in depressed people with physical illnesses may be explained substantially by the severity of the underlying condition (which has been controlled for in Clark's study). More investigation is needed before we can rule out a role for vegetative symptoms in the assessment of depression in the medically ill. Caution is certainly called for, where

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 a) existing depression scales have not been formulated for or adequately tested on the medically ill (an exception is the Hospital Anxiety and Depression scale by Zigmond and Snaith, 1983); and

b) evidence shows that rates of psychiatric disorders in the medically ill recorded using these perhaps inappropriate measures, are substantially elevated when compared to a "well" population; and

c) there is considerable lack of clarity in the definitions of depression in the medically ill.

The use of clinic samples of the medically ill introduces a selection bias in many of the studies where those with mental health problems are more likely to use health care facilities and are more likely to reach inpatient status in a general medical hospital (Rodin & Voshart, 1986). In addition to these points, the vegetative symptoms, if a large component of the psychiatric classification, cannot represent a clinical syndrome because of the large variation in the medical conditions which are covered in most of the studies. They represent conditions with a variety of affected organs and metabolic abnormalities.

In considering a few of the more commonly used scales for the assessment of depressive disorders, it is clear that the loading to somatic/vegetative symptoms is often substantial. The Hamilton scale provides a structured rating by a psychiatrist to be used with patients already diagnosed as suffering from problems of depression (Hamilton, 1960). Items relating to gastro-intestinal and general

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somatic symptoms, menstrual irregularity, a preoccupation with bodily health, insomnia, loss of weight and loss of sexual arousal account for 46 % of the total score for depression. The self-report interviewer-assisted Beck Depression Inventory (Beck, 1978) is widely used as a screening instrument and as a measure of severity in the assessment of depression in the medically ill. It has not, however, been standardised for use in general hospital settings. Items such as "I feel there are permanent changes in my appearance that make me look unattractive", or "I get tired from doing almost anything", or "I worry about my physical health" will clearly be affected by the presence of a physical illness. Along with symptoms of sleep, appetitive and weight dysfunctions, such items contribute 33 % of the total depression score. A large false-positive group of mildly depressed medical patients will therefore be identified using the Beck scale where standard cut-off points are used (Moffic & Paykel, 1975; Clark et al. 1983).

Many of the diagnostic interviews, for example the Clinical Interview Schedule (Goldberg et al 1970) or the Psychiatric Assessment Schedule (Surtees et al 1983) assess symptoms according to the DSM-III, RDC and Feighner criteria. Each of these comprise a significant number of vegetative and physiological components (representing up to 63 % of the symptoms making up a diagnosis of depression.

# 1.6 The use of non-vegetative symptoms in the medically ill as predictors of depression.

Since depression scores are contaminated by vegetative symptoms in the medically ill, alternative means of assessing depressive disorders

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must be resorted to. The presence of global sleep disturbances, weight loss and changes in libido can not be regarded as indicators of clinical depression in this group. Whilst these disturbances may be aggravated in medical patients suffering from depression, they also occur with considerable frequency in non-depressed patients with diverse conditions such as malignant carcinomas, cardiovascular disorders, arthritis and so on. Amongst general practice attenders, there is a significantly high and positive correlation between the presence of vegetative "mental" symptoms (such as disturbance of sleep, appetite, weight, libido) and psychic symptoms in those who have been diagnosed as depressed (Goldberg, 1985). For the medically ill, we can no longer predict such a strong correlation, but amongst the non-vegetative, cognitive and psychic symptoms there exist alternatives for identifying those who are concurrently depressed.

Clark (1983) identifies as good markers for depression in the medically ill, those symptoms which are common in depressed patients but uncommon in medical patients. The important studies have compared symptom profiles of patients referred to psychiatric clinics with diagnoses of depressive disorders and patients from primary care or general hospitals with specific medical ailments. One study uses the Beck Depression Inventory as a means of detecting depression amongst a medically ill population. The non-somatic items appear to discriminate well between the depressed and the non-depressed patients (Cavanaugh, 1984). Thus, a revised Beck inventory can be used to pick up those physically ill patients who are also depressed. Having removed the somatic items the new scale measures only a single dimension of affect based on the cognitive components of the symptoms of depression. It is the affective and cognitive items in the

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assessment instruments which appear to be best suited for diagnosing depression in this group. The somatic symptoms should only be used to support a diagnosis if severe and seemingly out of proportion to the organic illness (Cavanaugh, 1984).

Α matched comparison study of medical inpatients and psychiatric-depressed patients (Moffic & Paykel, 1975), concluded that "most of the differences between medical and psychiatric depressives do appear to reflect greater appropriateness of the phenomena to the life situations in which they develop". This raises the issue as to whether the primary depression of a psychiatric patient differs fundamentally in type from that which is experienced by someone with a debilitating or life-threatening organic dysfunction. Issues such as these will be raised later on in this thesis. The study by Moffic and Paykel, did however provide some tentative conclusions as to the nature of certain symptom patterns. The presence of suicidal intent, helplessness and pessimism were explained in terms of their "appropriateness" to a life restricted by physical illness, the former being regarded as "inappropriate" and therefore uncommon, whilst the latter two were "understandable" expressions and commonly found in patients with medical illnesses. Medical patients were found to display more anxiety, more agitation and self-pity and more psychomotor retardation than the group with depressive diagnoses only. there were no significant differences on somatic Surprisingly, symptoms or expressed guilt. A feature which clearly distinguished the two groups was the feeling amongst the medically ill that there was a quality" to their depression which was regarded as "distinct fundamentally different to their normal experiences of sadness and dejection.

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A disorder is considered to be "secondary" if it starts after another another disorder which is present at the time of the second condition. A study investigated the depressive disorders which are secondary to substance abuse, somatoform, anxiety and personality disorders and depressions which are secondary to medical illnesses (Winokur et al. 1988). Those with medical illnesses were found, according to a DSM-III checklist, to show significantly less suicidal thoughts and attempts than the other groups. This confirms the finding in an earlier study (Stewart, 1965), where none of a group of depressed patients with a medical illness had seriously thought of or had attempted suicide, whereas 45 % of a group of manic depressives had completed, and a further 5 % attempted suicide. However, in this study, the small numbers of subjects call for some caution. Of 5 patients with depression and a medical illness, 60 % had expressed a wish to die. The same proportion was found in the 20 manic depressives. 80 % of the medically ill and only 35 % of the psychiatric inpatients regarded their illness as a punishment. Crying, hopelessness and concentration difficulties were reported almost as frequently in the medically ill as in the psychiatric group.

Clark's latent trait studies (1983; 1985) have already been discussed in some detail. Whilst most of the vegetative symptoms, including fatigue, sleep, appetite, weight and libido disturbances, proved hypochondriasis and body image disturbance unable t.o discriminate between the depressed and non-depressed of the medical patients, certain of the remaining symptoms appear to have good diagnostic powers. Those with good discrimination according to levels of depressive severity indicate that a sense of dissatisfaction occurs

at a low threshold and is therefore common in the milder disorders; indecision, crying, and loss of social interest are associated with increasingly severe depressions; regarding an illness as punishment or as an indication of failure and suicidal thoughts identify those with high levels of depressive severity.

Clark works on distinguishing those symptoms which identify the depressed as opposed to the non-depressed in the two diagnostic groups. The following represent those symptoms which discriminate well in a psychiatric depressed group but not in a medical population:

Hopelessness	Irritability
Guilt	Body image disturbance
Self-hate	Work inhibition
Self-blame	Fatigue

In the medically ill, the poor discriminatory ability of these symptoms suggests that they are affected by the medical illness. They should not be used as indicators of depressive severity in such population.

Crying is a symptom which appears to discriminate well in the medical group only. It is perhaps an important indicator of depression in the medically ill.

The remaining six symptoms were found to have good discriminatory powers in the medically ill and the psychiatric patients. They therefore come out of Clark's study as providing the best means of measuring a depression which coexists with a physical illness:

#### Dissatisfaction

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Loss of social interest Indecision A sense of failure A sense of punishment Suicidal thoughts.

It is of some interest that in this study, feelings of hopelessness and guilt proved not to discriminate well in the group of medically ill. Another study (Moffic & Paykel, 1975) found that medical patients scored higher than depressed inpatients on the Beck (BDI) measures of hopelessness and helplessness. Both guilt and hopelessness appear to occur frequently in depressive disorders and do not appear to correlate with measures of disability, thus their role as indicators of depression in the medically ill should not be ruled out.

Clark identifies suicidal thoughts as occuring quite infrequently in the depressed medical patients. It was reported as a discriminatory factor in the most severely depressed. The tapping of suicidal thoughts and behaviour in the medically ill will however usually exclude treatment non-compliance and self-destructive behaviour and evidence from other sources appears to suggest that rates of suicidal behaviour are elevated in the medically ill (Rodin, 1986).

# 1.7 The relationship between medical and psychiatric illnesses

The following discussion considers the relationship between medical and psychiatric morbidity and considers the hypotheses which may explain the frequent cooccurrence of the two:

(a) where an unrelated depressive and medical disorder coexist;

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- (b) where the apparent depressive symptoms are part of the underlying disease process;
- (c) where the depression is a disorder of "adjustment" (to the medical condition).

# An unrelated depressive and medical disorder coxist.

According to the Cluster Theory (Eastwood & Trevelyan, 1972), certain individuals have an increased susceptibility to both psychiatric and medical disorders. Investigations using general practice to attenders, psychiatric or general hospital inpatients demonstrate that the two types of disorder tend to occur in the same individuals. Eastwood and Trevelyan's study used screening and psychiatric state instruments to obtain diagnoses independently of the general practice consultation, identifying two groups with psychiatric disorders and a group of matched non-psychiatric controls. Half of the psychiatric group suffered major physical illness (liable to threaten or shorten life), whilst only 20 % of the control group did so. In many cases, the physical illness was unknown to the patient and the G.P. and thus the coexisting psychiatric disorder was not reactive. Similarly, a community study of psychiatric disorder in women in working-class areas of London (Brown & Harris, 1978) found that those with psychiatric disorders had marked health problems five times more often than those without. Milder health difficulties occurred almost twice as often in those with psychiatric disorders. Another community study (Downes & Simon, 1953) followed up a group of patients who had been diagnosed as "psychoneurotic" by their primary doctors. During the five years of the study this group was found to develop twice the

expected number of acute respiratory illnesses, accidental injuries and other acute illnesses. They were also more likely to develop hypertension, arthritis, gallbladders or coronary artery disease.

When a medical problem occurs in an individual with a prior history of affective disorders or during an episode of an affective disorder, then there is an increased likelihood that the medical problem will follow a chronic course (Feldman et al 1988). An accompanying psychiatric disorder is associated with a poor prognosis for many medical conditions (Moffic & Paykel, 1975). Psychiatric symptoms occurring for the first time in patients with a new episode of organic illness will tend to be more transient and responsive to the course of the illness than if an episode of psychiatric morbidity antedated the illness onset (Lloyd & Cawley, 1983). A group of 16 cardiac patients with evidence of previous psychiatric illness were compared with 19 cardiac patients who had developed their first episode of infarction, psychiatric morbidity following myocardial the classification of which was probably "reactive". Sixty-five cardiac patients were also used who displayed no evidence of psychiatric morbidity. Previous psychiatric problems tended to persist at 4 month and 12 month follow-ups, whereas those who developed psychiatric problems for the first time following an attack showed significant improvements after 4 months.

However, from what we have learnt of the course of affective disorders in general practice studies, the majority are likely to fall into remission after six months (Goldberg & Blackwell, 1970). Many of the point-prevalence cases detected in epidemiological research represent people with natural distress reactions to life situations and half of

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these reactions are unlikely to endure for longer than one month (Tennant et al 1981). Self-reported depressive symptoms have a poor test-retest reliability on reassessment only 5-7 days later (Hankin & Locke, 1982).

The coexistance of medical and psychiatric morbidity suggest that:

(i) Certain individuals appear to be more vulnerable than others to both. Whilst there may be certain factors in common involved in making someone susceptible, such as low social class, housing, hygiene and diet, it is likely that there is an interactive vulnerability effect between medical and mental health problems. For example, the finding that there is more cancer in patients with previous diagnoses of depression (Evans et al 1974) has been explained in terms of the hypothalamus-pituitary-adrenal axis of the disruption to the neuro-endocrine system, resulting in an immunological interference at the cell level (Perez & Farrant, 1988; Brown et al. 1982). The immunological deficiencies associated with depressive disorders (Murphy et al. 1987; Schleifer et al 1984) have also been used to explain susceptibility to infectious diseases. The role of stress in the suppression of the immune system is well known (Kronfol et al. 1983; Linn et al. 1982). Alternatively, individuals who have been identified as showing a stress-prone behaviour pattern, such as the Type "A" personality pattern, have been shown to have an increased risk of cardovascular diseases (Blumenthal et al. 1980).

(ii) The over-estimated prevalence rates of affective disorders in medical care reflect increased consulting behaviour among the psychiatrically ill. If the existence of depression is said to lower

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a "threshold of tolerance" to distress, then increased consulting behaviour for psychological and somatic symptoms will ensue. By reducing the tolerance to long standing symptoms they may be brought to the attention of the medical profession for the first time. Depression can exacerbate the pain and discomforts of a medical condition such as rheumatoid arthritis or it can induce psychophysiological symptoms of pain in the absence of physical illness. Atypical abdominal pain, chest pain and lower back pain are common presentations of affective disorders (Mayou & Hawton, 1986).

(iii) A psychiatric disorder will often result in amplification of the symptoms of a medical disorder, increasing hypochondriacal concern, and is likely to complicate the management of the medical disorder. It can significantly reduce treatment compliance which in conditions such as chronic renal failure could be life-threatening. Thus, stroke patients with prior psychiatric illness were found to be the least likely to stop smoking to reduce the risks of morbidity (Lloyd & Crawley, 1983).

"In many patients, depression is the generator, although not necessarily the physiological "cause" of somatic complaints. In others, underlying chronic organic disease results in depression, which, in turn, is manifested by exacerbation and/or exaggeration of the somatic symptoms assciated with that organic condition" (Katon, 1984).

This "psycho-maintenance" mechanism may result in secondary somatisation of the medical disorder. This can be regarded as a reaction to illness which may foster chronicity (Taerk et al. 1987). Imboden (1961) describes the chronic sequelae of infectious mononucleosis in terms of a pre-morbid depressive tendency. The prolonged symptom patterns result from a particular psychological

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response to illness. The vigilence with which individuals with depressive disorders pursue their somatic ailments, resulting in a plethora of tests and investigation by the medical profession, can lead to an increased awareness of and rumination on bodily malfunctioning (Anthony, 1970).

A controversial paper by Wessely and colleagues (Wessely et al. 1989) focuses upon the ambiguous aetiology of the chronic fatigue syndrome and comes down in favour of a psychological explanation of the disorder. Whilst not acknowledging the fact that many chronic sufferers of post-viral fatigue do show abnormal functioning on muscular and neurological tests and that a past or persistent virus can be located (Behan, 1988), their rehabilitative treatment programme is based upon the proviso that "there is no life-threatening illness The difficulties with their argument is that they present no left". working definitions of the syndrome in order to allow comparison with the diagnostic criteria used in other treatment studies. They stress that many patients referring with chronic fatigue have made their own However, the outline of the syndrome which they present diagnoses. does introduce an adequate model of the way in which an acute illness can give way to chronic disability. Whilst their exercise-promotion treatment strategies may not be helpful for those patients with the active syndrome, indeed improvement is seen to be dependent upon the removal of all sources of physical and mental strain, such a model may be appropriate for those few chronic sufferers in whom the disease process has burned itself out and patterns of illness behaviour and secondary somatisation are preventing recovery. It may also be appropriate to the development of chronicity in other disorders with symptom exacerbation from a psychological disorder or the secondary

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ill effects of muscular atrophy and weakness, hypoventilation and agoraphobia.

The model explains the persistence of the symptoms in terms of a cognitive-behavioural mechanism generated by the accompanying depressive illness. The necessary avoidance of activity in the acute stages of the illness have resulted in maladaptive "chronic avoidance behaviours". This avoidance of stimulation results in a degree of withdrawal from normal activities because of an increased sensitivity to the physiological sensations associated with fatigue. A fear of exacerbating symptoms along with increased cardiovascular unfitness allows the development of symptoms of fatigue at increasingly reduced levels of exercise.

#### Depressive symptoms which are part of the underlying disease process

The vegetative signs of chronic fatigue, sleep disturbance, changes in appetite, weight and libido are unreliable means of identifying depressive disorders in the medically ill. Either they represent the physiological impairment resulting from the disease process, or they are part of an underlying depression. They may represent symptoms from the medical condition which have been exacerbated and/or exaggerated because of an accompanying depression or the disease process may in itself have generated what is said to be an "endogenous-type" depression.

In psychological nosology, the "exogenous/endogenous" discrimination of an affective disorder on ground of aetiology has received little recent support. In terms of aetiology, an endogenous disorder is one

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for which no precipitating factors can be found. These factors, when events outside of the disease process, therefore regarded as "life-events", are regarded as not inducing a depressive disorder if it can be explained as the product of a morbid disease process in the central nervous system. The dilemma however rests in the conclusion by definition, endogenous disorders have no precipitatory that factors. This leaves out the explanation that an organic disorder (perhaps due to external causes such as bacterial, viral, chemical or toxic agents) may lead to physiological, neuro-chemical changes which generate a depressive disorder. Where both physical (eg. a virus) and psychological (eg. an ongoing stressor such as marital disharmony) factors are included as exogenous causal agents, considerable difficulties are introduced into the endogenous-exogenous (reactive) distinction, especially when their interaction is taken into account. The notion of an "endogenous-type" depression is therefore problematic for a number of reasons. The aetiologically linked subtype categories as "hypothetical, intangible, elusive predispositions seen are (constitutional or hereditory forces)... which could be conjectured but not demonstrated" (Lewis, 1971).

The introduction of aetiological classification in terms of "primary" and "secondary" agents (Feighner et al. 1972) aimed to clear up some of this confusion. A primary disorder is that which is not preceded by any other physical or psychiatric disorder, whereas a secondary psychiatric disorder is preceded by or may accompany another type of disorder. It may complicate schizophrenia, alchohol and drug abuse, organic brain diseases and incapacitating medical illnesses. The primary/secondary distinction is important in predicting prognosis, since the outcome of the secondary psychiatric disorder will depend

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upon the evolution of the underlying disease. Beyond this, it has not resolved the difficulties of distinguishing a depression generated by "acute organic reactions" and a depression which has evolved from the psychological consequences of illness. The problem highlights general diagnostic difficulties with superimposed conditions of different aetiologies:

"The problems of diagnosis (and classification) of instances of the co-appearance of conditions such as dementia in a retarded individual, or neurosis in a person with a frontal lobe syndrome, require significant attention, as well as iatrogenic disorders ranging from drug dependence in infants to tardive dyskinesia. The classification of problems linked to alchohol and drug dependence are a major area of controversy and will need research; the same is true for some of the conditions frequently seen in primary health care, for example the multiple complaint syndromes" (Sartorius, 1988).

The same case can be made out for the diagnostic dilemmas following head injury, where the effects of brain injury are often indistinguishable from the psychological effects of trauma (Slater & Roth, 1954) and in cases of supposed "organic affective disorder" (DSM-III) following a neurological, endocrine or immunological disease.

Theories abound concerning the occurrence of depressive symptoms in multiple-sclerosis. The accompanying depression may be directly caused by demyelination of nerve-fibres in the central nervous system (Skegg et al. 1988), a process which explains the early presentation of recurrent depressions years before the appearance of objective neurological signs (Whitlock & Siskind, 1980). However, the distress resulting from this degenerative disorder and the level of adjustment demanded can in itself adequately explain the abnormal psychological

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reaction. One study suggests that the depressive episodes are related to the location of the sclerotic lesions, where brain stem and diencephalon were involved (Young et al. 1976). However, depression accompanying many medical conditions is frequently found to correlate with the severity of the condition and the degree of disability involved (Brown et al. 1988; Mindham et al. 1981).

Chronic renal failure is associated with depression in between 10 and 40 % of cases (Rodin & Voshart, 1986). It is correlated with the degree of disruption to daily functioning, in terms of loss of work, sexual difficulties and frequent readmissions to hospital (Stern et al. 1977). However, the fatigue, apathy, irritability, anorexia and dysphoria which are sufficient to amount to a diagnosis of depression can be directly attributed to uraemia, the retention of waste materials in the blood.

Depression in Cushing's disease may be disease-promoted via the CNS and monoamine disruptions resulting from serotonin deficiencies. Early symptoms can include irritability and anger. The mood changes and dysphoria are not experienced as demoralisation but as spontaneous changes occurring in the absence of preceding depressive thoughts (Starkman et al. 1981). Similarly in cancer patients, poor appetite, insomnia, tiredness and memory problems are adequately explained in terms of the disease process (Silberfarb, 1985).

In order to be certain of the causes of the psychiatric problems, a symptom by symptom approach should be utilized in lieu of syndrome classifications. Extensive neuro-physiological and bio-chemical investigations would be required to iron out these aetiological

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dilemmas, and it is not always clear that such information is useful, in that the form of treatment available does not much depend upon it (Jenkins et al. 1985). The movement towards multi-axial schemes of classification perhaps do most to disentangle these confused presentations which occur at the boundaries between psychiatry, neurology and general medicine. The concurrent physical disorder, the psychological state, the social environmental antecedent and consequential factors, and the temperament of the individual are all given consideration on separate axes. Such an approach provides a systematic articulation of the important elements of a psychiatric condition, helping to distinguish organic brain states from personality or developmental disorders, providing information for comprehensive treatment planning (Mezzich, 1978).

# Depression as a disorder of adjustment to a medical condition

The American Diagnostic Statistical Manual (DSM-III) describes an "adjustment disorder", as a maladaptive reaction to an identifiable stressor whose onset is within three months of the stressor, and a "dysthymic disorder" as an unremitting disturbance of mood precipitated by physical illness and comparable to a major depressive disorder in terms of its vegetative symptomatology. Essentially the dysthymic disorder is more severe than the adjustment disorder, and the adjustment disorder more transient and more responsive to the the medical condition. Where a and relapses of remissions psychological dysfunction is described by means of these categories, it is to be understood that an individual is responding and adapting to the organic condition in an attempt to restore emotional and adaptive stability. At first, the individual's coping repertoire may

be inadequate and the emotional disorder is indicative of the distress which is experienced in the adaptive phase.

Illness can challenge and directly impair our sense of control over our own bodies. It can threaten self-integrity and self-confidence and it can provoke feelings of failure and an inability to cope. The onset of ill health has been described in the literature in terms of a "crisis theory" (Moos & Tsu, 1977). The individual falls into a state of physiological, social and psychological disequilibrium which sets problem-solving restorative mechanisms into motion. If habitual coping responses are inadequate the individual enters a crisis which will generate the momentum to allow adaptation. The individual faces major adaptive tasks. He or she must deal with the physical discomforts of the condition and the management of the treatment programmes. With a readjustment of goals and expectations, the individual must attempt to preserve a reasonable emotional balance and satisfactory self-image in the face of an often uncertain future. The individual must also attempt to preserve role relationships with important family and friends. Such adjustment is necessary for the restoration of psychological and physiological homeostasis.

The depression which accompanies a medical disorder is often regarded as an "understandable response" to the illness. It can represent "demoralisation" and a "sense of loss", and it is because of its "appropriateness" to the distress which is encountered that it is frequently not treated or even acknowledged to be an abnormal response by the medical profession. However, such adjustment disorders have been reported to respond favourably to counselling, psychotherapy and anti-depressant medications (Rifkin et al. 1983; David et al 1988).

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The Present State Examination (Wing, Cooper & Sartorius, 1980) presents some difficulties when used with the medically ill. A symptom is rated as present if it is "out of voluntary control, out of proportion to circumstances and accompanied by an unpleasant affect". In deciding whether a symptom is "clinically fairly severe" then it is probable that questions of "understandability" will be in the back of the rater's mind. The decision that depressive symptoms of depressed mood, hopelessness, thoughts of suicide etc. are out of proportion to level of distress induced by a medical illness, or that they the represent an "inappropriate" response is a difficult one to make. The wide disparities in the reported prevelance rates of affective disorder in the medically ill may represent the methodological study differences of subject selection and measurement instruments, but from another perspective they suggest the differential meanings which patients attribute to their malaise. Some patients will experience more disruption than others, and some will find their coping repertoire adequate to restore equilibrium. Where individuals have diverse pre-illness coping styles, personalities and a varied history of family and life-time disorders, it is impossible to state where the level of "appropriateness" lies. Where the PSE is used in the general hospital the exclusion criteria for "appropriate distress" should be abandoned (Mayou & Hawton, 1986).

Moffic and Paykel (1975) identified a qualitative difference between the depressions encountered among medical inpatients and those from a psychiatric hospital. The medical patients more frequently reported a "distinct quality" to their depression which was different from their normal experiences of dysphoria and sadness. This would suggest that

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an adjustment disorder represents more than just demoralisation, and that a distinction should be made between the transient and the more enduring distress states. The major identifying characteristic of a depressive adjustment disorder must be its reactive component:

a) The depression occurs concurrently with the medical illness, its onset post-dating the start of the medical condition. The depression may have been set off by a medley of frightening and unexplained symptoms or in response to the diagnosis.

b) The symptoms of depression are responsive to the natural cycle of the medical condition, worsening and abating with the remissions and relapses of the illness, and resolving when the medical condition is successfully treated.

c) During the natural course of the medical condition the level of depression reflects the illness severity and the degree of disability incurred by the physical condition.

This close correspondence between the two disorders is reflected in the research literature. Moffic and Paykel (1975) found that the level of depression correlated with illness severity. The high prevalence rates of depression accompanying end-stage renal disease is explained in terms of the fear of death and long-term disability (Wallace, 1980). A detailed exploration into Parkinson's disease finds that the total depression scores reflect the degree of functional disability (Brown et al. 1988). Measures of gross mobility and fine coordination correlate significantly with measures of dysphoria and the somatic components on the Beck Depression Inventory. Guilt, however, displayed no relationship with the level of disability.

Just as an individual may respond differently to malaise and loss of role function, so may a depressive response show differential correspondences with disability. Lloyd & Crawley's (1983) follow-up investigation into the sequelae of cardiac arrest illustrates that one group of patients responding to the attack with depressive symptoms after one week show improvement after 4 months, whereas a group showing good adjustment immediately after the arrest can develop psychiatric symptoms in its aftermath. An explanation of the type of psychological adjustment could be made in terms of the initial level of disability caused, the speed of the deterioration and the consequent level of disability at follow-up.

The following reflect patterns of adjustment found in arthritis and Parkinson's patients (Rodin & Voshart, 1986):

a) The disorder causes mild disability initially, with a moderate deterioration over time allowing adequate adaptation with a stable, non-depressed mood.

b) An initially mildly disabling state rapidly progressed to a state of marked disability causing a crisis situation in which an individual is unable to adequately adapt. The poor psychological adjustment precipitates a depressive reaction.

c) The disorder results in significant disability straight away and with only a slight deterioration over time, resulting in a level of disability comparable to b) above, the gradual deterioration allowing

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for adequate adaptation. If a disorder follows this course there is likely to be a high level of depression initially but with significant improvement at follow-up.

d) The condition causes disability so severe that the resulting high levels of depression are unchanging over time and unresponsive to the slight exacerbating and improving trends of the medical condition.

Clinical intervention for the depressive disorder may be necessary if the medical condition follows a chronic course (as in d. above), or if it interferes with the treatment regime of the medical disorder. Contrary to the findings of Moffic and Paykel, suicidal behaviour is common amongst the medically ill (Mayou & Hawton, 1986). Non-compliance with treatment regimes and deliberate self-poisoning are two life-threatening methods which are within easy reach of the medically ill. A depression can amplify the discomfort of the medical condition and treatment of the depression can prevent the multiple prescriptions of unnecessary pain-killers and benzodiazepines.

Caution must be exercised in the use of tricyclic antidepressants in the medically ill. In a trial of antidepressant use with medical-surgical inpatients, 32 % of patients had to terminate treatment because of delirium, nausea, vomiting and other side-effects which were exacerbating the medical condition. However, 40 % of patients with medical illnesses including cancer, diabetes and epilepsy responded favourably to anti-depressant treatment (Popkin et al. 1985). Rodin (1986) concludes that an accompanying depression should be treated chemically only if severe, persistent and unresponsive to the treatment of the medical condition. Controlled studies are needed to establish the risk-benefit status of such treatment in different medical populations.

# 1.8 <u>Aetiological considerations in the psychiatric manifestations</u> of Post-Viral Fatigue Syndrome

The following discussion aims to consider the psychiatric components of the post viral syndrome and the possible pathways through which a viral infection could induce a depressive disorder. In line with the foregoing discussion of the coexistence of depression in general medical conditions various hypotheses will be considered. To consider the depressive symptoms as an accompanying but distinct diagnosis, psychological "vulnerability" will be considered and pre-illness psychiatric morbidity. Depression as a complication of the disease process will be discussed in terms of the role of the virus, the immune system and neuro-chemical changes. Suggestions of inadequate adjustment to the condition will be considered.

# The role of the virus

The virus has been implicated as a causal or precipitating agent in the onset of depression; but its role is still controversial. Serological investigations of depressed inpatient populations have reported that compared to non-depressed individuals, those suffering from depression show significantly higher titres and antibodies to the Herpes Simplex virus (Lycke et al. 1974). Other studies have failed to find evidence of increased past exposure to viral agents amongst individuals with depression (Rimon & Halomen, 1969; Cappel et al.

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1978). One study (Pokorny et al. 1973) found that the titre and antibody levels tended to increase only as a function of age, and were not in themselves significantly different from a group of nonpsychiatric ambulant patients from a rehabilitation ward.

The assessment of antibody titres in depressed patients can tell us little about aetiology. Because of the clustering theory and the reduced immunocompetence associated with depression, it is perhaps not surprising that increased viral counts will be found in some studies. As reports of infectious mononucleosis have shown (Imboden et al. 1961; Klaber & Lacey, 1968; Hendler & Leah, 1978), infectious episodes have been known to leave an episode of depressive-like problems in their aftermath but viral induced depressions will probably be clearly contaminated with physical symptomatology and are not likely to be the types of depressive disorder which commonly lead to inpatient status. However, many of the patients described in the above studies required treatment with anti-depressant medication.

A depressive reaction is reported to follow infectious hepatitis, influenzas and glandular fever (Epstein Barr Virus), but how it is precipitated is not clear. Virological evidence has been found in the spinal cord, brain stem and central nervous systems in PVFS, including inflammation of the cerebral areas. "Unusual" electroencephalograph findings are evident but perhaps of "doubtful significance" (Pamiglione et al. 1978). No neuro-chemical investigations have been conducted into the effects of PVFS, but evidence from other avenues suggests that the high cortisol levels associated with a reduced immune response may enhance the serotonergic neuro-transmitter pathways involved in the development of anxiety and depression (Cowen

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& Anderson, 1985). These sequelae have been understood to underlie the increased susceptibility to disease and cancer following bereavement (Bartrop, 1977), and to explain the depressive problems associated with autoimmune thyroiditis, allergic reactions, diabetes, asthma, multiple sclerosis and rheumatoid arthritis (Farrant & Perez, 1987).

It is believed that many of the neuro-psychiatric manifestations of the post-viral syndrome reflect the neurological effects of the virus (Wakefield & Lloyd, 1987). The psychiatric symptoms can partly be explained in terms of the "acute organic reactions" of the disease process. The feelings of disorientation, the short-term memory and concentration deficits, the often chronic anomia and personality changes suggest a clear cut organic cause, which together with the depressive symptoms indicate something more than "pure neuroticism". The depression is described as extremely variable with diurnal patterns suggestive of organic cerebral involvement. Reports of "depression without a cause", "early morning waking" and "reversal of the sleep pattern" (Fegan et al. 1983; Behan et al. 1988) indicate more than a "reactive" phenomena.

A study of peripheral interest may have implications for the understanding of the "chemical" involvement of the virus in the development of psychiatric morbidity. The prospective investigation, was the effect of interferon treatment on chronic hepatitis-B infected patient attending a clinic for sexually transmitted diseases (McDonald et al. 1987). The treatment with interferon had resulted in cerebral impairment which was confirmed by electroencephalograph changes. The reported chronic fatigue, drowsiness, disorientation, retardation and social withdrawal are reminiscent of the post-viral fatigue syndrome.

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The study randomly allocated 60 male subjects to a period of 3 to 6 months treatment or non-treatment. Psychiatric assessment, by means of a self-report instrument (General Health Questionnaire, Goldberg, 1972), a semi-structured clinical interview (Clinical Inverview Schedule, Goldberg, 1970), was administered both before and after the clinical interferon trial.

The treated groups showed an increase in GHQ scores and in the number of CIS cases following treatment. The non-treated group showed a fall in psychiatric morbidity level on follow-up. The increases in the morbidity score following the interferon treatment was most pronounced in the treated HIV positive patients. The treated groups reported fatigue, loss of interest, lack of concentration, depression and anxiety and previous phobias, obsessional thoughts and rituals were accentuated. It appears that such changes can be attributed to the interferon treatment. The extent of the clinical changes in treated patients with an HIV status points to the interaction effect of the interferon treatment and the natural interferons produced by the virus in the CNS. The comparable clinical status in the post-viral syndrome could be explained by the excessive release of endogenous interferons in the muscles and neural cells as a result of a persistent low-grade intracellular infection (Wakefield & Lloyd, 1987). Although no evidence has been found for circulating interferons in the post-viral fatigue syndrome (Jones et al. 1985), studies have shown signs of persistent enzyme activity (2', 5'-oligoad-enylate synthethase) in cells (Morag et al. 1982). This enzyme is induced by interferon and may serve as a marker of its presence and possibly of its effectiveness as a therapeutic agent (Jones & Miller, 1987).

pathway has been hypothesised from the Another neuro-chemical discovery of damage to the dorsal raphe nucleus from Coxsackie B (Maurizi, 1985), which runs through the core of the brain viruses stem, from the medulla to the back of the midbrain. It is hypothesised that the physiological and psychiatric symptoms of PVFS reflect the serotonin deficiencies caused by this damage. The clinical signs are suggestive of Reye's syndrome. The serotonin underproduction is understood to be linked to the alteration in pain thresholds and can be involved in other pain syndromes. It is also suggested as the cause of some depressions, emotional instability and A more integrated research approach between sleep disturbances. neuro-physiology and psychiatry is needed in order to understand these connections.

#### The role of the immune system

The increased prevalence rates of cancer in depressed patients (Whitlock & Siskind, 1979) has led to investigations into the association of immunological deficiencies in the depressed. In one of the more carefully controlled studies, reduced lymphocyte numbers were detected in patients with major affective disorders (Murphy, 1987). The finding has been confirmed in both hospitalised samples and more moderately depressed outpatients (Schleifer et al. 1984). The reduced levels of peripheral blood T-cells seems to relate to the level of severity of the depression, with moderately depressed outpatients showing less differences in mitogen responsiveness to controls than an inpatient group. A reduced immune responsiveness at times of ongoing stress or acute life events (Kiecolt-Glaser et al. 1987; Jemmott et al. 1983) has led to much speculation regarding the relationship between immune responses and mental functions. If the onset of a depressive disorder can be explained in terms of the presence of a corresponding viral ilness, then perhaps the mediating factor is the immune system.

The acknowledgement of PVFS as an immunological disorder is perhaps another clue to the association of the syndrome with depression. The question to consider is whether an abnormality in the immune system can affect emotional and cognitive functioning. Studies of meditation (Smith et al. 1985), hypnosis (Black et al. 1963) and early stress and separation, have suggested how early experiences and state of mind immune The close inter-dependent can modify the response. relationship between the CNS, the hypothalamus-pituitary-adrenal axis and the immune system, supported by work on stress (Farrant & Perez, 1987), suggests a link from immunology to mental disorders (Perez 1988).

Depression is associated with various somatic diseases where an immunological involvement is likely. Whilst depression could develop as a result of a stress-induced increase in cortisol levels, it is also probable that the decreased immuno-competence following infection or disease-related alterations in the immunological-CNS-neuroendocrine homeostasis, could trigger a depressive reaction which is not part of a pre-illness stress state. The state of depression has in itself been regarded as a process of "withdrawal", a protective response against environmental toxic agents resulting from the deficient immune system (Perez & Farrant, 1988).

#### The role of psychological factors

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Hinkle (1968; 1974) proposed that individuals differed in their tolerance to stress explaining a susceptibility to both physiological and psychiatric illnesses. Such a threshold of tolerance could also explain the progression of illness from an acute to a chronic debilitating stage. Hinkle explained this process in terms of the mediation of biochemical and physiological processes in the voluntary and autonomic nervous and endocrine systems. However, a tolerance to stress which could be explained in terms of psychological or personality factors has often been proposed for an explanation for the development of chronicity in medical illnesses. It is known that psychological factors are important in the determination of outcome in illnesses. In a study by Rutter (1963), it was the physical psychological measures of anxiety and depression at first hospital visit which predicted six month outcome of peptic ulceration; no physiological parameters were significantly correlated.

Moffic and Paykel talk of a "vulnerability" factor which is as important in the prediction of psychiatric illness in the medically ill as is the presence of the medical illness itself. To experience an episode of depression with a medical illness, a patient is more likely to have experienced a previous psychiatric illness than a non-depressed medical patient. In a study of stroke patients (Lloyd & Crawley, 1978), half of those who developed a psychiatric illness in the first week after infarction had been psychiatrically ill at some time before illness. Those without this adverse psychiatric history who nevertheless responded to infarction with anxiety and depression recovered quickly from the psychological symptoms.

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This vulnerability was expressed in Taerk's (1987) study of PVFS in which 50 % of the group had had pre-illness episodes of psychiatric illness. Taerk describes this vulnerability:

"This syndrome likely represents the result of an interplay between psychological and organic factors in a susceptible individual. That is, while the precipitant to the illness is an acute (usually viral) illness, the development of chronicity could be related to a particular response to the illness and its associated debilitation, which triggers a depressive syndrome".

Previous episodes of depression may suggest a psychological susceptibility in terms of a) a particular way of responding to stressful life-events, thus the development of a psychological sequelae following a viral infection; or b) that the syndrome is in itself somewhat analogous to an episode of depression and could be seen as a post-viral depression of an acute organic nature. However, the other half of Taerk's sample showed no indication of previous disorder, had led healthy and active lives prior to the acute viral infection and showed no family history of psychological disorder.

Imboden (1961) identified a "pre-morbid depressive tendency" in a group who developed prolonged symptoms after influenza. The depressive sequelae similar to that in the post-viral syndrome was seen to represent a particular "response" to illness. Whether or not the depressive symptoms represent a response to stress in a vulnerable individual or are part of the organic disease-process, there may be particular responses to the illness which predispose to the development of chronicity and which may be responsible for some of the secondary effects of the syndrome. It would of considerable interest to investigate the contribution of previous psychiatric history and coping responses to the course of the post-viral fatigue syndrome, and

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to the nature and severity of the accompanying psychological symptoms. The psychological profiles of those sufferers in the acute stages of illness with evidence of persistent infection must be compared to the profiles of those chronic sufferers who show no further evidence for virological involvement.

# Research Design: A Comparative Investigation into the Post-Viral Fatigue Syndrome, Arthritis and Major Depressive Disorder

# 2.1 Introduction

The following study was set up to investigate the psychological accompaniments to the post-viral fatigue syndrome. It was hoped to establish whether these psychological features were of a sufficient type and severity to warrant a diagnosis of depressive or anxiety disorder. The aim was to assess the prevalence of psychiatric morbidity and to determine whether its presentation resembles that of a clinical group of subjects receiving psychiatric support for a non-endogenous major depressive episode.

The reports of accompanying dysphoric and neurotic symptoms suggest that the fatigue syndrome may be closely related to the major affective disorders. The depressive symptoms which accompany it have much in common with the presenting features of a depressive illness (Mathew, 1981). It has also been reported that many sufferers of the post-viral fatigue syndrome have responded to treatment with anti-depressant medication (Salit et al. 1987; White et al. 1985; Wessely et al. 1989). Whilst the demonstration of persistent infection (Yousef et al. 1988), and abnormalities in immune system functioning (Behan et al. 1985) have stressed the biological

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underpinnings of this disorder, it is not possible to understand the condition without an appreciation of its psychological features. The following study aims to investigate the similarities between the post-viral fatigue syndrome and the major depressive disorders in order to address the question as to whether the syndrome can be regarded as a variant form of clinical depression.

Another aim of the study was to investigate life-time prevalence of psychiatric disorder occurring prior to the current episode. One study has shown that in a group of patients with suspected post-viral fatigue syndrome there were significantly more episodes of previous life-time psychiatric disorder than in a group of matched controls (Taerk et al. 1987). Thus, it is hypothesised that individuals susceptible to psychiatric disorder may be more likely to develop the syndrome. It has also been suggested that a previous episode of affective disorder may render a person more vulnerable to a prolonged and depressive sequelae to a viral infection (Cadie et al. 1976). Thus, it is expected that those who report a previous episode of depressive illness will be likely to present with a more severe depressive profile accompanying the fatigue syndrome.

It is feasible that the psychiatric symptoms accompanying the post-viral fatigue syndrome can be explained as a secondary reaction to the onset of a disabling disorder, which could be regarded as a problem of adjustment, or as an understandable response to the distress induced by the illness. Psychiatric symptoms accompanying physical disorders are often responsive to the fluctuating trends of the physical condition, and improve in times of remission (Moffic & Paykel, 1975; Lloyd & Cawley, 1983). The "utter despair" presented by

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many of the sufferers of the post-viral fatigue syndrome has not always been recognised by psychiatrists to be of sufficient severity to satisfy the criteria for a mental disorder (Ramsay, 1986). Other sufferers of the syndrome report no previous psychiatric disorder and no family history of mental illness (Behan et al. 1988). What is more, very poor responses to psychotropic medication have been reported (Winbow, 1986; Behan et al. 1988), and one G.P. who specialises in the syndrome has regarded this poor responsiveness to anti-depressants almost as a diagnostic marker of the syndrome (reported in a newsletter of the New Zealand Myalgic Encephalomyelitis Association, 1986).

It is not easy to assimilate these suggestions with Salit, White and Wessely's observations. There have been no reported placebo controlled or double-blind studies of antidepressant treatment to date. For the purposes of this following study, a hypothesis was made concerning the possible reactive component to the psychiatric complications of the syndrome. A physically disabled group with an arthritic illness was used for a comparison of affective features. Depressive disorder frequently accompanies arthritis, and its presence is largely explained as a secondary reactive disorder (Wells et al. 1988). Arthritis sufferers were chosen as a comparison group because of the equally debilitating nature of the condition.

The depressive episodes which accompany a physical condition may be understood in a number of ways:

a) They may result from a realistic cognitive appraisal of the condition; the negative thoughts may be associated with an inability

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to attain previous levels of performance in daily tasks, or to deal with the new problems which are raised by the illness.

b) They may result from the lack of involvement in positively reinforcing and rewarding situations, as a past repertoire of activities may now be inappropriate to the constraints which have been imposed by the condition.

c) They may result from the secondary effects of the condition. The responses of the family and significant others, financial difficulties from the loss of earned income, difficulties encountered with the medical profession and a diagnosis supposing a functional illness may all be important.

d) Alternatively, there may be some organic explanation for the psychiatric symptomatology. Extensive neurological and bio-chemical investigations are yet to be conducted in this disorder, and to prove, rather than postulate, causes of this kind for psychiatric symptoms is notoriously difficult.

## 2.2 Defining the post-viral group: the diagnostic difficulties

There is, as yet, no definitive non-invasive diagnostic test for the post-viral fatigue syndrome. This poses a serious difficulty in a study such as this. It is, of course, very important to attain maximum separation between the groups under investigation and the problems here lie in the definitive separation of the "suspected" cases of post-viral fatigue and cases of major affective disorder. The approach taken by the Centers of Disease Control (Holmes et al. 1988), in the

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development of operational diagnostic criteria for the post-viral fatigue syndrome was the exclusion of all those with a psychiatric illness and those who were taking any psychotropic medication. Such an approach clearly has its limitations.

Some individuals selected from an outpatients unit and currently receiving psychiatric treatment may be in the pre-diagnostic stages of investigation for a predominantly physical condition, such as carcinoma, multiple-sclerosis or indeed a post-viral syndrome. Early investigation and treatment by a psychiatrist was not uncommon in the medical histories of "confirmed" cases of post-viral fatigue syndrome cases investigated here. Where the opinions of the medical profession are divided over the validity of a syndrome of post-viral fatigue, and lacking diagnostic certainty, opportunities for self-diagnosis are considerable. An organic label of chronic illness may be welcomed by some individuals who find a psychiatric explanation for their distress abhorrent. Considerable care must be exercised in conducting research into disorders which have not been clearly defined, particularly when subject selection is composed around a self-referred population. Individuals refusing diagnostic exploration and specialist consultation should be treated with caution.

Amongst "suspected" cases of the post-viral fatigue syndrome, there are likely to be a number of individuals suffering from a major depressive disorder. There are also a number of neuro-muscular disorders which resemble the syndrome, for example, occult multiple sclerosis, myasthenia gravis, familial periodic paralyses and various endocrine myopathies. Similar clinical pictures could be found for McArdles's syndrome, carnitine deficiency syndrome and Reye's

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syndrome. Extensive clinical and laboratory exploration can rule out such diagnoses, and a history of such negative findings has become the starting point of diagnosis for this syndrome (Behan et al. 1988).

The current state of knowledge points to a group of enteroviruses as the most likely candidate viruses in the aetiology of the post-viral fatigue syndrome. These common infective agents (polio-, Coxsackie and echo-viruses) are responsible for a large number of 'flu like conditions. They enter through the gastro-intestinal tract infecting nervous and muscular tissue. The Coxsackie B group of enteroviruses are believed to be aetiological agents for the majority of cases of the post-viral fatigue syndrome (Behan et al. 1985;1988).

The Coxsackie viruses are implicated in the disease processes of myocarditis, paralytic encephalomyelitis, polymyositis, Bornholm's disease and acute onset diabetes and are associated with wide-spread lesions and inflammation of heart and skeletal muscles and local tissue damage of the central nervous system, thereby consistent with known features of the post-viral fatigue syndrome. The viruses have been shown to cause immunological dysfunctions in mice infected with myocarditis, the likely mechanisms being through activation of suppressor T cells in the host (Bendinelli et al. 1982). They have also been traced in the muscle samples taken from patients with the fatigue syndrome (Behan & Behan, 1988).

Isolation of these viruses is difficult. Current infection is often diagnosed on the basis of a four-fold or higher rise in specific neutralising antibodies, but equivalent titre-levels have been located in control subjects from the general population (Bell et al. 1983),

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and this poses some problems for the validity of the diagnostic test. However, whilst only 4 % of 950 controls had specific Coxsackie B titres of such a level, they were found in 70 % of a group with suspected post-viral fatigue syndrome (Behan et al. 1985); so raised titre levels, with the clinical signs of the disorder and negative findings on a variety of other tests are often taken together as confirmation of the diagnosis.

New techniques may provide a more definitive diagnosis. A procedure using a hybridization probe tests for the presence of Coxsackie B-specific nucleic acid sequences in muscle biopsies (Bowles et al. 1989). The ELISA technique for the serological diagnosis of Coxsackie B has also been described (McCartney et al. 1986).

For this study, diagnostic confirmation rests upon the evidence of raised antibody titres to the Coxsackie B viruses found in the serum. In some of the subjects, a viral protein test (VP1+ test) had also been conducted indicating a persistent infection with the virus. Raised Coxsackie titres, with positive VP1+ test in some, were accepted, alongside a characteristic clinical picture as sufficient to confirm the diagnosis of post-viral fatigue syndrome. All of the subjects had shown evidence of chronic generalised fatigue for at least 6 months.

#### 2.3 The selection of subjects

## a) The post-viral fatigue syndrome group

A group of 20 subjects were contacted via the North-Eastern and

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Cleveland self-help organisations of the Myalgic Encephalomyelitis Association (P.O. Box 8, Stanford le Hope, Essex SS17 8EX). The group leaders were contacted in order to compile a list of sufferers who had received diagnostic confirmation for their disorder. Details of diagnostic investigations were discussed with the subjects who in the majority of cases were able to confirm their serological status with letters which has been written to their family doctors by consultant virologists / cardiologists. In a few other cases, the diagnosis was checked with the specialist G.P.s treating the conditions. The selected subjects met the following criteria:

(i) they were aged between 16 and 65 at the time of the investigation;
(ii) all had suffered from a fatigue syndrome for at least 6 months;
(iii) all had received diagnoses of past or persistent infection with
one of the Coxsackie B enteroviruses on the basis of raised specific
anti-body titres and / or a positive viral protein test (VP1+); (iv)
all of the subjects had received diagnostic confirmation from one of
the two general practitioners specialising in the syndrome.

### b) The arthritis group

Twenty people suffering from an arthritic condition were chosen as a comparative physically disabled group. They were selected from the local self-help groups of the Arthritis and Rheumatism Council. Arthritis results in extreme fatigue and physical retardation and is accompanied by chronic pain. Because of the resulting restrictions to movement and mobility and the demands which are made for altered family and social roles, it was believed to be a suitable condition for comparison with the post-viral fatigue syndrome. There are

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reports of a high risk of secondary depressive disorders in this group (Wells et al. 1988). All had had specialist confirmation of their arthritic status.

The arthritis subjects were initially contacted by the group leader of the Arthritis and Rheumatism Council who correctly felt that she was unable to supply names and addresses without first explaining the nature of the study to them. Letters were sent out to a selected members suffering from rheumatoid arthritis, group of 20 osteroarthritis and ankylosing spondylitis. Attempts were made to bias the selection in order to approximate the age and sex distributions of the post-viral subjects. There was an emphasis towards the younger group members. The subjects wrote back expressing their willingness to be involved in the study. There was a 100 % response rate - all agreeing to take part.

#### c) The group with major depressive disorder

Twenty patients were selected from the out-patient unit of Bishop Auckland General Hospital and the in-patients of Winterton Hospital in South-West Durham. These cover a wide catchment area and are expected to form a representative population of individuals receiving psychiatric care. The subjects were diagnosed as suffering from a major depressive disorder according to DSM-III criteria (without delusions, hallucinations or bizzare behaviour, not superimposed on underlying schizophrenic or paranoid behaviours, and not complicated by organic medical disorders, problem drinking or substance abuse). The DSM-III is a system for classifying psychiatric disorder in the USA based upon clearly defined diagnostic criteria and is widely used

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by psychiatrists throughout the world (American Psychiatric Association, 1980).

In order to cover the full range of severity representative of a population treated by a consultant psychiatrist, in-patients, day-patients and out-patients were selected. The patients were interviewed following an appointment with one of two consultant psychiatrists (either as a first referral or as a repeat consultation). Many of the patients were starting on a therapeutic anti-depressant trial on the day of the interview. Medication reported is the treatment which has been taken up to the date of the interview. The subjects selected are an otherwise unselected group of depressed patients in different courses of the illness, from first referral through to near recovery. Those subjects who had substantially improved were still regarded by the psychiatrists as in need of further treatment.

## 2.4 Current psychiatric status in the post-viral fatigue group

The first goal of the investigation is to describe the depressive symptoms of a sample of people diagnosed as suffering from post-viral fatigue. Using operational diagnostic procedures and well established assessment instruments, these symptom profiles of the post-viral fatigue subjects, will be assessed against criteria for the syndrome of major depressive disorder.

Classification of disorders can be based (a) on present symptomatology, (b) on prognostic features of the disorder, such as response to treatment or clinical course, or (c) on aetiological

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factors. The state of knowledge of prognostic and aetiological features in psychiatric disorders is limited, demanding that the weight of diagnostic decisions rest upon symptom descriptions.

Structured and standardised interview instruments have been devised which have improved the reliability of diagnostic decisions, and which have proved their worth in international epidemiological studies. The Present State Examination (Wing et al. 1974) and the Clinical Interview Schedule (Goldberg et al. 1970) are two such instruments. Operational definitions provide precise indications as to which combinations of symptoms are adequate to establish a diagnosis. The CATEGO diagnostic computer programme accompanying the PSE mimics the diagnostic decisions which would be taken by a consultant psychiatrist in the form of a complex logical decision tree based upon a series of condensations of symptoms into syndromes and categories. Specific weighting is given to certain symptoms which factor analytic and discriminant analysis has shown to hold particular associations with particular syndrome profiles.

Another symptom approach to diagnosis involves symptom lists, which may be checked by the patient in questionnaire format. Their economy and ease of administration make them valuable tools in the screening of people with a high probability of being depressed, and in the rating of global severity. Studies have shown self-rating scales to compare favourably with interview-based assessments in identifying individuals with mood disorder, and in distinguishing between degrees of severity (Kearns et al. 1982). However, the logic of arriving at a diagnosis or a severity rating from adding together the scores from a variety of symptoms has been questioned, although justification for

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it can be made on mathematical grounds (Hamilton, 1968). It is clear that two quite different disorders could arrive at a similar severity rating from substantially different underlying symptoms. Using the Montgomery & Asberg Depression Rating Scale (MADRS, 1979), Cooper and Fairburn found no difference in overall severity in a sample of depressed and bulimic patients, but symptom discrepancies were identified when a bimodality emerged from a discriminant function analysis. The intercorrelation of psychiatric symptoms in bulimia nervosa was substantially different from that of the syndrome of major depression (Cooper & Fairburn, 1986).

The self-rating of psychiatric symptoms demands a literate and cooperative subject whose physical or psychiatric condition does not unduly affect the comprehension and concentration which is required for the task. The need for adequate engagement and for an appropriate degree of insight into one's mental state makes the use of self-report scales with the severely ill somewhat problematic. However, their ease of application and the elimination of "observer" bias make them useful research tools for the screening of disorder in medical or community settings. With wordings appropriate to the ways in which a patient expresses his or her own emotional and physical state, they can play a valuable role confirmatory of or supplementary to a clinical assessment.

For the purposes of this investigation, a combination of self-reported and researcher-administered assessments was used, as recommended for community studies of psychiatric disorder (Snaith, 1981).

# a) The Self-Assessment of Depression and Anxiety

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The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was selected for this study as an appropriate scale for application in the community for the assessment of mood disorders in the physically ill. The scale was designed for use in a general medical setting after requests from a physician for help in distinguishing those patients with a normal distress response and those with a definite mood disorder which would be responsive to anti-depressant medication.

Scales which have been compiled on the basis of research with a psychiatric inpatient population are inappropriate for use with groups of individuals selected from the general population. Firstly, such scales would differ in terms of their item-content; the inclusion of items associated with severe disorder, such as suicidal preoccupation or delusional overlay would not be useful for the detection of mild disorders and could lead to a substantial proportion of missed cases (false-negatives). Secondly, scales designed for use in psychiatric settings largely play a "discriminatory" role, where the main objective is the distinction between clinical syndromes amongst a population with a very strong likelihood of being a psychiatric case. A scale applicable to a general population or medical setting cannot rest upon a strong probability of caseness but must be sensitive to the detection of sub-threshold and threshold cases of disorder.

A specific feature of the Hospital Anxiety and Depression Scale (HADS) is that its assessment of depressive and anxiety symptoms does not rest on symptoms which could also be present because of the existence of a physical condition. The use of conventional rating scales with general medical populations often appear to overdiagnose mood disorder

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in the physically ill (Kutner et al. 1985). Some "false-positive" cases, in whom a mood disorder is identified from a scale score, when there is no mood disorder, result from the overlap of symptoms associated with the syndrome of depression or anxiety disorder and the symptoms which are part of a physical condition. This overlap of symptoms incorporates, (i) the somatic symptoms of organic pathology, which may be due to endocrine, neurological or metabolic changes, and (ii) symptoms resulting from the impact of the illness: hopelessness may be appropriate in a life-threatening condition; guilt and self-blame may be understandable responses to the loss of role function and the contributory factors to family problems resulting from the illness.

Thus, in the formulation of the HADS items, symptoms were chosen which could adequately detect an accompanying mood disorder in the physically ill. It is not clear how the authors decided upon the selected symptoms, although it appears to be a somewhat intuitive procedure in which "symptoms of somatic reference" and "items relating to both emotional and physical disorder" are eliminated. The elimination procedure appears to be largely based upon the "vegetative" / "psychic" distinction which occurs in the literature of psychiatric symptomatology. The dichotomy has been utilised in the discrimination of psychiatric sub-types, especially the supposed distinction between "endogenous" and "reactive" depressions. The vegetative symptoms are purported to contain no cognitive or psychic component and are understood to be caused by the involvement of the involuntary bodily functions of the autonomic nervous system. In terms of an endogenously induced depressive illness, such symptoms were believed to be a product of morbid disease processes. However,

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many symptoms which may be affected by disease play a confusing role. Loss of libido and loss of appetite may reflect one sign of a more general diminished interest or pleasure. These symptomatic changes are closely bound up with situational events and cognitions. Guilt surrounding the consumption of food, or delusions about being poisoned may result in weight loss. Loss of libido and problems of sexual functioning are closely tied up with anxieties surrounding interpersonal relationships.

The vegetative / psychic separation appears to be ill founded and many of the symptoms supposed to be vegetative may have a distinct cognitive component. As well as indicating physical pathology, they may be part of the vocabulary of a patient who habitually somatises his or her feelings. The primary-care consultation procedure perhaps even demands such a presentation (Goldberg, 1979). Alternatively, an underlying mood disorder may exacerbate physical complaints, reducing pain tolerance and resulting in a hypochondriacal hypervigilence of bodily sensations (Blacker & Clare, 1987). When a mood disorder coexists with a physical illness there is likely to be a joint and interacting contribution to symptomatology.

After eliminating "vegetative" symptoms, the remaining HADS items were selected in order to achieve the best possible separation between anxiety and depression. The subscales were validated in a sample of 133 patients attending medical assessment units, outpatient and post-natal clinics, and the low correlation found between the two subscales suggests that they are assessing different dimensions of a mood disorder. A high correlation between anxiety and depression scores therefore indicates a mixed "neurotic" disorder (Channer et al.

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The depression scale items of the HADS focus on an anhedonic state. Klein (1974; 1980) hypothesised that anhedonia was a marker for a certain type of depressive illness which was associated with a more favourable response to anti-depressant drug treatment. Support for Klein's hypothesis is found by Clark et al. (1984), who have compared the follow-up of depressed patients defined as "hedonic" with those defined as "anhedonic" on the basis of scores on "The Pleasure Scale", designed to assess patients' degrees of responsiveness to a variety of normally enjoyable situations. It was those psychiatric patients who were most anhedonic on admission who showed the most rapid symptom amelioration within the first 3 weeks of treatment, and the greatest clinical recovery on 7 months follow-up, even though their Pleasure scores remained stable. Two-thirds of the sample had reached complete recovery following their acutely depressed states of 7 months earlier. This was significantly greater than the rate of recovery among those inpatients identified as hedonic (p=.018, Fisher's exact test).

Whatever doubts we may have about its theoretical basis, an anhedonic response discriminates well between the depressed and non-depressed in a physically ill sample (Clark et al.1983;1985). Dissatisfaction and loss of social interest (taken from patient reports on the Beck Depression Inventory), were found to be the best discriminators of depressive illness in a large randomly selected group of medical patients. The important point is that they were seemingly unconfounded by the presence of physical illness or accompanying distress.

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Anhedonia can be expressed as a sense of dissatisfaction or a loss of social interest, or an inability to look forward to the future with pleasure. Klein (1974) postulated that it corresponded to a non-reactive "melancholic" state in which an all pervasive sense of loss dominates the patient's outlook. He describes an "endogenomorphic" depression representing a dysfunction of the areas of the brain concerned with reinforcement and pleasure responsivity.

"It is postulated that if the pleasure mechanism becomes unresponsive, one cannot experience pleasure either from current sensory input or via the method of anticipatory or recollective imagery. The person with a normal pleasure mechanism when thinking of a future pleasurable situation, experiences an anticipatory glow. If the pleasure mechanism is malfunctioning, however, this glow does not occur and the person simply has the cold experience of anticipating a situation that does not evoke any warm affective response".

Klein believes that such a response can be distinguished from a condition of severe disappointment or demoralisation in that someone who suffers an acute reactive depression would retain the capacity for experiencing pleasure given the appropriate input.

For Klein, the "endogenomorphic" subtype represents this lack of reactivity independent of precipitating factors, and is responsive to drugs which have a reparative effect on the malfunctioning pleasure centre. It remains another question whether the HADS, comprising such an orientation, can successfully distinguish between the reactive demoralisation and despair resulting from physical illness and a depression of a more "biogenic" type.

In view of the considerable secondary anxiety induced by symptoms of angina, research in a cardiology unit suggests that the HADS may be

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useful in distinguishing between reactive stress and psychiatric disorder (Channer et al. 1985). Using a discriminant logit analysis, the HAD scores were able to identify those patients displaying positive responses to a treadmill exercise test and those showing a test response and chest pains atypical of angina. Those patients with negative test responses had significantly higher scores for depression and anxiety and significantly more atypical pain than those with the positive diagnostic results.

The HADS has been validated in general medical out-patient units (Aylard et al. 1987), a general practice setting (Wilkinson et al. 1988), a genito-urinary clinic (Barczak et al. 1988), a breast cancer clinic (Burton & Parker, 1985), and a clinic for inflammatory bowel diseases (Andrews et al. 1987), where it has performed well alongside other patient-report (GHQ-28) and researcher-administered rating scales (MADRS and Clinical Anxiety Scale), and interview based assessments (Present State Examination).

It is suggested by Zigmond and Snaith (1983) that subscale scores of depression and anxiety reaching 8 or more should be considered as "probable" or borderline cases of disorder approaching clinical diagnostic criteria. Scores of 10 and over, they suggest, should be regarded, quite conservatively, as definite cases of depressive or anxiety disorder which could by independent psychiatric assessment be thus classified. Attempts at minimising the false-positive diagnoses of depression and anxiety disorder, and false-negatives, with the physically ill have found that the best results occur using HADS cut-off scores of 8+ on the scale ranges of 0-21 (Aylard et al. 1987; Wilkinson et al. 1988; Barczak et al. 1988). In this study, it was

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decided to use the more stringent cut-off of 10 for a definite case and 8-10 as a borderline case because of the problems of overdiagnosis of depressive disorder in this group.

#### b) Interview-based assessment of current psychiatric disorder

The Psychiatric Assessment Schedule (PAS) was designed for a comparative study of diagnostic systems for the assessment of psychiatric disorder in a community sample. It deals mainly with the symptoms of the affective disorders. It is made up of the 40 item the Present State Examination (PSE) with selected version of observational items. In addition, symptoms from the SADS interview (Endicott & Spitzer, 1978) which correspond to a diagnosis according to Research Diagnostic Criteria (Spitzer & Endicott, 1978) were added in the same format as the PSE items. These additional symptoms provide a more complete profile of the presentations of depressive and anxiety disorders in community populations. Items corresponding to increased appetite and weight gain, and problems from sleeping more than usual are not included in the PSE. Subjective reports of troubled sleep, pre-occupations with thoughts of death and some details about panic attacks are also not adequately covered in the current version of the PSE.

Information about symptoms obtained through the interview can be used to assess levels of severity of psychiatric disturbance and to arrive at tentative diagnostic or syndrome groupings according to standardised diagnostic schemes. Such groupings aim to replicate the decision of a psychiatric clinician, who in making treatment guidelines must arrive at a criterion of "caseness". The PSE was

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devised for use in a hospital setting and decisions are made on the basis of high thresholds of clinical severity. A symptom is rated if it is "clinically fairly severe" and judged to be "out of proportion to the circumstances, unpleasant and not easily turned off by the patient's own efforts or external distractions".

The problem is one of the distinction between "disorder" and "understandable distress". There are considerable problems in the making of such judgements with the physically ill. Whether or not we would expect a house-bound arthritis sufferer to feel hopeless about the future and to feel that he or she is not as good or as able as other people, the symptoms of hopelessness and self-depreciation may cause considerable distress and impairment of functioning. If such a person felt unable to see a future ahead and suffered from thoughts of worthlessness in the company of other people, then this may be sufficient to count for disorder even though it could be easily "understandable" in terms of the disability imposed by the arthritis.

The symptom by symptom ratings on the PSE are largely based on clinical information, such as the frequency, intensity or duration of the symptoms. A few of the symptoms are rated according to degree of impairment to daily functioning or social and family relationships. When interviewing a community sample of physically ill persons, the judgement as to the "appropriateness" of the symptoms should perhaps be suspended. In this study, symptoms were rated on their severity and duration regardless of whether or not they could be seen as appropriate responses to physical illness. The adoption of the approach suggested by the authors of the Present State Examination would pose considerable problems for the diagnosis of reactive

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depression in the physically ill (Mayou & Hawton, 1986).

The 40 PSE items, plus 10 observational items and the additional 7 SADS symptoms were used as part of a symptom by symptom comparison of the three subject groups. Any symptom reaching the threshold severity rating was considered as present. The total symptom score of the PSE has been used in past studies as a psychiatric severity rating. Here, the additional SADS items have been included. The full symptom severity scores of 0 to 2 (or 3) are used in the computation of psychiatric severity. In themselves, the severity scores are not diagnostically meaningful, but a higher score, consisting of the ratings of more symptoms at more clinically severe degrees, is suggestive of a more severe disorder. Of course, the different severity scores could consist of differently rated symptoms in different cases.

In order to make the symptom conglomerations more meaningful in clinical diagnostic terms, the PSE symptoms were entered into the ID-CATEGO programme (Wing et al.1978). The ID (Index of Definition) allocates each subject to one of eight levels which indicate the degree of confidence that sufficient symptoms are present to justify a clinical classification. An ID of between 1 and 4 places a subject below the threshold of clinical "caseness". An ID of 5 represents a borderline case, and ratings between 6 and 8 a more definite case. The Index of Definition applies weights to those highly discriminating symptoms of affective disorder whilst assessing the expected symptom combinations. Those subjects who reach an ID rating of 5 or higher are allocated a CATEGO classification, allowing a tentative diagnosis according to the International Classification of Diseases (WHO, 1974).

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The CATEGO programme has a hierarchical structure based upon the commonality and corresponding severity of each symptom. The presence of certain symptoms signify a level of severity and assumptions are made as to the presence of other symptoms lower in the hierarchy. For classification of depressive disorder, pathological guilt, morning depression, loss of libido, depressed mood on examination and early morning waking are highest in the hierarchy. This hierarchical classification does not explicitly recognise mixed disorder. Where symptoms of an anxiety disorder and a depressive disorder coexist, anxiety is subsumed under depression.

The PSE classifications based upon the ID-CATEGO programme have been shown to be more stringent than other diagnostic schemes. For example, in a community study, the Index of Definition identified only 8.7 % of subjects as cases, whilst the Research Diagnostic Criteria diagnosed 13.7 % as reaching the threshold for clinically diagnosable disorder (Dean et al. 1983).

The 40-item PSE has proved reliable with trained lay interviewers with little clinical experience (Cooper et al. 1977) and with non-clinical interviewers (Weissman & Myers, 1980). The reports of the risks of over-rating disorder relative to psychiatrists when lay interviewers use the PSE (Sturt et al. 1981; Wing et al. 1977), have not been borne out in recent studies (Craig et al. 1987). The longer training courses now available provide a level of exposure to clinical populations which aims to instill notions of clinical thresholds to the raters. It has been reported that over-rating tends to increase as field-work progresses (Rodgers & Mann, 1986); this may be because the training of

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a non-psychiatric interviewer displaces the model of normality held before the start of training with a move back to this model when subsequent interviews are predominantly with a "normal" sample (Copeland et al. 1974). In order to avoid this "drift" during the course of the field-work in this study, it was hoped to conduct the interviews of the three groups simultaneously, at the rate at which they were referred. The interviewing of the post-viral fatigue syndrome and arthritis subjects was randomly dispersed but the interviewing of the psychiatric patients was post-poned until the end of the study, due to unforseen delays in receiving Ethical Committee approval for the study.

The author was trained in the use of the Psychiatric Assessment Schedule by Professor T.K.J. Craig, at the London Hospital on a one week course in July, 1988.

#### 2.5 The recording of life-time psychiatric disorder

The data from the PAS rates the psychiatric presentation of the past month. In addition subjects were asked if they had ever experienced an episode of psychiatric disturbance which had caused impairment to their daily functioning. They were asked to recall episodes previous to any present episode (at least 12 months separation from current disorder), as recorded on the PAS. Life-time episodes were recorded if the subjects reported psychiatric illnesses resulting in considerable impairment of family, social and work roles for at least one month, and for which they had been treated by a psychiatrist / clinical psychologist or by their family doctor. Reported episodes in which clinical help had not been sought, but for which similar degrees of impairment were reported, were recorded only for those subjects who had described no episodes of treated life-time disorder. These are regarded as possible life-time episodes. Past treatment with psycho-tropic medication, and episodes resulting in admission to psychiatric hospital were noted.

The difficulties of inquiring about detailed symptom profiles of episodes which may have occurred some time ago were thought to be far too numerous to justify the benefits which would have been gained from the resulting syndrome and diagnostic information. Such an investigation would have substantially prolonged an already lengthy interview and would have introduced problems of retrospective bias and memory difficulties in the location of certain symptom patterns with particular episodes. Since research evidence indicates that symptom patterns frequently change on follow-up, syndrome identification would be problematic. Ratings of symptom severity would also cause considerable difficulty.

In retrospect, in would have been better to have incorporated a more standardised assessment of life-time psychiatric disorder. A Past History Schedule has now been compiled for use alongside the Present State Examination (McGuffin et al. 1986). It is designed to be administered in interview format prior to the PSE, collecting reports of dated life-time episodes of psychiatric disorder. Detailed symptomatic information is then gathered for the worst reported life-time episode. The Past History Schedule has demonstrated good inter-rater reliability and adequate concordance with case-note assessments.

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# 2.6 Further assessment of reactivity, hopelessness and somatic symptoms

There are many problems associated with the application of traditional psychiatric diagnostic models to the psychological symptoms accompanying a physical illness. Where the symptoms are seen to have developed "in reaction to" the physical state, they are judged to represent a degree of understandable distress and are seen as conceptually different from true primary psychiatric illness.

The problem is analogous to the age old debate about the classification of depression in psychiatric nosology. The concept of "reactivity" has for a long time been bound up with the supposed bimodal separation of "endogenous" and "neurotic" depressions. These were believed to be distinguishable in terms of aetiology. "Endogeneity" came to be understood as an absence of precipitating factors, or a lack of reactivity once symptoms were established.

It has been shown that those depressions corresponding to an "endogenous" syndrome are no less likely to have been precipitated by a severe disappointment, loss or ongoing stressor than those corresponding to a "reactive" syndrome (Akiskal et al. 1978; Paykel, 1979). The symptoms of 615 patients were entered into a cluster analysis which achieved a separation of two factors corresponding to an "endogenous" and "non-endogenous" depression. The two groups did not differ in the frequency, number or severity of reported life-events prior to the onset of the index episode (Grove et al. 1987).

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However, the current state of knowledge appears to favour a more dimensional approach to the classification of depression (Kendell, 1976; Foulds & Bedford, 1975), with normal demoralisation being considered on a continuum with clinically severe depression. Those depressions which are regarded as depressive reactions, distress syndromes, adjustment disorders and perhaps also grief reactions are seen to lie at the lower end of the continuum, and in terms of course and treatment responsiveness, do appear to differ from those depressions falling more towards the "psychotic" end (Copeland, 1983). These depressions do appear to retain some degree of reactivity during their course.

Descriptions of the psychological sequelae of physical disease resemble those of depressive distress syndromes or "adjustment disorders", which may follow on from severe life-events or chronic on-going stressors (Derogatis et al. 1983; Winokur et al. 1988). In comparison to psychiatric depressed populations, depressed medically ill patients were found to display more pessimism and hopelessness but less suicidal ideation (Moffic & Paykel, 1975). The severity of the depression appears to be affected by the severity of the physical condition (Feldman et al. 1988), the prognostic expectations and the availability of effective treatment (Larcombe & Wilson, 1984). There appears to be no clear relationship with the actual physical diagnosis (Moffic & Paykel, 1975). The depressive response has been likened to a "grief-reaction", as a response to loss and to the perceived implications for future activity and longevity (Lloyd & Cawley, 1983); and to a "shock effect" - depression will improve with time as coping repertoires adjust (Dovenmuehe & Verwoerdt, 1963). Depression can also be caused by the financial, social and relationship problems which

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result from the illness.

Affective and behavioural changes accompany any illness. Secondary demoralisation can develop, and with it a decreased ability to anticipate future pleasure and to induce positive reinforcement from others. Thus, there will be much which is in common between primary depressions and those developing secondary to physical illness.

The aim of this part of the study was to see if there are any differences between the depression accompanying the post-viral fatigue syndrome and the major depressive disorders. If the depression accompanying the post-viral syndrome can be explained in terms of a response to disability and the complications imposed by the physical illness, then we would expect it to share features with the type of disorder encountered in the arthritis sufferers.

The comparison was based upon:

- a) the assessment of anhedonia;
- b) the assessment of hopelessness;
- c) the assessment of somatic features.

# a) Anhedonia

The Fawcett-Clark Pleasure Scale (Clark et al. 1983) was designed to identify a sub-type of depression corresponding to Klein's "endogenomorphic" type. That is, a depression which results in a pervasive impairment of the capacity to experience pleasure and to respond with enjoyment to the anticipation of pleasure. Loss of

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interest may extend to an inability to enjoy food and hobbies and a complete loss of libido. There may be profound loss of interest in the environment and lack of investment in the future.

scale aims to assess these anhedonic states by asking subjects to The imagine themselves in normally pleasurable situations and to report on the degree of pleasure they would induce. A person suffering from an adjustment disorder may not report any enjoyment, and may express a profound loss of interest in previously pursued activities. They may, nevertheless, retain an ability to imagine pleasure. The Pleasure Scale allows subjects to imagine pleasurable situations remote in time and presented under fictional or ideal circumstances. The scale items correspond to situations in which subjects can experience a sense of peace and relaxation, of excitement or financial gain and uncomplicated close relationships with family and friends.

The subject is asked to imagine the pleasure they would receive from a situation regardless of its real life applicability. Thus, it enables a physically ill person, within their existing emotional state, to imagine themselves free from the fetters of their illness, free from the fatigue which it imposes upon them and from the restrictions which the disability entails. For a depressed person to achieve this sense of separation from current misery, situational and emotional reactivity is required.

Fawcett and Clark's research shows that the majority of depressed inpatients and outpatients showed a distribution of these pleasure scores within the range of those from a group of normal subjects. Only 12 % of a depressed sample showed an extreme anhedonic response

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which was distinguishable from the rest of the group on the basis of a mixture analysis (Fawcett et al. 1983). The Pleasure scores correlated significantly with other measures of depression (Beck Depression Inventory), hopelessness, subjectively experienced social impairment, and an anhedonia scale (Chapman, 1976). The implication is that the majority of individuals suffering from depression retain some reactivity to environmental events (assuming that the scale scores can be so interpreted.

The anhedonic depressed in Fawcett's research were significantly more depressed and more hopeless, and expressed greater social impairment the hedonic depressed. The hedonic group had a greater than predisposition towards "neuroticism", as measured on the Maudsley Personality Inventory, and had made significantly more suicide attempts. Items from the Beck Depression Inventory showing an association with hedonic depression included hypochondriasis, irritability, indecision and pessimism. Those symptoms associated with anhedonia confirmed the pervasive loss of interest in appetitive and sexual desires, the desire to live and engagement in work and social contacts. Another study has provided further support for the existence of a distinct anhedonic subtype (Young et al. 1986) and there is some evidence to suggest that a person with a hedonic depression (distinguished on the basis of a rating scale) will respond differently to tricylic antidepressants (the response to which is more likely to be negative), and have a substantially different illness outcome (ie. one of longer duration) to a person with a more anhedonic depression. (Chaturvedi, 1986).

It is still not perfectly clear what type of disorder the Pleasure

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Scale is really identifying but it has been hypothesized (Winokur et al. 1988) that a depression corresponding to an adjustment disorder secondary to physical disability may remain hedonic. The assessment of anhedonia provides a qualitative dimension for the comparison of depression accompanying the post-viral fatigue syndrome and major depression which is referred for psychiatric hospital treatment. A comparison of groups on such a dimension may have treatment implications for the post-viral syndrome.

#### b) Hopelessness

The reasons for investigating the symptom of hopelessness are three-fold. Firstly, hopelessness is regarded as one of the core symptoms of a depressive disorder, and as the "missing link" between depression and the risk for suicide (Dyer & Kreitman, 1984). Reports of suicide are not uncommon in the case histories of post-viral fatigue syndrome sufferers (Kendell, 1967; Ramsay, 1986). Secondly, hopelessness implies a sense of giving up, a feeling that one cannot make things better for oneself. The outlook is bleak and coping repertoires may be switched off. An individual with a physical disorder may engage in negative cognitions relating to their inability to function as they had previously done, and to cope with the challenges raised by their illness. Such responses, are understandable in the early stages of disorder, but if they persist imply poor adjustment in emotional and practical terms. Hopelessness may prove to be an important target symptom in the treatment of depressed physically ill patients, particularly those displaying signs of poor adjustment or suicidal intent. Cognitive-behavioural work with such patients would be beneficial. Thirdly, hopelessness

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theories of depression maintain that hopelessness though loss is part of a causal chain which leads to depression (Alloy et al. 1988; Brown & Harris, 1978).

A controlled treatment trial of cognitive-behavioural therapy was conducted with 20 depressed patients with multiple sclerosis showing a significant improvement on 4 measures of depression, a self-report scale, a clinician rating scale and a rating made by a significant other, in comparison to a waiting-list control condition (Larcombe & Wilson, 1984). Cognitive work with such a group was previously believed to be destined to failure because of the supposed cerebral involvement in such depressions, and because of grossly the debilitating and restrictive nature of the disorder. Many claims have also been made to support the supposition that depression in multiple sclerosis may be essentially a result of biochemical changes brought about by the disorder, and has been reported to occur prior to the onset of neurological features (Whitlock & Siskind, 1980). The success of this approach to treatment in patients with multiple sclerosis demands some outcome studies of the efficacy of the cognitive-behavioural approach in the post-viral fatigue syndrome.

The Hopelessness Scale consists of 20 statements which were taken from the verbalisations of depressed inpatients. A subject completing the scale must respond with an affirmation or a negation to each of the statements according to whether the thought has been incorporated in their recent world picture. The scale was validated by Beck and his colleagues using independent clinical ratings of hopelessness and attitude to the future (Beck et al. 1974). A principal-components factor analysis defined three factors. "Feelings about the Future"

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resolves around affective associations of hope, faith and enthusiasm. "Loss of Motivation" is concerned with giving up and no longer trying to achieve anything. "Future Expectations" focuses on one's outlook towards the future and one's anticipations of achievement, of uncertainty or of darkness.

The scale has been validated amongst a sample of depressed inpatients with open-ended questioning concerning the patients' outlook and expectations (Green, 1989). Emerging from this study was the finding that hopelessness was not an essential feature of depression, which could exist in its absence. Many of the depressed patients experienced difficulty in verbalising thoughts about the future. They appeared to hold only vague feelings of either gloom or benevolence and avoided thinking about the future as much as they could.

# c) <u>Somatic features</u>

Fatigue is regarded as the cardinal feature of the post-viral fatigue syndrome - a profound fatigue precipitated by minimal physical activity and with abnormally slow recovery from exertion (Ramsay, 1986; Behan et al. 1988). The fatigue is experienced predominantly in the muscle groups but many sufferers will also complain of a central fatigue or lassitude, unvarying throughout the day and making any activity appear too much effort. The resulting aversion to exercise and a vicious cycle of avoidance, inactivity, cardio-vascular unfitness and fatigue has recently been described by clinicians who stress the importance of psychological factors in the formation of fatigue (Stokes et al. 1988; Wessely et al. 1989; Lloyd et al. 1988). There are indications that the fatiguing of individuals with post-viral fatigue is different from normal fatiguing. Fatigue has been reported to increase noticeably after emotional and mental strain as well as after physical exertion (Fegan et al. 1983; Keighley et al. 1983). Sleep is generally non-restorative. Lassitude, lack of mental drive and concentration have also been reported (Stokes et al. 1988). Eventually permanent muscular weakness may develop (Ramsay, 1986).

A recent review of the post-viral fatigue syndrome criticised current research for its imprecise definitions of fatigue (David et al. 1988). There are numerous possible sites and mechanisms in abnormal fatiguability, from the higher centres of the central nervous system, through the neuromuscular junction to the actual filaments in the muscles themselves. Cardio-vascular or repiratory problems may exacerbate fatigue at low activity levels (Lloyd et al. 1988); altered exercise and pain tolerance may lead to an early cessation of activity (Wessely et al. 1989), and reduced attentional and concentration capacity can impair performance.

It is important to note that fatigue is a central complaint in a number of physical and psychiatric disorders (Manu et al. 1988). Tiredness, subjective anergia and retardation were reported to be common in bulimia nervosa patients (Fairburn & Cooper, 1984), and in disorders induced by hyperventilation (Stokes et al. 1988), and chronic drinking. These disorders produce complex alterations in the balance of potassium, magnesium, calcium and phosphate ions, which can directly impair muscle metabolism (Pearson et al. 1986). It is associated with abnormalities of the endocrine and immune systems (Kennedy, 1988). Fatigue is a prominent symptom in Addison's disease and can be induced by an abrupt cessation of corticosteroids in patients on long-term treatment. Similarly, in psychiatric disorder, low morning cortisol levels were reported in a series of 25 patients with "chronic fatigue" (Poteliakhoff, 1981). A syndrome of fatigue, drowsiness, retardation and mental confusion has also been reported after treatment with interferons (McDonald, 1987). Interferons are released by the lymphocytes in the aftermath of viral infection.

Fatigue is also a common presenting feature of depressive disorders. It is included in the operational criteria for major depression and dysphoria in DSM-III, is incorporated in the Hamilton, Beck, GHQ and HADS rating scales. The Present State Examination rates the symptom of "Tiredness" as unpleasant, unresponsive to attempts to overcome it and inappropriate to the situation which has induced it. Thus, an individual will experience a sense of malaise which is out of proportion to the amount of exercise undertaken. "Subjective anergia and retardation" is expressed as a sense of listlessness and lack of energy with retardation of movement, resulting, in its extreme form, in gross underactivity. In the Hamilton Depression Rating Scale (Hamilton, 1967), ratings of fatiguability are made under "General Somatic Symptoms", with disproportionate fatigue and diffuse muscular achings with a feeling of "heaviness" in the limbs. In its extreme form it is expressed as a difficulty in "getting going". In addition, "Retardation" corresponds to a slowness of thought, speech and emotional responsiveness which unduly affect the interview.

In one medical outpatients' clinic, of 100 adults referred with a

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complaint of chronic fatigue, 66 % met criteria for a psychiatric mood disorder which could adequately explain their fatigue (Manu, 1988). Patients were describing feelings of extreme exhaustion first thing in the morning before daily activity had begun, and of lacking in the energy required to accomplish tasks involving sustained effort and attention. An abnormal state of exhaustion after normal exercise was reported, contributing to occupational and social impairment. Diagnoses of major depression, somatization disorder and a variety of anxiety disorders were made. In this study, in only 5 % of patients could fatigue be explained in terms of physical disorder.

It is possible that fatigue experienced in the affective disorders reflects the after-effects of weight loss and sleep disturbance, which are common symptoms of depression and anxiety disorders. It is possible that a loss of interest and drive with environmental disengagement may be responsible, with a generalised avoidance of activity and work inhibition.

Motor retardation in the affective disorders has been demonstrated in a number of studies. It has been assessed using motor activity monitor readings of wrist-movements (Royant-Parola, 1986; Wolff, 1985), speech pause time (Hardy et al. 1984) and experimental reaction time (reviewed by Miller, 1975). Subjective ratings have indicated that depressed subjects often perceive themselves to be slower than they actually are (Willner, 1984) and that their main deficits involve the initiation of activity rather than its performance (Libet & Lewinsohn, 1973). The relationship between subjective fatigue, motor retardation and abnormal mood states is not clear and has not been adequately explored in the research literature. The physiological bases for fatigue in the post-viral fatigue syndrome are currently under dispute. The location of organic defects in muscle fibres and metabolism would greatly advance the search for an acceptable diagnostic test for the condition. Exercise tests of muscle strength and fatiguability have been used, but with unclear results. An exercise test is a limited means of assessing fatiguability. Motivational states and bodily perception of effort and pain may intervene during exercise before the muscles show signs of physical strain.

Researchers from the Muscle Research Centre in Liverpool have devised exercise tests to distinguish between "central fatigue" (due to a failure of neural drive at a voluntary level), and "peripheral fatigue" (occurring at or beyond the neuro-muscular junction) (Stokes et al. 1988). The first task involves the testing of the exercise capacity of the whole body by means of the voluntary performance on a cycle ergometer. Then muscle performance is tested using experimental electrical stimulation of peripheral nerves. Performance deficits, in a group of 30 patients with excess fatigue ("effort syndrome"), occurred only during the voluntary activity. The contractile properties of the muscles and the extent of recovery after exercise in the involuntary test were no different from those of 20 well subjects. The authors believe that the easy fatiguability of the patients is caused by an increased perception of effort and fear of pain. The subjects selected in this study may resemble a group of patients suffering from the post-viral fatigue syndrome, although such a diagnosis has not been clarified. It is stated that the subjects show no evidence of neuromuscular disease on clinical, biochemical or

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histological examination, and that not all had a history of viral infection at the onset of the fatigue. Although clinical presentation is similar to that of a group of confirmed cases of post-viral fatigue syndrome, it is not clear how well these findings would extend to this group.

A further test of strength and endurance on voluntary forearm contractions was used with a group of 20 chronic fatigue sufferers and 20 healthy hospital employees in a Clinical Neurophysiology Unit in Sydney, Australia (Lloyd et al. 1988). Again, the results demonstrated normal functioning of the muscles during exercise. Problems exerienced in the recovery of muscle strength after exercise were reported in a few of the fatigue syndrome subjects but the majority demonstrated exercise endurance and recovery similar to the normal subjects. It is hypothesised by the authors of these studies that the experience of "fatigue" in a syndrome such as the post-viral fatigue condition is an abnormality of perception of muscle force and effort rather than of actual force production.

The findings in these studies may be consistent with the relative paucity of objective evidence of abnormalities in the muscles of affected individuals. However, it is possible that organic pathology may be more subtle, and recent techniques of investigation have uncovered changes which may explain the fatigue.

Muscle biopsies have shown minor abnormalities, with changes in necrotic and type II muscle fibres (Behan et al. 1985; Byrne et al. 1985) suggesting easy fatiguability and muscle tenderness. The mild increase in fibre atrophy could however be consistent with disuse and

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may be a secondary effect of long term illness. Results using a highly sensitive single-fibre electromyography demonstrated abnormalities of muscle fibre conduction in 75 % of tested post-viral subjects (Jamal et al. 1985).

Phosphorous nuclear magnetic resonance (P-NMR) has detected a defect in intracellular acidosis in affected muscles (Arnold et al. 1984; Behan et al. 1985). The changes in cell metabolism are out of proportion to the expected changes after exercise and can explain the easy fatiguability and slow recovery after exertion. The defect may be caused by an early and excessive production of lactic acid. It appears though, that such tests do not give consistently positive results (Radda, 1988) and may occur in patients with different medical histories.

The pathophysiological basis for the fatigue is still somewhat unclear. What is more, subject selection in these studies is not consistent. The exercise task study by Stokes selected subjects from a patient population on the basis of a reported history of chronic negative findings of clinical, histological and fatique and biochemical investigations. Serological status is not reported, only a belief that evidence of infection with an enterovirus does not confirm the syndrome (Stokes et al. 1988). Lloyd's study employs diagnostic criteria involving subjective signs, clinical examination (including lymphadenopathy) and immunological status on a weighted scale. Of 20 patients, only 5 showed evidence of a past or persistent infection with the echo-virus Epstein-Barr, 2 with toxoplasmosis. Cell-mediated immunity was found in only 75 % of the subjects. Behan's study, whilst finding strong evidence to support the

aetiological role of the Coxsackie B viruses, has not taken this as the criterion for case selection. Whilst all subjects gave a history of a probable viral illness at the start of their disorder, in most cases this was non-specific and subjects were included without sereological confirmation of past infection.

A comparison of the types of fatigue and retardation found in the post-viral and the major depressive disorders would contribute much to our understanding of the fatigue syndrome. In this study, three methods of assessment are used in order to bring some light to these somatic features.

Firstly, an observational rating scale was used. Three items on the scale correspond to different types of Retardation, distinguishing between the effects on motor activity, verbal activity and intellectual activity. Additionally, a rating of peripheral muscular fatigue was made. The items were taken from the Bech-Rafaelson rating scales for anxiety and depression developed from the Hamilton Depression Scale (Bech et al. 1986).

Secondly, an Activity Schedule was used. Activity was recorded as the times spent in five activity categories during the 24 hour period on the day before the interview. Subjects were requested to recall a) the time spent asleep; b) the time spent in bed awake; c) the time spent resting or dozing on a chair or sofa; d) the time spent ambulent in the house; and e) the time spent out of the house. The 24 hour assessment began with the time at which the subject had gone to bed on the night before last. An activity score of 1 was given to the amount of time the subject had spent in bed awake. This includes the time

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spent in bed before sleep, the time spent awake during the night, the time spent after waking and any time of resting in bed during the day. A score of 2 was given to the time subjects spent resting or dozing on a chair or sofa. A score of 3 was given to the time spent ambulent in the house and a scale of 4 to time spent out of the house. A total Activity rating was arrived as by using these scores to multiply against the respective time allocations in minutes.

# 2.7 Summary of methodology and assessments

The interviews conducted lasted up to one and a half hours. Some of the interviews were prolonged because of a desire on behalf of many of the post-viral fatigue sufferers to relay the story of their illness and especially the difficulties which they had encounted in finally receiving diagnostic confirmation and acceptance from their family doctors. In the case of 3 subjects, the interview was unduly tiring the subjects; consequently, the self-reported pleasure and hopelessness scales were completed in the absence of the interviewer and returned by post within 2 days. All of the interviews of the post-viral and arthritis groups were conducted in their own homes. There was a tendency for the interviews with the arthritis sufferers to take less time than those for the post-viral or depressed subjects. The duration of interview tended to reflect the severity of psychiatric symptomatology.

Sixteen of the major depression interviews were conducted in the out-patient unit at Bishop Auckland General Hospital. Meeting the patients after their consultation with the psychiatrist encouraged high response rates. There was only one refusal. This procedure

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meant that some severely socially withdrawn or aggressive patients could be included in the study. Many commented that they were better able to discuss their illness after meeting the psychiatrist and that they would have been unwilling to take part had I met them at home. Two interviews were conducted in the patient's home and two in the psychiatric in-patient unit at Winterton Hospital.

The interview followed the following sequence:

1. Personal demographic details and the medical history of disorder were recorded. The arthritis subjects and those with the post-viral syndrome were asked to approximately date the onset of their condition (ie. the time at which their family doctor was consulted, or the time at which there was impairment to work and social roles). Details of medical investigations, tests and diagnoses were recorded and consultants who had been seen during the course of the illness. The first date of referral to the psychiatrist was noted.

2. Subjects were asked to report on life-time episodes of psychiatric disorder, treatment history and any episodes which had resulted in a period of hospitalisation. The episodes were approximately dated. Subjects were asked if there was any family history of severe medical or nervous problems.

3. The Hospital Anxiety and Depression Scale (HADS) was completed by the subject with the interviewer on hand to explain any items which caused confusion. Items were read out to any subject who had difficulty reading because of impairment of vision.

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4. The Psychiatric Assessment Schedule was administered to the subject assessing the one-month present status of psychiatric symptoms.

5. The Fawcett-Clark Pleasure Scale was completed by the subject assessing anhedonia and reactivity of the present psychiatric state.

6. Beck's Hopelessness Scale was completed.

7. Subjects were questioned about the previous day's activities, in order to compile the total Activity score.

8. Observational items from the Psychiatric Assessment Schedule and the Fatigue-Retardation items from Bech-Rafaelson's Depression Scale were completed by the interviewer.

# Results of the comparative investigation into the Post-Viral Fatigue Syndrome, Arthritis and Major Depressive Disorder

# 3.1 Statistical procedures

In this three sample comparative study, the group with post-viral fatigue syndrome is compared with the group with an arthritic condition and with the group with a major depressive disorder. This three group comparison requires that the post-viral group is used twice in the analyses. Care must be taken to ensure against type 1 errors resulting from repeated tests using the same data. Methods of comparison are therefore used in which the post-viral group plays a role analogous to that of a "control" condition against which two groups are compared. The significance levels for each separate comparison are adjusted accordingly.

Where the variables being compared are measured on at least an interval scale and have reasonably symmetrical distributions in each of the samples, a one-way analysis of variance is initially used. Using data from all three groups, the ANOVA establishes whether there is a difference in population means. The non-parametric equivalent for variables measured on ordinal scales, or which are skewed is the Kruskall-Wallis test, in effect an analysis of variance utilising the ranks of scores. This once again is the first step in the procedure which asks the question, "is there any significant difference between the mean scores in the post-viral, arthritis and psychiatric treatment groups". Kruskall-Wallis values without correction for tied ranks are reported as a more conservative test of group difference.

Following a significant ANOVA or Kruskall-Wallis test, further comparisons are performed to ascertain where the difference or differences lie. For the ANOVA three-sample test an "experiment" error rate is set at 0.05 (two-tailed). This significance level accepts a 5 % probability of a Type I error (incorrectly rejecting the null hypothesis of no difference). Dunnett's test for multiple comparisons using a control mean is then used in the individual comparisons (Kirk, 1968). In order for an individual comparison to be considered as significant, the difference in means between the two groups must exceed the value d, which is given by:

d = 2 X (MS error) / n

X is the two-tailed value derived from Dunnett's percentage points table corresponding to the number of independent groups (k) and the degrees of freedom associated with the mean-square error (v); n is the number of subjects in each of the groups under comparison. The value of X for k=3 and v=57 is of 2.27 (Dunnett's table). Entered into the equation:

d = (2) (2.27) (MS error) / 20

The post-viral group is first compared with the group with a mean score furthest apart from the post-viral mean. If the difference

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between their means is greater than the value for d, a further comparison is made between the post-viral and the remaining group.

Following a significant Kruskal-Wallis test at the 0.05 level of significance, individual comparisons are made using a Mann-Whitney U-test. Dunn's procedure (Kirk, 1968) for the adjustment of significance levels divides the chosen "experiment" error rate (in this case 0.05) by the number of comparisons to be performed (in this case two). The corresponding U value for an individual comparison is 114 for a significance level of 0.025. The first comparison is between the post-viral group and the group whose average ranking is furthest away from it. Following a significant result at the 0.025 level the post-viral group is compared with the remaining group. In both of these procedures, as soon as a non-significant result occurs no further comparative tests are performed.

A similar procedure is followed for categorical variables. An overall chi-square test of significance is followed by tests on component 2 x 2 tables, with significance levels adjusted as in Everitt (1977), page 44.

In the profile of individual psychiatric symptoms, two distinct comparisons will be made. The symptom by symptom comparison with the arthritis sufferers aims to question the extent to which the psychiatric complications of the post-viral syndrome are a response to disability. The arthritis group thus acts as a control for the disabling and distressing effects of physical illness. The symptom comparison with the individuals receiving treatment for a major depressive disorder aims to establish whether the post-viral syndrome

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subjects suffer from a condition of a similar kind and severity.

For measurement of the degree of association between sets of scores the Pearson product-moment correlation coefficient (r) is used, unless the scaling is ordinal, when the Spearman-rank correlation coefficient (rho) is used.

# 3.2 Descriptions of the groups

# a) The post-viral fatigue syndrome

Of those subjects with a "confirmed" diagnosis of a fatigue syndrome "induced" (supposedly) by an enterovirus of the Coxsackie B family, 12 are female and 8 are male. This reflects the reported ratio of prevalence between the sexes of approximately 3 to 2 (Behan et al. 1988). The mean age of the sample is 46 years (SD 13.0). The onset of disorder could be an episode of acute self-limiting viral illness, preferably with a confirmed substantial increase in specific antibody titres, or the onset of a sequelae of the fatigue symptoms some time after the initial acute attack. There are numerous difficulties in dating onset on the basis of a retrospective account by the patient, and subjects reported periods of ill-health lasting from 12 months to 43 years. The reported mean duration of the syndrome was 10.9 years (SD 10.7). Whilst adequate epidemiological information is scarse, reports of incidence suggest that most cases occur before middle-age, with a mean age of onset of 30 in both sexes (Parish, 1978). (The fact that incidence is not higher amongst the young and the very old is difficult to explain on grounds of viral aetiology). Of the selected subjects, 2 are single, 17 are married and 1 is divorced.

In the North-Eastern area there are two general practitioners who specialise in the assessment and treatment of the post-viral fatigue syndrome. One is retired from his practice and now devotes much of his time to the diagnosis and treatment of the syndrome; the other works in a quiet country practice and devotes two surgeries a week to Fifteen of the post-viral fatigue syndrome patients it. were currently having their condition monitored by one of these specialists. Twelve of these 15 were being treated with injections of gamma-globulin, a concentrated solution of the anti-body fraction of human blood, and as yet the only treatment which is on offer to Two others had refused the gamma-globulin therapy; one sufferers. expressed considerable anxiety about the possibilities of contracting AIDS from a pooled blood product, and the other had responded poorly to a trial dosage and has consequently discontinued the treatment. А third, in the early stages after diagnosis, had not yet commenced treatment. (The remaining five of the 20 subjects were receiving treatment from their family doctors, rather than one of the two general practitioner specialists).

Three subjects in this group were being treated at the time of data collection with anti-depressant medication and eight subjects have been prescribed benzodiazepines to control anxiety symptoms, control pain and aid sleep. One subject uses a ventilin inhaler to control symptoms of hyperventilation and another has been prescribed an amphetamine stimulant by her family doctor in order to ameliorate the chronic lassitude and retardation. A few of the subjects were unaware that the medication they had been prescribed was psychotropic, but reported that it helped with symptom management. A further six subjects reported that they had been treated with anti-depressants at some time during the course of the fatigue syndrome, and a further four reported past treatment with benzodiazepines.

#### b) The arthritic conditions

In the arthritis group 16 of the subjects are female and 4 are male. Over half of this group (12) suffer from a rheumatoid arthritis which epidemiological work has shown to be more prevalent in women. The majority of cases of rheumatoid arthritis start between the ages of 35 and 40 (Havard, 1987). Six of the group suffer from osteoarthrosis, which is also slightly more prevalent in women but which can occur at any age. Its incidence is usually higher, however, in individuals over 50 years of age. Two subjects suffer from ankylosing spondylitis. This is predominantly a disorder of men, with an age of incidence from late teens to 40 years. Although attempts were made to bias the selection of the arthritis subjects in favour of the younger subjects, the mean age of the arthritic group is 54 years (SD 8.7). They reported being affected for a mean of 19 years (SD 12.5), ranging from 4 years to 46 years. Four of the subjects are single, 15 are married and 1 subject is divorced.

Rheumatoid arthritis can have a gradual onset, with acute periods of "flare-up" and accompanying fever. Joints become swollen and painful. With recurrent attacks the affected joints become chronically swollen and fixed, with marked wasting of adjoining muscles from disuse. Eventually general health can be affected with chronic anaemia, lassitude and weight loss. Over time, the condition may stabilise or there may be gradual deterioration as more limbs become affected.

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There may be an auto-immune basis for this disorder. Osteoarthrosis is degenerative, with destruction of the central part of the cartilage lining the affected joints and overgrowth of the outer cartilage resulting in the production of bony spurs.

Ten of the arthritis group are currently receiving treatment from specialist rheumatologists. Six are being treated by their own G.P.s and one has recently discontinued specialist treatment and is now attending acupuncture sessions. The remaining three subjects are currently controlling their conditions symptomatically with medication from their local chemists. Two of the subjects are being treated with anti-depressant medication, and 3 with benzodiazepines. A further 3 sufferers had been treated with anti-depressants at some stage after the start of their conditions. There was no evidence of past treatment with anti-anxiety drugs. A combination of analgesics, non-steroidal anti-inflammatory drugs and corticosteroids were being taken by the 16 individuals receiving specialist or G.P. care.

# c) The major depressive disorders

Of the 20 subjects receiving psychiatric treatment for a major depressive disorder, 13 were female and 7 were male. The mean age of the subjects is 42 years (SD 10.8). Their current episodes of depression had lasted for a mean of 2 years (SD 3.4), although the majority of cases were of fairly recent onset, with 6 subjects having been depressed for under 12 months. One subject had suffered from a recurring depressive illness for the past 15 years, with no protracted periods of remission to warrant the identification of separate episodes. Four of the subjects are single, 9 are married and 7 are currently divorced or separated.

Two of the depressed subjects were inpatients in a psychiatric unit at the time of the interview, and a further 6 had been admitted at some time during their current episode. Three subjects had been taken to a general hospital during current episodes after attempted suicide by overdose. Fifteen subjects were taking anti-depressant medication, 7 with accompanying benzodiazepines or sleeping tablets (that is, up to the time of the interview, after which many were being put onto an anti-depressant/placebo trial), and a further 4 subjects were taking anti-anxiety drugs only. One subject, only one month after a suicide attempt, was taking no medication. Three subjects were taking additional medication, in one case to control diabetes, and another a thyroid dysfunction; the third subject was taking medication for the treatment of atropine-like Parkinsonian symptoms.

Of these subjects, four had attempted suicide in the past and eight had spent some of a previous depressive episode in a psychiatric unit. Nine subjects had previously been treated with anti-depressant medication, many with accompanying benzodiazepines, and three subjects had previously received electro-convulsive therapy.

# 3.3 Comparing the descriptive features of the three groups

Although all selected subjects were between the ages of 16 and 65, analysis of variance reveals a significant between group difference in age (F=6.6, df2, p<0.01). With a difference in means of 8 years between the post-viral and arthritis groups, the arthritis subjects are significantly older (the difference exceeds Dunnett's value of 7.9

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at the 0.05 significance level). The 5 year mean difference between the post-viral group and the group receiving treatment for a major depressive disorder also indicates a significant difference: the depressed subjects are significantly older than the post-viral subjects.

Marital status is significantly different between the three groups (chi-square=11.3, df4, p<.02). The comparison between post-viral and depressed groups is significant at a borderline level, given the adjustment of significance levels (chi-square=7.6, df2, p<0.05), with significantly more in the post-viral group currently married than in the depressed group. Marriage, or more particularly, an intimate and confiding relationship has been shown to protective against depression (Brown & Harris, 1978) but evidence has also pointed to the extensive family and marital distress which can ensue from ill health (Rutter, 1966). The comparison between the post-viral and the arthritis groups, however, indicates small differences which do not reach statistical significance (chi-square=0.8, df1, p=0.7). There is no significant group difference in the sex of the subjects (chi-square=2.0, df2, p=0.4). The two physically ill groups are therefore substantially well matched on marital status and all three groups are well matched on sex.

# 3.4 Disability and severity of disorder in the post-viral and the arthritic conditions

The arthritis group was chosen as a physically ill population which was to act as a comparison for the disability which is imposed by a chronic medical condition. Arthritis results in extreme fatigue and

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physical retardation and is frequently accompanied by chronic pain. The myalgia in the post-viral fatigue syndrome is often accompanied by joint pain caused by localised muscle involvement and in its early diagnostic stages has occasionally been mistaken for a rheumatic or arthritic condition. Common to both disorders are the resulting restrictions to movement and mobility and the demands for altered family and social roles. Whilst bodily deformity usually occurs in the arthritic conditions only, a few chronic sufferers of the post-viral fatigue syndrome may have severe muscular wastage.

The of disability raises various methodological assessment difficulties. One persistent problem has been the plethora of definitions and measurement techniques which have been employed in the research literature. Assessments have largely adopted a functional approach, and use observation or reports of personal incapacity as regards a collection of activities regarded as essential for daily World Organisation (supplement to the living. The Health Classification Diseases) classification International of of "impairment", "disability" and "handicap" incorporated this functional approach (W.H.O., 1980). The activities, focussing on ambulation and mobility, body care, sensory-motor ability and social activity attempt to cover the range of behaviour considered normal for a human being.

In assessing disabilities, problems emerge when behavioural categories are broken down into those tasks requiring manipulation, reach, mobility, sudden intense or sustained effort, coordination and concentration, for instance. Application of a behavioural index to individuals with psychiatric disorders (where it is the predominant impairment, or where it accompanies a physical illness) poses

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considerable problems. A disinclination to perform an activity resulting from anhedonia or depression could disguise physical capacity. What is more, in the disabled, the toleration for incapacity varies and because of the demands which individuals make upon themselves, full capacity may not be realised. This may be particularly the case in the post-viral fatigue condition where sufferers have learnt through experience how much they can "push" themselves, and the physical and emotional costs which will result should they exceed their bodily limits.

An influential large scale study of the measurement of disability (Sainsbury, 1973) found that over one-fifth of individual items assessed on objective tasks failed to accord with results from self-reports. Only 1 % of this discrepancy was explained by an individual's over or under-estimation of capacity. Problems largely lay in the formulation of satisfactory standard practical tests which could reflect the degree of incapacity experienced in the individual's own homes. The uncertainties and confusions in the subject's minds when they were asked what they had difficulty with, and how difficult they found these activities, highlight some of the methodological problems encountered in such research.

In the present study, the predominant aim was the assessment of the psychological profile, and a satisfactory measure of disability would have considerably lengthened the interview. This would have been undesirable because of their potential for easy fatigability, even through the social interaction required for an interview. We can be sure, however, that both the post-viral and the arthritis groups were considerably impaired. All but two of the subjects with the post-viral syndrome had ceased employment; one had begun part-time work again a couple of mornings a week but was spending a considerable amount of the afternoons in bed to compensate. The other, a farmer, out of sheer necessity, was having to fulfil part of his work requirements but seemingly to the detriment of his health. Two of the arthritis sufferers were at work, one working from home because of his disabilities.

a) In the Psychiatric Assessment Schedule, subjects were asked to evaluate their physical condition according to a subjective evaluation of incapacity. Prompts asked them to consider the degree to which their condition had disrupted their lives and caused restrictions in the past month. The assessment was made irrespective of the actual condition of the subject's physical health during the past month. A crude measure of 1 is given for a report of a poor physical condition with only mild incapacity and restriction to everyday life. A score of 2 indicates a report of moderate incapacity and restriction resulting from the physical condition. A score of 3 is given for a report of severe or total incapacity.

The results in Table 1 indicate that the majority of subjects consider themselves at least moderately incapacitated by their physical disorder. Because of the insensitivity of the measure, the majority of the scores are on the ceiling of the scale and thus we are unable to classify the subjects further as to the extent to which they consider their conditions to have incapacitated them. The distribution of scores analysed on a two-by-two contingency table, dividing the groups between the scores of 2 and 3 on the scale, shows no significant differences between the groups on the self-reporting of

# COMPARISON OF POST-VIRAL AND ARTHRITIS GROUPS ON RATINGS OF DISABILITY (Psychiatric Assessment Schedule)

Table 1

Subjective Incapacity	-	Post-viral	Arthritis
mild	(1)	0	
moderate	(2)	4	   7   
severe	(3)	16	12

Table 2

Apparent Incapacity		-	Post-viral	Arthritis
	mild	(1)	1	0 1
	moderate	(2)	0	4
	severe	(3)	19	16

incapacity (chi-square=1.1 df1, p=0.3).

An additional assessment was made of apparent incapacity according to the subject's actual physical condition during the last month. Attention was paid to the fluctuating course of the condition, the ability in the past month to perform daily tasks and to make life-style adjustments to discomfort and handicap. The ratings were on a scale of severity from 1 to 3. A score of 1 is given for a current mild condition where a subject appears to be functioning adequately in spite of apparent physical discomfort. A rating of 2 represents a condition in which a subject does have to make major adjustments in order to fulfil daily objectives. The subject will be restricted in terms of what can be physically endured and daily functioning will be limited. A rating of 3 is given to those subjects whose condition is severely incapacitating. There will be a substantial amount of dependency in this group, with individuals who are unable to lead their daily lives without major assistance. The ratings of apparent incapacity are reported in Table 2.

The subject in the post-viral group scoring 1 was recovering from a long debilitating period of illness and in the past month had, with specialist help, attempted to build up a programme of exercise and was gradually resuming activities in the household. Of the arthritis sufferers, 16 were unable to work or to perform household tasks without considerable help and had been almost housebound for the past month. The four sufferers scoring 2 on the scale of apparent incapacity appeared to have made considerable adjustments to their continuing discomfort and disability and did not appear to be severely incapacitated. With scores once again divided between moderate and severe incapacity, there is no significant difference between the two groups (chi-square=0.9, df1, p=0.3).

The subjective evaluations appear to be more optimistic in the assessment of incapacity than the ratings of apparent incapacity, independently assessed by the researcher. Where individuals had been suffering from their condition for a number of years, giving time for emotional adjustment and physical adaptation, they sometimes reported being content with the lower degrees of functioning of which they were now capable. It is likely that this could affect a subjective rating of incapacity.

b) Secondly, illness duration was assessed in the two conditions on the basis of a self-reported date of onset. The reported date of onset in the post-viral group was frequently that of an acute viral illness which was followed by fatigue and muscle pain. The day of remembered vividly by many of the subjects, and onset was characterised by acute attacks of vertigo or myalgia in parts of the body. In others, dating was less precise and the dates on which employment ceased or on which doctors were first consulted have been used. In some, the reported onset coincided with a treated episode of depression or anxiety. It is impossible to ascertain whether such onsets represent actual episodes of major depressive disorder or whether they are the undetected beginnings of a viral syndrome. It is possible that an episode of depression may have come first and induced susceptibility to a virus. Many subjects reported stressful life occurrences and situational adversity at the time of onset of ill-health. In cases where the onset of illness is reported to have started in childhood, there is additional uncertainty. Finding a

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diagnosis of post-viral fatigue is a relief to many sufferers, and in the efforts to achieve diagnostic closure past episodes of illness and distress may be seen in terms of the current illness.

According to the dates of onset as reported, the arthritis group had on the whole suffered from their condition for longer than the post-viral group. The median duration of their condition from the time of assessment was 18.2 years, with semi-interquartile range 26.7 - 8.1 years. The difference is significant (U=111, df1, p<0.01). In the post-viral group, the median duration was 8.3 years (SIR 14.3 -3.5 years). The distributions in both groups were skewed to the right with a large number of individuals presenting with conditions of more In the arthritis group this has resulted from the recent onset. attempts to select younger sufferers in order to achieve a better age match with the post-viral group. Many of the post-viral fatigue subjects have benefitted from recent increased medical interest in the syndrome and the improved viral hybridization tests which provide clearer case recognition (Behan et al. 1988). With earlier diagnosis, many more sufferers are joining the self-help groups at an earlier stage.

In spite of improved early diagnosis for those sufferers with a condition of more recent onset, the duration of diagnostic uncertainty is often prolonged distressingly. The median duration of this period for the post-viral group was 3.8 years (SIR 10.8 - 1.4 years). One subject reported having suffered from his condition for 42 years before a diagnosis was made. We cannot be sure of the accuracy of the reported date of onset of the condition and this confounds the validity of a measure such as the duration of diagnostic uncertainty.

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The dating of onset for the arthritic conditions is less problematic. In over half of the cases diagnostic confirmation was given by medical specialists very soon after functioning was first impaired. The median period of diagnostic uncertainty was reported as 0 years (SIR 4.8 - 0.0). One subject, however, did not receive a specialist diagnosis for 14 years in a condition with a very gradual onset. The post-viral subjects had experienced a significantly longer period of diagnostic uncertainty than the arthritis group (U=90, df1, p<0.05).

c) Thirdly, the groups were compared on the amount of time they had spent out of the house on the day prior to the interview. This measure is taken from a 24 hour assessment of graded activity categories. Time spent out of the house is regarded as the most physically demanding of the activity categories. It requires a certain degree of mobility and ability to sustain effort in a task for some prolonged period.

The post-viral subjects had spent a median of 77.5 minutes (SIR 0 - 303.8) of the previous day out of their houses. The arthritis subjects had spent 265 minutes (SIR 180 - 480). Thus, on this measure, the arthritis were less incapacitated than the post-viral group (U=114.5, df=1, p=0.02). Eight of the PVFS group had not left the house on the day prior to the interview. Only two of the arthritis group had not left the house.

The accuracy of these self-reported estimates is of course questionable. And whilst indicators of time spent out of the house may reflect a degree of incapacity incurred because of illness, the effects of a superimposed depressive or anxiety disorder must be

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considered. Depressive symptoms of anhedonia and social withdrawal or agoraphobic situational anxiety may restrict the subject's ability to engage in activities which will take them out of their own homes. From these results, however, it is suggested that the PVFS subjects may be more restricted and disabled by their conditions than the subjects with the arthritic disorders (given that the measure of time spent out of the house can be so interpreted).

#### 3.5 Comparison on current psychiatric symptomatology

# a) The Hospital Anxiety and Depression Scale (HADS):

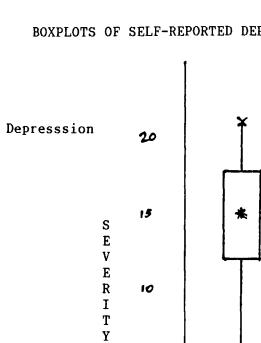
Self-reported ratings of symptoms during the past two-weeks.

Figures 1 & 2 present the box-plots of ratings on the depression and anxiety subscales of the HADS for each of the groups.

Median depression scores of 8 (Semi-interquartile-range 12 - 6) are reported for the post-viral group, with scores of 15 (SIR 18 - 12) for the depressed group, and 3 (SIR 5 - 2) for the arthritis group. The median anxiety scores for the post-viral group are 9 (SIR 12 - 7), for the depressed group 17 (SIR 19 - 12), and for the arthritis group 4 (SIR 9 - 2).

There is little overlap in the scores for the middle 50 % of each group, other than for a slight overlap in the anxiety ratings of the post-viral and arthritis groups. The scores for the depressed subjects are distributed with a slight skew to the upper end of the scales. The lowest scores are recorded for two subjects who are

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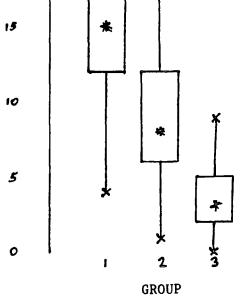
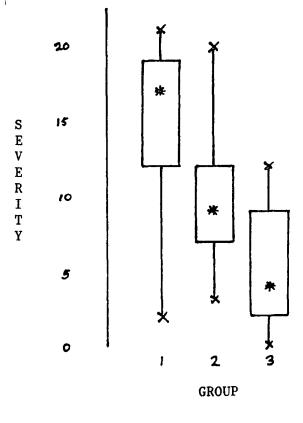


Figure 2

Anxiety



1 = Major Depression
GROUP: 2 = Post-viral Fatigue Syndrome
3 = Arthritis

receiving treatment for depression but are in the early stages of recovery, and for one subject whose depression is expressed predominantly in somatic terms. The arthritis group scores fall largely within the lower range of the scales with a tendency towards higher scores on the anxiety subscale. The scores of the post-viral group are distributed over the full range of the scale and form a fairly normal distribution.

The difference between the three groups in depression scores from the HADS is significant (Kruskal-Wallis H=30.9, df2, p<.0001). The scores of the post-viral fatigue syndrome group are significantly different from the scores for the depressed group (Mann-Whitney U=80.5, df1, p<.001), and from the scores for the arthritis sufferers (U=68.5, df1, p<.001).

The difference in anxiety scores between the three groups is also significant (H=25.3, df2, p<.0001). The post-viral group scored significantly higher than the arthritis group (U=68.5, df1, p<.001), but significantly lower anxiety than the depression group (U=77.5, df1, p<.001).

The ratings of anxiety and depression can be regarded as reflecting (i) variants of the same underlying disorder presenting in a quantitatively different way, as progressive symptomatic stages on a continuum of severity; (ii) two distinct disorders which are qualitatively different; or (iii) as a mixed disorder which is distinct from either a primary anxiety or a primary depression.

Symptoms of anxiety and depression commonly occur together and are

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highly correlated. High reports of anxiety symptoms are often subsumed under a largely depressive profile and a milder depressive disorder may present itself largely in terms of anxiety. Depressive disorders have been shown to occur without the text-book cardinal features of depression (depressed mood, hopelessness, guilt and anhedonia) and therefore may present predominantly with anxiety (Hamilton, 1988). The ratio of anxiety and depressive symptoms may vary with the course of a depressive illness (Kendell et al. 1974). In one study there was a change in diagnosis between anxiety and depressive disorder in 26 % of hospital admissions on a five-year follow up (Roth 1972). Over time, long-standing anxiety states have and been shown to develop largely depressive features, thus individuals presenting with anxiety symptoms may have an increased predisposition towards the development of a disorder expressed predominantly in terms of depression. What is more, individual responsiveness to anti-depressant medication appears to be an inaccurate discriminant between those patients presenting with predominantly anxiety symptoms and those presenting depressive symptoms (Johnstone et al. 1980). What has largely been uncovered by factor-analytic and latent trait studies is a dimension of general psychiatric disturbance which shows a strong correlation with both anxiety and depressive features (Goldberg et al. 1987; Stavrakaki & Vargo, 1986).

The correlation of scores on the depression and anxiety subscales in this study reflects this close relationship (rho=.75, p<.001 when the groups are pooled). However, the examination of the correlations for each group separately suggests that the relationship between the symptoms of depression and anxiety is not uniform.

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In the depressed group the correlation between the scores is high (rho=.67, p<.001). Using a cut-off of 10 (on the HAD 0-21 scales) as a quite conservative criterion of a "case" of depressive or anxiety disorder, 17 of the 20 subjects in the depressed group were above the threshold both on anxiety and on depression; one subject reached the criterion on the anxiety subscale only; and the remaining two subjects scored below the criterion.

In the post-viral fatigue group, the correlation between depression and anxiety scores was significant but the relationship between the two was not as strong as that in the depressed group (rho=.53, p<.01). Eleven of the 20 subjects overall reached case criteria on either of the subscales. There were 6 scoring 10 or over on both the anxiety and the depression subscales, therefore suggestive of a "mixed disorder". Three more post-viral subjects reached the criteria for a case on the anxiety subscale only and a further 2 subjects were classified as suffering from a depressive disorder with sub-threshold ratings on the anxiety subscale.

In the arthritis group the correlation between depression and anxiety scores is significant but small (rho= .38, p<0.05). With much lower scores overall in this group, only 4 subjects can be classified as psychiatric cases; all of these presented scores representative of an anxiety disorder. Whilst the HADS is designed to be sensitive to the type of depressive disorder accompanying a physical condition, without symptom contamination caused by the condition itself, it has not been systematically validated on an arthritis group. The organic components of the condition result in joint stiffness and chronic pain

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### CASES OF MOOD DISORDER IDENTIFIED ON THE HOSPITAL ANXIETY AND DEPRESSION SCALE

### Table 3

### Depressive disorder

	< 8 "No case"	8-9 "Borderline"	>10 "Case"
Post-viral	   9 	   3   	8
Arthritis	   17 	   3   	0
Depression	3		17
	· · · · · · · · · · · · · · · · · · ·		

### Table 4

### Anxiety disorder

•	< 8 "No case"	8-9 "Borderline"	>10 "Case"
Post-viral	7	   4    _	9
Arthritis	13	   3   	4
Depression	1		18

# Table 5

	NON	-CASE		l	CASI	Ξ			
Group	1	2	3	4	5	6	7	8	
Post-viral				8	3	6	2	1	
Arthritis		2	8	5	3	1	1		
Depression			2	ו   	1	4	5	8	
				I					

### ALLOCATION OF SUBJECTS ACCORDING TO THE INDEX OF DEFINITION (PAS)

making relaxation difficult. It is possible that muscular tension and restlessness may be raised for reasons other than anxiety.

Tables 3 & 4 show the HAD scores in each of the groups. By lowering the case threshold to subscale scores of 8 (the recommended threshold in research studies of physically ill depressed), a further 3 post-viral subjects meet the criteria for a depressive disorder (an overall frequency of 55 %), and a further 4 subjects an anxiety disorder (65 % of subjects overall). Lowering the threshold increases the number of "cases" in the arthritis group to 15 % for depressive disorders and 35 % for anxiety disorders. In the depressed group the subject scoring in the borderline range on the anxiety subscale increases the total to 95 % with the 85 % meeting the criteria for a depressive disorder remaining the same.

#### b) The Psychiatric Assessment Schedule (PAS):

symptoms occurring in the past month.

PAS severity scores were entered into the CATEGO programme (Wing et al. 1974). An appropriate diagnostic category is supplied where the index of definition scores are 5 or above. The eight levels of the index of definition indicate increasing confidence that sufficient key symptoms are present to allow a diagnosis to be made. The distribution of cases in each of the groups according to the index of definition levels are presented in Table 5.

Thus, 12 of the PVFS group achieved PAS profiles of sufficient severity and type to satisfy the criteria for a psychiatric diagnosis. Eight of the PVFS group (40 %) were allocated to a subclass of

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retarded depression with a corresponding major classification of R+, the chief symptoms of which are depressed mood with one or more of the symptoms of retardation, agitation, guilt or self-depreciation. Two of the PVFS group (10 %) were allocated to the subclass phobic neurosis, subsumed under a major classification of A+, anxiety states. The chief symptoms are subjective or observed anxiety which may be situational or specific. Patients are allocated to this class only if depressive symptoms do not dominate. The two PVFS subjects received subclass classifications of neurotic depression and simple depression, both satisfying the criteria for a major classification of N+, neurotic depressions. The chief symptoms of this category are depressed mood and anxiety. Tentative diagnoses made according to the International Classification of Diseases (ICD-9) place 10 of the PVFS subjects into a general class of neurotic depression and 2 in a class of other neuroses.

Of the arthritis sufferers, five met an index of definition of 5 or above, thereby receiving a tentative psychiatric diagnosis on the CATEGO analysis. Four subjects (20 %) were allocated to a subclass of retarded depression, and one a subclass of phobic neurosis. Major classifications of R+ and A+ are awarded respectively. Diagnoses of neurotic depression or other neuroses were given.

Of the depressed group, all but two met the criteria for a psychiatric diagnosis. The two who failed to reach an ID of 5 or above were two subjects who were in the process of remission, whilst still being treated for their depression. Eighty percent of the group were allocated to a subclass of retarded depression, although they more often achieved this classification as a result of symptoms of guilt

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and self-depreciation, as opposed to the retardative symptoms which were the main reasons for such allocations among the post-viral fatigue subjects. One depressed subject was given a CATEGO subclass of phobic neurosis, and one a subclass of simple depression. Seventeen were given tentative diagnoses of neurotic depression, with mixed anxiety and depressive features, and one was given a diagnosis of other neuroses, in which the anxiety features predominated.

On the basis of the CATEGO diagnoses, it is clear that the presentation of psychiatric symptoms in the PVFS does not substantially differ in type from that of a group of patients receiving treatment for a major depressive episode. All three groups present disorders characteristic largely of the neurotic type, with a mix of neurotic and depressive features. In terms of "caseness" (an ID level of 5 or above), 60 % of the post-viral fatigue group, 25 % of the arthritis group and 90 % of the depressed group met the criteria. Each of these levels of caseness exceed the 9.9 % found by Bebbington

et al. (1981) in their study of a community sample. It is also clear that the post-viral fatigue subjects are significantly more disabled with psychiatric morbidity than the group of subjects with arthritis. The recent prevalence rate of psychiatric disorder (from the Diagnostic Interview Schedule, Robins et al. 1981) among arthritis sufferers in Wells et al.'s community study (1988), was 25.3 % (DSM-III), almost identical to that from the present study.

Such significant psychiatric morbidity concurrent with the post-viral fatigue condition, is intermediate between the degrees of morbidity in the arthritis and the depressed groups. It suggests that in the

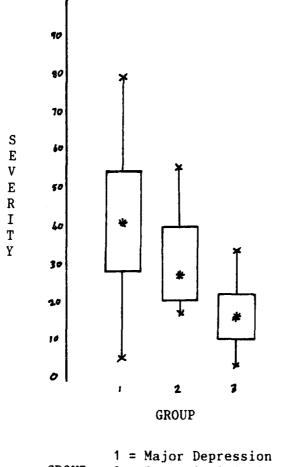
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post-viral group it represents more than just a reaction to disability. It also raises the important question as to whether the post-viral fatigue syndrome is a variant form of depressive disorder. In what is to follow, the patterns of current symptomatology and life-time episodes will be explored in an attempt to establish the extent to which the syndromes differ or whether the argument can be supported that the post-viral fatigue condition is merely one somatic presentation of an underlying depressive disorder.

The total severity score of the PAS incorporates the rating of symptoms, identified with precise terminological definitions and strict criteria for clinical severity. The symptoms, if they are "clinically fairly severe", can receive ratings of 1 or 2, or of 1 to 3, according to their persistence during the past month, their unvarying nature and the degree to which they have disrupted an individual's life (usually if the symptom is judged to be present under or over 50 % of the time). The total severity range of the 57 rated items is 0 to 110.

The group scores are presented in the box-plots in Figure 3. The post-viral group scores are significantly higher than those in the arthritis group (U=69.5, df1, p<.001), but do not differ significantly from the scores of the depressed subjects (U=143, df1, p=.1). The severity scores have a median of 38 (SIR 48 - 27) in the post-viral group, a median of 21 (SIR 32 - 14) in the arthritis group, and a median of 42 (SIR 61 - 35) among the depressed subjects. A significant group difference is demonstrated in the psychiatric severity scores (Kruskal-Wallis H=21.9, df2, p<.0001).

BOXPLOTS OF PSYCHIATRIC SEVERITY (from the Psychiatric Assessment Schedule)



GROUP: 2 = Post-viral Fatigue Syndrome
3 = Arthritis

The overall severity scores obscure symptomatic differences between the three groups. Whilst severity scores may not be significantly different between the depressed and the post-viral groups substantially different symptom ratings could be contributing to the separate scores. In order to uncover different syndromal patterns symptoms were rated as either present or absent. The severity ratings were collapsed to ratings of 0 if the symptom was not of a sufficient severity to warrant a rating as "clinically fairly severe", and to a rating of 1 if the symptom was coded 1, 2 or 3 on the severity scale. The frequency of ratings of 1 per group was then calculated for each symptom as a percentage. The 42 most common symptoms are presented. Table 6 shows the symptoms among the subjects with major depression in descending order of frequency, with the corresponding frequencies for the post-viral group alongside. Chi-square statistics calculated on the raw scores are used to compare the frequencies. Table 7 presents the comparison of symptoms for the post-viral group and the subjects suffering from arthritis.

The comparison of symptom frequencies in the depressed and post-viral groups illuminate many similarities in the presentation of psychiatric disorder. The frequency with which symptoms of muscular tension, loss of weight, panic attacks without autonomic symptoms, irritability, subjective inefficient thinking, hopelessness, simple ideas of reference and the avoidance of anxiety provoking situations occurred did not differ between the two groups of subjects. But the occurrence of these symptoms in the post-viral subjects could be explained in terms of the illness. The pain associated with muscle tension, loss of weight and mental inefficiency may be organically determined: simple ideas of reference and expressions of hopelessness were often

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### FREQUENCY OF REPORTED SYMPTOMS IN DEPRESSED AND POST-VIRAL GROUPS

	DEPRESSION	POST-VIRAL	CHI-SQ	
Muscular tension	90	90		
Subjective nervous tension	90	75	0.7	
Depressed mood	85	50	4.1	* *
Restlessness	85	55	3.0	*
Worrying	85	50	4.1	**
Tiredness and exhaustion	80	95	0.9	
Subjective anergia/retardation	80	95	0.9	
Subjective inefficient thinking	75	80		
Brooding	75	45	2.6	*
Loss of interest	70	40	2.5	*
Concentration	70	90	1.4	
Subjective sleep problems	70	80	0.1	
Social withdrawal	65	35	2.5	*
Self-depreciation	65	15	8.4	***
Lack of self confidence	65	55	0.1	
Pathological guilt	65	25	4.9	* *
Anxious foreboding	65	15	8.4	* * *
Irritability	60	55		
Early morning waking	60	25	3.7	**
Free floating automomic anxiety	60	30	2.5	*
Loss of libido	60	70	0.1	
Autonomic anxiety meeting people	60	25	3.7	* *
Nervousness between attacks	55	25	2.6	*
Simple ideas of reference	55	50		
Tension pains	50	30	0.9	
Hypochondria	50	35	0.4	
Panic attacks	50	30	0.9	
Situational autonomic anxiety	50	35	0.4	
Avoid anxiety provoking situation	45	45		
Hopelessness	45	40		
Thoughts of dying / suicide	45	35	0.1	
Delayed sleep	40	60	0.9	
Suicidal plans / acts	40	15	2.0	
Guilty ideas of reference	40	0	7.7	***
Increased weight / appetite	35	20	0.5	
Loss of weight / appetite	30	25		
Diurnal variation, mornings worse	30	10	1.4	
Observed slowness / underactivity	30	70	4.9	* *
Specific phobias	30	10	1.4	
Pre-menstrual exacerbation	30	20	0.1	
Panic attacks without autonomic sym	. 15	10		
Hypersomnia	5	50	8.0	***
Anxiety due to delusions	5	0		

\* = p < 0.1
\*\* = p < 0.05
\*\*\* = P < 0.01
\*\*\*\* = p < 0.001</pre>

## FREQUENCY OF REPORTED SYMPTOMS IN POST-VIRAL AND ARTHRITIS GROUPS

J	POST-VIRAL	ARTHRITIS	CHI-SÇ	UARE
Tiredness and exhaustion	95 %	70 %	(2.8)	*
Subjective anergia/retardation	95	80	(0.9)	
Muscular tension	90	60	(3.3)	*
Concentration	90	25	(14.7)	* * * *
Subjective sleep problems	80	50	(2.7)	*
Subjective 'nervous tension'	75	35	(4.9)	* *
Subjective inefficient thinking	75	15	(12.2)	****
Observed slowness / underactivity	70	75		
Loss of libido	70	30	(4.9)	* *
Delayed sleep	60	45	(0.4)	
Restlessness	55	60	<b>, ,</b>	
Irritability	55	15	(5.4)	**
Lack of self confidence	55	30	(1.6)	
Worrying	50	33	(0.4)	
Depressed mood	50	15	(4.1)	**
Simple ideas of reference	50	30	(0.9)	
Hypersomnia	50	15	(4.1)	* *
Avoidance of anxiety provoking sit		30	(0.4)	
Brooding	45	20	(1.8)	
Loss of interest	40	0	(7.7)	* * *
Hopelessness	40	15	(2.0)	
Hypochondriasis	35	30	(,	
Situational autonomic anxiety	35	20	(0.5)	
Social withdrawal	35	20	(0.5)	
Thoughts of dying/suicide	35	5	(4.0)	* *
Tension pains	30	20	(0.1)	
Free-floating autonomic anxiety	30	15	(0.6)	
Panic attacks	30	5	(2.8)	*
Nervousness between attacks	25	5	(0.5)	
Autonomic anxiety meeting people	25	15	(0.2)	
Pathological guilt	25	10	(0.7)	
Loss of weight/appetite	25	0	(3.7)	* *
Early morning waking	25	20	(,	
Increased weight/appetite	20	5	(0.9)	
Pre-menstrual exacerbation	20	15	(010)	
Anxious foreboding	15	10		
Self-depreciation	15	25	(0.2)	
Suicidal plans/acts	15	0	(1.4)	
Specific phobias	10	20	(0.2)	
Panic attacks without autonomic syn		15	, /	
Diurnal variation, mornings worse	10	10		
Guilty ideas of reference	0	0		

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\* = p < 0.1
\*\* = p < 0.05
\*\*\* = P < 0.01
\*\*\*\* = p < 0.01</pre>

bound up specifically with thoughts about the illness. The avoidance of situations perceived likely to exacerbate the fatigue, and the panic which could result when they could not be avoided are closely bound up with the ways in which the illness is managed by the sufferer.

Tiredness and exhaustion and subjective expressions of anergia with retardation are the most commonly reported symptoms in the post-viral subjects. They are present in 95 % of the group. These fatigue items are only slightly less frequently reported in the depressed group. Concentration difficulties, subjective sleep problems, delayed sleep and loss of libido occurred slightly more often in the post-viral group but the differences in frequencies did not reach statistical significance.

Perhaps these symptoms could also be explained as effects of the primary illness. The two symptoms which occurred significantly more often in the post-viral group are a rating of slowness and motor activity, assessed by the researcher, and a patient report of hypersomnia. This has been reported in the literature as a hypersomnolence unaccompanied by hypnagogic hallucinations, sleep catalepsy which, paralysis or in its severe form, may be indistinguishable from the sleep disturbance in narcolepsy (Behan et al. Whilst compatible with accounts of delayed or troubled 1988). sleep, those reporting that they were sleeping up to one or two hours more than usual often described a reversal of the sleeping cycle. Thirty percent of the depressed group were rated as physically slow and retarded and these were generally the most severely depressed, including those subjects of in patient status. Many of the depressed

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out-patients appeared more agitated in movement and speech during the interview. Characteristic of many of the post-viral subjects was a slowness of gait, movement and facial expression.

Of those symptoms occurring significantly more frequently in the depressed group, depressed mood, brooding, loss of interest, social withdrawal, pathological guilt, early morning waking and guilty ideas of reference are cardinal features of a depressive disorder. Τn addition, restlessness, worrying, self-depreciation, anxious foreboding, free-floating anxiety and social anxiety are common features of a mixed "neurotic" disorder. All of these symptoms occurred significantly more often in the depressed subjects. Α current feeling of depressed mood was reported in only half of the post-viral group, and less than half reported that they had generally lost interest in things around Feelings of guilt, them. self-depreciation and social anxiety, and feelings of impending doom were uncommon.

However, these major symptoms of depressive disorder must be taken seriously. A symptom comparison with the arthritis group shows that subjective "nervous tension", irritability, depressed mood, loss of interest, thoughts of dying and suicide and panic attacks are all reported significantly more often in the post-viral group than in the equally disabling arthritic disorders. Significantly more tiredness, muscular tension, sleep difficulties, inefficient mental capacities and loss of libido are reported in the post-viral group. Regarding the overall ratings of psychiatric symptom severity the post-viral subjects are intermediate between the scores for the depressed and the arthritis groups.

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Only restlessness, self-depreciation, specific phobias and panic attacks without autonomic symptoms were commoner in the arthritis sufferers. None of these differences, however, reached statistical significance.

On the whole, the arthritis subjects appeared to be better adjusted to their conditions, had come to terms with the disability and had adjusted their life-styles accordingly. Many talked of the home improvements they had introduced which had substantially improved their daily functioning. Where distress was more considerable it was expressed largely in terms of the symptoms of anxiety. As the HAD scores demonstrate only 3 subjects approached a borderline depressive disorder. Although arthritis is a substantially different disorder to the post-viral fatigue syndrome, the reports of fatigue, sleep problems, muscular tension and pain are common to both. Both disorders can be chronic and disabling. What perhaps distinguishes the two is the knowledge that there will be no substantial remission or recovery in the arthritic conditions other than the relief offered by surgical joint replacements. Many of the arthritis sufferers reflected upon a future which they understood would bring further incapacity, discomfort and dependence. They could hold no hopes of complete recovery and most had come to terms with this. With this knowledge they were able to plan for a future, within the limitations they had come to accept.

Holding onto the hope of complete recovery was a major concern for the post-viral subjects. The despair expressed by many was concerned with the loss of such hope. Something which stood out in this group was the

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inability in many of the subjects to look towards a future at all. The fatigue and lassitude of the illness forced them to function only from one day, or from one hour to the next, preventing them from making plans even for a near future. With a condition made up of frequent relapses, remissions and symptom fluctuations there was often a sense of some loss of control.

#### c) Further analysis of psychiatric symptoms

Attempts have been made, in the literature on psychiatric classification and on the assessment of depressive and neurotic disorders in general practice and other medical settings, to distinguish between different types of psychiatric symptom. The somatic or physical symptoms, which are associated with more severe psychiatric disorders or which may be part of the organic pathology of many physical conditions, have been distinguished from the more cognitive and behavioural components of a psychiatric condition. The reason for such a separation is that physical ill-health can produce symptoms which mimic a syndrome of major depression or which may alter or disguise genuine psychiatric symptoms.

Whilst extreme anergia, retardation and cognitive inefficiency are believed to be central symptoms of the disease process in the post-viral fatigue syndrome, they are not currently explicable in terms of organic pathology, and these same symptoms are also associated with the more severe depressive illnesses. Symptoms which occur more frequently in milder depressive illnesses, such as depressed mood, loss of interest and guilt, are surprisingly less common in the post-viral fatigue syndrome.

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The Psychiatric Assessment Schedule (PAS) can be separated into somatic and non-somatic items. Fifteen somatic items are presented in These items have been selected because they reflect bodily Table 8. changes which could have been brought about by endocrine, neurological, immunological or metabolic organic dysfunctions, independently of any effect they may have on mental state. They are those physical symptoms of affective disorders which have been shown to overlap with the symptoms of various medical disorders encountered in general hospital and general practice setings (Stewart, 1965; Schwab, 1967; Kathol & Petty, 1981; Clark et al. 1983), and also those symptoms of depressive illnesses which have been regarded as indicative of biological depressive disorder (Carney et al. 1967).

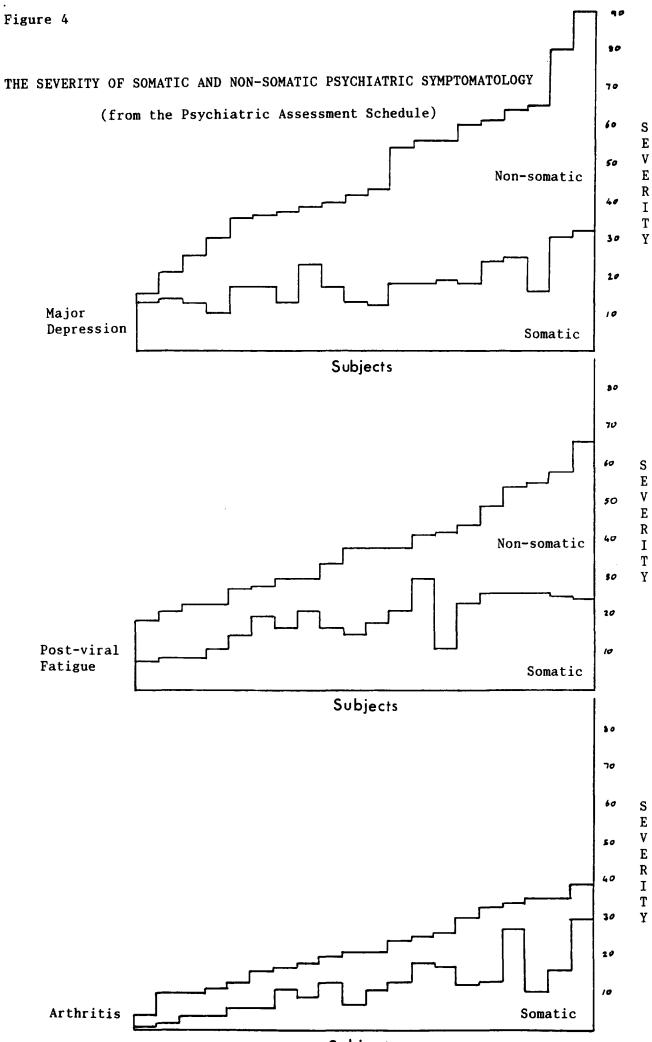
Figure 4 illustrates the separation of somatic and non-somatic symptom severity scores from the PAS for each of the subject groups separately.

The following analysis looks at the role which somatic symptoms play in the psychiatric symptomatology of the post-viral fatigue syndrome. It is possible that ratings of psychiatric severity may be elevated because of the inclusion of these items in the PAS. Some of these symptoms may be part of the organic disorder, and therefore may not be accurate indicators of psychiatric state; on the other hand, they may be a distinct part of an existing psychiatric disorder. Even where symptoms are demonstrated to be due to physical pathology, their severity and frequency of occurrence may be affected by the presence of a concurrent depressive disorder. An understanding of the symptoms which are signs of, or influenced by, a superimposed mood disorder

### SOMATIC SYMPTOMS EXTRACTED FROM THE PSYCHIATRIC ASSESSMENT SCHEDULE

4

Tiredness and exhaustion
Subjective anergia and retardation
Observed slowness and underactivity
Muscular tension
Tension pains
Restlessness
Subjective sleep problems
Delayed sleep
Hypersomnia
Early morning waking
Loss of libido
Loss of weight
Increase in weight
Pre-menstrual exacerbation
Diurnal variation, mornings worse



Subjects

would be important as they could be ameliorated by psychotropic drug treatment, counselling or cognitive therapy.

Dichotomous symptom codings for the presence or absence of the somatic items were used. A subject was classified as a psychiatric case or non-case on the basis of the self-reported scores on the depression and anxiety subscales of the HADS. A case had a score of between 10 and 21 on either or both of the depression and anxiety subscales. Each of the symptoms, coded present or absent, was then by case or non-case in a 2 x 2 table. cross-tabulated The cross-tabulation was separated for the post-viral and arthritic groups. Because of the small number of subjects in each of the cells, the Fisher exact probability test was used.

There was no significant difference in the presentation of 12 of the somatic symptoms in the post-viral subjects classified as psychiatric cases (on the basis of HAD scores) in comparison to those who were not. It appears, therefore, that these symptoms are not in themselves characteristic of an underlying psychiatric disorder in the post-viral fatigue syndrome. The 12 symptoms are presented below:

> Tiredness and exhaustion Subjective anergia and retardation Muscular tension Subjective sleep problems Delayed sleep Hypersomnia Early morning waking Morning depression Loss of libido Pre-menstrual exacerbation Increase in weight Loss of weight

Significant differences in presentation between the psychiatric cases

and non-cases of the PVFS, were found for 3 of the symptoms. Each of these was found to occur with a greater frequency in those sufferers identified as psychiatric cases.

Thus, reported restlessness, tension pains and observed slowness and underactivity may reflect the presence of psychiatric disorder in the post-viral fatigue syndrome. However, the 12 somatic symptoms described in the list above are less clear indicators of psychiatric illness and may equally occur in those subjects not meeting the criteria for a psychiatric case.

Using the symptom severity ratings for each of the somatic symptoms, severity was correlated with three psychiatric severity scores: the HAD depression score (0-21), the HAD anxiety score (0-21) and the total severity of the non-somatic items taken from the PAS (0-82). Spearman correlation coefficients are reported for the association of somatic symptom severity and the psychiatric severity scores. These are presented in Tables 9-11, for the post-viral, arthritis and depressed groups separately, and illustrated in Figure 5.

In the post-viral fatigue syndrome, tiredness and exhaustion are frequently reported irrespective of the diagnosis of a depressive disorder. However, it is clearly also related to the severity of depression as assessed on the HADS (rho=.36, p<.0.05). This positive correlation shows that more severe ratings of tiredness and exhaustion are associated with a more severe depression.

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CORRELATING THE SEVERITY OF SOMATIC SYMPTOMS WITH PSYCHIATRIC SEVERITY

### Table 9

a) Post-viral fatigue

		DE	PRESSIC (HADS)	N	ANXIETY (HADS)		N-SOMATI (PAS)	C	
I									-
	Tiredness and exhaustion	1	.36	*	17		02		1
I	Subjective anergia	1	.41	**	05		.10		1
	Observed slowness	1	.25	*	.43	**	.47	**	1
I	Subjective sleep problems	1	.10		.14		.08		1
I	Delayed sleep	1	.07		.23		.09		1
I	Early morning waking	1	.09		06		.13		1
ł	Hypersomnia	1	12		17		06		1
ł	Morning depression	1	.17		.10		.25		1
1	Loss of libido	1	.28	*	.20		.32	*	1
1	Tension pains	1	.19		.48	**	.33	*	ł
Ι	Muscular tension	1	.35	*	.60	* * *	.57	***	l
ł	Restlessness	1	.12		.52	***	.03		ł
ł	Pre-menstrual exacerbation	n	07		14		09		ļ
I	Increase in weight	1	14		41	* *	45	* *	H
l	Loss of weight	1	06		.18		.06		1

### Table 10

b) Arthritis

		DEF	RESSIC	ON	ANXIETY	NO	N-SOMAT	IC .	
		(	HADS)		(HADS)		(PAS)		
1		1							-
ļ	Tiredness and exhaustion	ł	.54	***	.31	*	.52	* * *	1
1	Subjective anergia	1	.50	* * *	.11		.13		
Ι	Observed slowness	1	03		48	**	08		1
]	Subjective sleep problems	ł	.58	***	.26		.10		1
1	Delayed sleep	1	.29	*	.29	*	.26		1
ł	Early morning waking	I	.17		.11		.25		1
1	Hypersomnia	1	.22		.10		.16		1
1	Morning depression	1	.24		.35	*	.47	**	1
1	Loss of libido	1	.46	**	.39	**	.44	**	1
I	Tension pains	1	.12		.54	***	.53	***	ł
1	Muscular tension	1	03	*	.53	***	.43	**	1
1	Restlessness	1	.06		.76	* * *	.57	***	1
1	Pre-menstrual exacerbation	1	06		.61	* * *	.53	***	
Ŧ	Increase in weight	1	06		02		.10		1
T		1							_1

Spearman correlations:

\* = p < 0.05 \*\* = p < 0.01 \*\*\* = p < 0.001 CORRELATING THE SEVERITY OF SOMATIC SYMPTOMS WITH PSYCHIATRIC SEVERITY

### Table 11

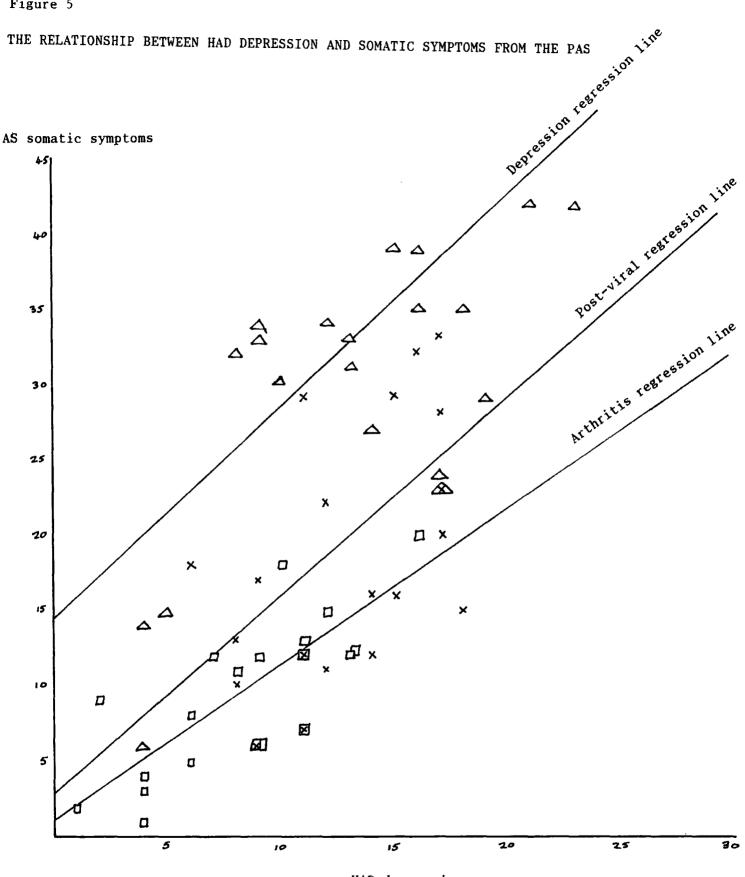
c) Major depressive disorder

		RESSIC HADS)	N	ANXIETY (HADS)	NO	N-SOMATI (PAS)	C
Tiredness and exhaustion	Ι	.39	* *	.49	* *	.56	* * *
Subjective anergia	Ι	.64	* * *	* .49	**	.61	* * *
Observed slowness	I	.06		.03		.02	
Subjective sleep problems	Ι	.28	*_	.27	*	.34	*
Delayed sleep	Ι	.27	*	.30	*	.22	
Early morning waking	I	.31	*	.19		.45	* *
Hypersomnia	I I	.34	*	.10		.12	
Morning depression		.06		23		.01	
Loss of libido	I I	.30	*	.25	*	.26	*
Tension pains	1	.16		.38	**	.45	* *
Muscular tension	1	.05		.48	* *	.34	*
Restlessness	ł	.39	**	.55	***	.62	* * *
Pre-menstrual exacerbation	n	04		.20		.27	*
Increase in weight	1	16		03		04	
Loss of weight	1	.42	* *	.39	* *	.50	* * *
	Ì						

Spearman correlations: t = p < 0.05

\* = p < 0.05 \*\* = p < 0.01

\*\*\* = p < 0.001



HAD depression

Δ = Major Depression

= Post-viral Fatigue Syndrome Х

= Arthritis The rating of subjective anergia and retardation has a similar and slightly stronger association with the HAD depression score (rho=.41, p<0.01). Observed slowness and underactivity is more severe when HAD depression, anxiety and non-somatic PAS symptoms are worse (rho=.25, .43 and .47, p<0.01).

Seventy percent of the post-viral subjects reported some loss of libido. The rating of its severity is correlated with the HAD depression score (rho=.28, p<0.05), and with the PAS non-somatic symptoms (rho=.32, p<0.05). Severity ratings of tension pains and restlessness show a positive association with HAD anxiety ratings (rho=.48, p<0.01; rho=.52, p<0.001); muscular tension has a strong association with anxiety (rho=.60, p<0.001), and a slight association with HAD depression (rho=.35, p<0.05). Loss of weight was not associated with depression, but those who reported increased weight showed significantly less anxiety (rho=-.41, p<.01), and non-somatic symptom ratings (rho=-.45, p<.01). Only 25 % of subjects reported loss of weight within the past three months but many commented on a previous extreme weight loss, usually at the start of their illness. The reported increases in weight may represent the reversal of past losses, which therefore explains the association with better psychiatric ratings.

The symptoms associated with sleeping difficulties show very little correlation with depression and anxiety in the post-viral group. Sleep disturbance is common in the post-viral fatigue syndrome. Reversal of the sleep cycle and hypersomnia are frequently reported. A physiological component of this disturbance has been traced to a

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histocompatibility antigen (HLA), which is implicated in other sleep disorders such as narcolepsy (Behan & Behan, 1988). However, not all of the subjects in this study who reported an increase in the amount of time they spent sleeping saw this as a problem. It is quite likely that the increase in sleeping time is a function of a changed life-style, and the reduced activity levels resulting from illness. Many of the subjects reported extreme difficulties sleeping, with delayed sleep in 60 % and early morning waking in 25 %. Many of those reporting subjective sleep problems experienced disturbed nights with frequent awakenings and an inability to sleep without medication. One subject reported as little as 2 hours sleep on the night before the interview, and the lower 25 % of subjects reported under 4.2 hours of sleep. It is only in the top 15 % that subjects reported sleeping for 9 hours or more.

When subjects with arthritis were classified as cases or not on the basis of the HAD scores, tiredness and exhaustion, subjective anergia, subjective sleep problems, delayed sleep, hypersomnia and early morning waking, loss of libido and weight changes were not associated with their being cases or not. The symptoms were as likely to occur in those subjects without a diagnosable mood disorder as in those subjects who met the criteria on the depression or anxiety scales. There were 5 somatic symptoms, however, which were more likely to subjects classified as cases. Symptoms of reported occur in restlessness (Fisher's exact test, p<0.05), muscular tension (p<0.05), tension pains (p<0.1), pre-menstrual exacerbation (p<0.01) and diurnal variation of mood (p<0.1) are all commoner in the cases. Observed slowness and underactivity was commoner in those arthritis sufferers who were not identified as cases (p<0.01).

The correlation matrix (Table 10) shows that 9 of the symptom severity ratings are significantly associated with the severity of anxiety. Symptoms of restlessness (rho=.76, p<0.001), tension pains (rho=.54, p<0.001) and muscular tension (rho=.53, p<0.001) tend to be worse when anxiety scores are higher. Whilst these are cardinal symptoms of classic anxiety disorders, they are also those symptoms which are amongst those most likely to occur alongside an arthritic disorder because of the pain and discomfort accompanying the disorder and the consequences of limited mobility.=.61, p<0.001) and morning depression (rho=.35, p<0.05) are also associated with the anxiety ratings. Joint stiffness and pain is usually at its worst in the first few hours after waking in arthritic conditions (Black's Medical Dictionary, 1987), and it is therefore not suprising that many subjects reported that they felt emotionally at their worst during this part of the day.

Tiredness and exhaustion and loss of libido were more severe when increased anxiety and depression ratings were higher. Subjective anergia was related to the severity of depression (rho=.50, p<0.001), as was the report of subjective sleep problems (rho=.58, p<0.001). Increasingly severe ratings of observed slowness and underactivity in the arthritis subjects were associated with lower HADS ratings, especially for the anxiety scores (rho=-.48, p<0.01). Sleep is often disturbed in the sufferers of arthritis. The physical discomfort experienced results in frequent night and early morning waking. The lower 25 % of this group reported that they had slept for under 5.5 hours on the night before the interview. It was those subjects who reported sleeping as a problem, however, who also reported increased ratings of depression. The correlation of the reported severity of

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sleeping difficulties and psychiatric severity (rho=.58, p<0.001) suggests that those arthritis sufferers who express concern about their sleeping patterns should be considered for a superimposed depressive disorder.

All but one of the depressed group are classified as cases on the HAD scale, so it was not feasible to test for the probability of somatic symptom occurrence by means of "caseness". The severity correlations, nonetheless, point to some very strong associations between somatic symptom severity and other psychiatric symptoms. The strongest associations show that it is the fatigue items, restlessness, muscular tension and tension pains which are the most likely to be worse when the other psychiatric symptoms are more severe. These symptoms as indicators of psychiatric severity are common, in varying degrees, to all three of the groups. Although their presence will more often than not be associated with the physical condition in the post-viral and the arthritis groups, their severity can discriminate between those with and those without a concurrent psychiatric mood disorder.

### 3.6 Comparison on life-time psychiatric symptomatology

Research by Taerk et al. (1987) into the psychiatric accompaniments to the post-viral fatigue syndrome led to suggestions that prior episodes of affective disorder acting through psycho-immunological pathways, could make an individual susceptible to virally precipitated illnesses, and to a prolonged and depressive aftermath to viral infections. A history of psychiatric problems is also believed to be a factor in determining which individuals in the acute stage of infection will respond with a mass of psychiatric symptoms suggestive

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of a depressive disorder (Cadie et al. 1976).

In this study, it was expected that:

1. Subjects suffering from the post-viral fatigue syndrome would have experienced more life-time episodes of psychiatric disorder than those subjects afflicted with an arthritic condition.

2. Previous episodes of psychiatric disorder would predict current severity of psychiatric symptoms. A question of particular interest is whether the relationship differs between the groups.

Sixteen of the post-viral group (80 %) had experienced a previous life-time episode of a depressive or anxiety disorder. Twelve of these had received treatment for their disorder and 4 had remained untreated. Of the 12 who were treated, 6 had been treated by a psychiatrist or clinical psychologist and 6 by a general practitioner. Of these, 5 cases resulted in treatment in a psychiatric inpatient setting.

In the arthritis group, 9 had experienced a previous life-time episode of a depressive or anxiety disorder (45 %). Of these, 6 had been treated and 3 had not. Of those previously treated, 3 had been treated by a psychiatrist or clinical psychologist and 3 by a general practitioner. Two of the subjects with a previous life-time episode had been treated as inpatients in a psychiatric hospital for a period during their episode.

Twelve of the depressed group (60 %) had experienced a previous

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life-time episode of depressive or anxiety disorder (distinct from the current episode). Of these, 9 had received specialist treatment from a psychiatrist, clinical psychologist or general practitioner and 3 had received no treatment. All previous treated episodes had resulted in psychotropic medication, and 7 had been admitted as psychiatric inpatients at some time during the episode. The overall difference in the frequency of life-time episodes (distinct from current episode) was of borderline significance (chi-square=5.2, df2, p<0.1), with a trend towards more episodes in the post-viral group in comparison to the arthritis group.

Life-time episodes were coded on a three-point scale, with 1 = 1 life-time episode (treated), 1/2 = 1 life-time episode (untreated), and 0 = no life-time episode. This variable was entered into a regression analysis, with two dummy variables distinguishing between the depressed, arthritis and post-viral groups (00 = PVFS; 01 = depression; 10 = arthritis). The severity of current psychiatric symptoms from the PAS interview was used as the dependent variable.

The regression analysis demonstrated a significant effect for the life-time variable (F change = 13.2, p<.001), and a significant group effect (F change = 14.4, p<.001). With both variables in the equation the predicted severity score can be determined by the following equation:

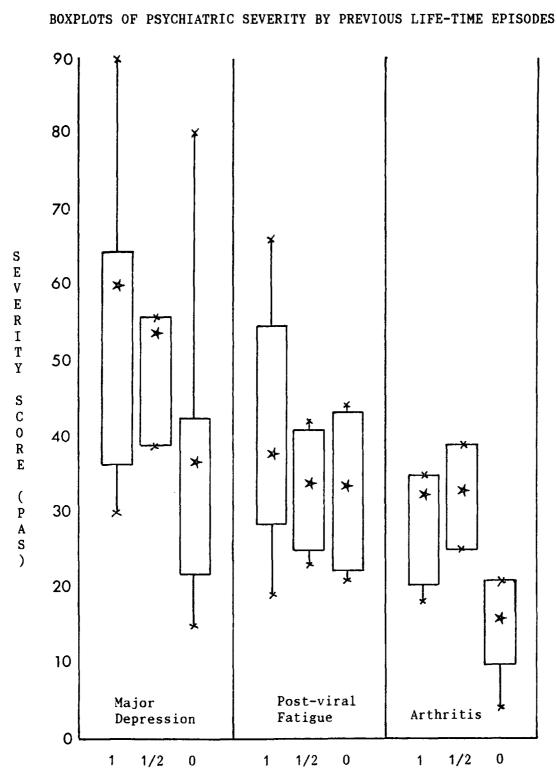
```
S = 28.0 + 14.1 (Life-time episode) + 0.0 (if post-viral group) or
+ 11.9 (if depressed group) or
- 11.2 (if arthritis group).
```

There is a significant main effect of previous life-time episodes.

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There was no significant interaction between the variable and group. The analysis shows that a life-time episode of affective disorder is associated with more severe current symptoms. A past borderline or untreated disorder is also associated with more severe current symptoms, although to a lesser extent to a treated disorder. However, there is no evidence that the association is significantly different in the three conditions. The regression analysis was run separately for the three subject groups. The most significant effect of life-time episodes upon current presenting psychiatric symptoms was in the arthritis group (F=16.5, p<.001). A previous life-time episode with a more severe presenting profile in the depression group (F=6.5, p<.02). The contribution of life-time episode to the presenting symptom profile in the post-viral group failed to reach significance (F=1.3, p<.26).

The analysis is open to suspicion, as the outcome variable is only roughly quantitative, and the coding of previous episodes as 0, 1/2 and 1 is based more on guesswork than measurement. Figure 6 shows the same data presented in robust form as 5 number summaries. Confirming results of the regression analysis, there is a negative the relationship between severity score and the coding of previous psychiatric episode in all three groups, although there is a less steep slope in the post-viral than in either of the other groups. The severity range of the post-viral subjects is greatest among those who have had a previous treated episode as opposed to those who have not, and there is certainly a trend towards increasing current symptom severity with previous life-time episode. However, such а relationship is not of sufficient order to reach significance.



1 = Life-time episode (treated)
 1/2 = Life-time episode (untreated)
 0 = No previous life-time episode

It has been hypothesised that a past history of affective disorder can predispose towards a more depressive profile of a current disorder. One study has shown that more current symptoms of fatigue, sleep and appetite disturbances, motor agitation and retardation, poor concentration, loss of interest, guilt and suicidal thoughts were found in a group of mothers who had experienced a previous episode of depression compared to a group of mothers with no history of disorder (McGee et al. 1983). An existing disorder with a history of past psychiatric problems is suggestive of a more severe underlying or remitting disorder, or perhaps indicates a certain predisposition to breakdown under stress with a suceptiblity to anxiety and emotional instability. It has been reported that individuals with a past history of depression have a tendency to display higher scores on Eysenck's "Neuroticism" scale than persons without a past psychiatric episode (Katz & McGuffin, 1987). A direct linear relationship was found between the neuroticism score and the current rating for depression, and those with a past life-time episode reported significantly more symptoms than those with no past history. Neuroticism has been shown to have a diagnostic and prognostic significance for current depressive disorder (Weissman et al. 1978). pathways involved in these studies may correspond to the The suggestions by Taerk and co-workers that past psychiatric disorder in post-viral fatigue sufferers can determine the particular response to illness that fosters chronicity.

However, the interesting finding in this analysis is that the effect is somewhat weaker and non significant in the post-viral group, also weaker than that found among the arthritis sufferers. Thus, current severity scores are somewhat less affected by past psychiatric status

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in the post-viral sufferers. The hypothesis of psychiatric vulnerability is perhaps not therefore strongly supported. If the post-viral fatigue condition was regarded as a variant form of depression, one would have expected the effect to have been as strong as that displayed in the depressed group.

# 3.7 <u>Is the post-viral fatigue syndrome a variant form of depressive</u> <u>disorder?</u>

A major aim of this study is an attempt to determine whether the post-viral fatigue syndrome is a variant form of a depressive illness and whether it can be successfully differentiated from a sample with a major depression on the basis of its psychiatric symptom presentations. If it is a depressive equivalent, we would expect a similar pattern of current symptoms between the two groups. An exploratory analysis of this type was conducted by Fairburn and Cooper (1986) in which a bimodal distribution emerged from a stepwise discriminant function analysis on the psychiatric symptom data of depressed and bulimic patients (Present State Examination, Wing et al. 1974). Thus, they could conclude that from their data, it appeared that bulimia was not a variant form of depression. Such a question is of considerable importance in the understanding of the post-viral fatigue syndrome.

Discriminant function analyses have been widely used to validate psychiatric syndromes by means of a search for a "point of rarity" between two related disorders. Symptoms are entered in a stepwise method, in which those providing the best predictive diagnostic discrimination are entered first. A linear combination of the independent variables is formed and serves as the basis for assigning cases to groups. Discriminant analytic procedures are more appropriate when using continuous independent variables to predict to a dichotomous outcome variable, and therefore, when used with categorical or only marginally continuous symptom data (such as the rating of symptoms on the PSE), there are problems in interpreting results from these models. It is not the most appropriate procedure for the analysis of psychiatric data (Everitt, 1977; Grove et al. 1987).

In this study, a logistic regression analysis is used (BMDP). It is a modelling technique which is appropriate for predicting to a dichotomous outcome variable using categorical or continuous variables. In this analysis, it is a means of predicting from selected symptoms (X1, X2, X3, etc.), to whether each particular case is suffering from the post-viral fatigue syndrome or a major depressive disorder. The predicted outcome (Y), is expressed as a probability, or likelihood of an individual case being identified as suffering from the post-viral fatigue syndrome. The values of Y range from 0 to 1, with Y=1 representing a case of post-viral fatigue, and Y=0 a case not suffering from the post-viral fatigue syndrome and therefore suffering from a major depressive disorder.

Logit 
$$p = \log (P / 1-P)$$

represents the conditional probability (P) of being a case of post-viral fatigue where Y=1, and the probability (1-P) of being a case of depression where Y=0. This is the log of the odds-ratio which can be extracted from the simple 2 x 2 contingency table:

#### SYMPTOM

#### Present Absent

Log of odds =  $\log (a/c) - \log (b/d)$ ,

where (a/c) is the odds of being of a particular outcome where a symptom is present, and (b/d) where the symptom is absent. The logit is the log of the odds that an individual falls into one response category rather than the other, and has a range of (-infinity, infinity) corresponding to the range (0, 1) of a probability.

The purpose of the analysis is to assess the extent to which the X variables (symptoms) predict the correct disorder. Logit p is explained by means of a regression equation combining coefficients for the X variables (b1, b2, etc.) and a constant (a), where

Logit p = a + b1 X1 + b2 X2 ... etc.

The combined parameter estimates provide the value to which base "e" will be raised in order to compute a predicted logit. So,

exp (a+b1X1+b2X2...) = (P / 1-P)

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The task of the analysis is to select a model which predicts well the observed data values.

However, selecting a model involves a trade-off between a well fitting model and one which by its simplicity makes sense. More complex models which utilise a larger number of parameters will fit the data better than simple models where only a few discriminating variables are considered. In the present study, there are 42 PAS symptoms and only 40 cases. Sweeping through possible models using all 42 is not an acceptable procedure, as the ratio of variables to cases is much too high.

In order to arrive at the model specified in this study, only a small number of symptoms whose frequencies differed most significantly between the post-viral and the depressed samples were considered. For the first step in the model selection, symptoms for which there was a significant group difference in the reported frequencies (at a significance level of p<0.01), were selected from the frequency table (Table 6). Self-depreciation, anxious foreboding and guilty ideas of reference were reported significantly more frequently in the depressed-treatment group. Hypersomnia was reported significantly more frequently in the post-viral group at the 0.01 level of significance, and from the fatigue items (from the Bech-Rafaelson depression scale), peripheral fatigue was selected, as it was also more frequently in the post-viral group at the reported 0.01 significance level. One further discriminating symptom, observed slowness, was selected because it was reported more often in the post-viral group, this time at the 0.05 significance level. This gave 6 symptoms and 40 cases.

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The six symptoms were entered into a step-wise logistic regression analysis. Self-depreciation, hypersomnia, peripheral fatigue and guilty ideas of reference were entered into the model but then removed since they did not satisfy the requirements of the analysis (p value must be less than 0.10 for entry into the model). Anxious foreboding made the most significant contribution to the model with a reduction in chi-squares of 11.0 (df1, p=0.00). Observed slowness, with a reduction in chi-square of 5.0 (df1, p=0.02) also remained in the model. With only two remaining parameters in this model the overall improvement in chi-square, from the model defined by the null hypothesis (that is, where no variables are added as predictors), is 15.9 (df2, p<.001).

Secondly, an attempt to improve on this model involved running an analysis using those remaining psychiatric symptoms which were reported significantly differently between the depressed and the post-viral group at the 0.05 level of significance. The intention of this analysis was the selection of another parameter which proved to be a good predictor of disorder. Depressed mood, worrying, pathological guilt, early morning waking and anxiety meeting people were all reported more frequently in the depression group as opposed to the post-viral sample. These five symptoms were entered into a stepwise logistic regression analysis. Pathological guilt was the only symptom which met the requirements for entry into the model. When entered into the previous model which already included symptoms of anxious foreboding and observed slowness, the reduction in the chi-statistic was 4.53 (dfl, p=0.01). Finally, these three symptoms: anxious foreboding, observed slowness and pathological guilt, made up the model for the final run. The coefficients for the parameters and the constant with their standard errors are presented in Table 12. The coefficient / standard error ratio is treated as a t statistic and the significance values correspond to the critical values judged at the respective degrees of freedom.

Expressions of anxious foreboding, pathological guilt and an observation of slowness and retardation provide a means of predicting whether a subject is suffering from major depression or from the post-viral fatigue syndrome. They are the symptoms which appear to be the best at discriminating between the two groups.

Table 13 presents a summary description of the predictions of the logistic regression on the basis of the reported presence or absence of the three symptoms. For each combination of the X variables (symptoms), the observed numbers in the post-viral group (Number Y=1), the observed number in the depressed group (Number Y=0), the number of cases of post-viral fatigue as a probability (Observed Probability Y=1), the predicted probabilities of post-viral cases (Predicted Probability Y=1), with their standard deviations and the predicted log odds are presented. The comparison of the observed probabilities and the predicted probabilities gives some indication of the predictive power of this 3-parameter model.

To illustrate a case and the predictive powers of the parameter estimates in correctly diagnosing the post-viral fatigue syndrome, the first line of Table 13 will be taken as an example. The individual

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#### Table 12

### LOGISTIC REGRESSION ANALYSIS: COEFFICIENTS OF 3 PARAMETER MODEL

	Coefficient	Standard error	Coefficient S.E.	df
Anxious foreboding	-1.25	0.4	-2.8	(12) *
Pathological guilt		0.4	-2.0	(14) *
Observed slowness	0.84	0.4	2.1	(16) *
CONSTANT	-0.47	0.5	-1.0	(17)

\*\* p<0.01 \* p<0.025

## Table 13

#### LOGISTIC REGRESSION ANALYSIS: PREDICTORS OF 3 PARAMETER MODEL

X1	X2	Х3	Number Y=1	Number Y=0	Obs.Prob Y=1	Pred.prob Y=1		Predicted log odds
						· · · · · · ·		
1	1	0	0	7	0.00	0.03	-0.57	-3.44
1	1	1	0	2	0.00	0.15	-0.68	-1.77
0	1	0	1	3	0.25	0.28	-0.19	-0.95
1	0	0	1	2	0.33	0.16	1.03	-1.66
1	0	1	2	2	0.50	0.50	-0.02	0.01
0	0	0	4	2	0.67	0.69	-0.31	0.84
0	1	1	4	1	0.80	0.67	1.07	0.72
0	0	1	8	1	0.89	0.92	-0.56	2.51
			I					

X1 = anxious foreboding

X2 = pathological guilt

X3 = observed slowness

presents with the symptoms of anxious foreboding (X1) and pathological guilt (X2), but observed slowness (X3) is not reported. Predicted Y is the predicted probability of having post-viral fatigue syndrome. The parameter values taken from the table of coefficients (Table 12) are entered into the regression analysis providing the following equation:

Predicted 
$$Y = -0.47 + (-1.25) + (-0.89) - (0.84) = -3.45$$

constant	symptom X1	symptom X2	symptom X3	log
	is present	is present	is absent	odds

The log odds vaue of -3.45 (corresponding to the -3.44 in the table, the small difference accounted for by rounding), representing the power to which base "e" can be raised, is translated into a predicted probability. Thus,

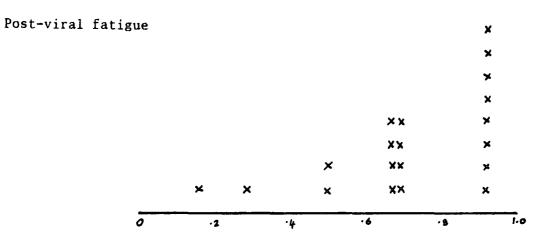
$$exp(-3.45) = 0.03$$

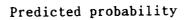
which means that an individual presenting with these symptoms would have only a 3 in a 100 chance of being a case of post-viral fatigue. Therefore, according to this model, such a case would be predicted to fall into the depressed group.

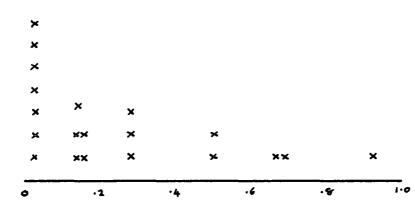
The predicted probabilities of being a case of post-viral fatigue are presented in Figure 7 for the actual post-viral subjects and the depressed subjects independently. The model is perhaps as adequate as any might be considering the nature of the two syndromal disorders. Eight of the post-viral subjects are predicted into the correct group

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## PREDICTED PROBABILITIES OF IDENTIFYING CASES OF POST-VIRAL FATIGUE







Predicted probability

,

## Major Depression

with a confidence level of 92 % and 16 are predicted as suffering from the post-viral syndrome with at least 67 % certainty. Of the depressed subjects, 12 are predicted to have under 2 chances in a hundred of being cases of post-viral fatigue. There is some overlap in the predictions but considering the vast similarity of presenting psychiatric and somatic symptoms in the two disorders the model does surprisingly well.

The above analysis is illustrative of one possible model which could be used to distinguish between depressive and post-viral fatigue diagnoses on the basis of presenting psychiatric symptoms. Ιt presents a model in which only 3 symptoms can successfully predict disorder with a high degree of confidence. The greatest certainty of a diagnosis of post-viral fatigue syndrome as opposed to a presenting depressive equivalent is where a patient presents with observed slowness of movement but with no signs of anxious foreboding (a fear of starting the day because of a feeling that some disaster is going to happen), or pathological guilt (an exaggerated sense of self-blame which is unpleasant, beyond voluntary control and out of proportion to the situation). A presentation of these two latter symptoms within a psychiatric profile is highly suggestive of a depressive disorder. Other symptoms, self-depreciation, hypersomnia, peripheral fatigue or guilty ideas of reference did not successfully discriminate between the two groups.

In many ways, it has been shown that the mental state of the post-viral fatigue syndrome sufferers resembles that of the depressed patients. There are similarities in the frequency ratings of symptoms, the prevalence of life-time disorder and of diagnostic

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classification derived from the CATEGO analyses. The logistic regression model discussed in this section has demonstrated major discriminating characteristics between the two disorders. Whilst the post-viral fatigue syndrome cannot be unambiguously regarded as a depressive-variant, it is clear that in many ways the presenting affective symptoms are related. The predicted probabilities in Figure 7 show some degree of overlap in which patients cannot be clearly distinguished on the basis of presenting symptoms. This is perhaps indicative of the diagnostic difficulties encountered at first presentation of the disorder.

Finally, one proviso which should be applied to these findings, in common with the findings from all discriminant analyses, is that the model which has been selected best fits the data from which it is derived, thus matching any sample idiosyncrasies. In order to attest to the potential discriminant power of this model, it must be replicated using new data sets.

## 3.8 <u>Towards a further understanding of the psychological problems in</u> the post-viral fatigue syndrome

(a) Reactivity: the measurement of anhedonia

The Pleasure Scale (Clark et al. 1983) tries to measure degree of reactivity to situational events. Largely unreactive responses to imagined situations of fulfilled family and sexual relationships, self-achievement, fortuitous and relaxing events suggests an anhedonic condition characterised by an inability to experience pleasure irrespective of the situation. Anhedonic depression is a sub-type of major depression occurring at the extreme end of depressive severity, and associated with disorder which is least likely to be triggered by stressful life-events (Clark et al. 1983; 1985). The symptoms of depression in sufferers of arthritis are hypothesised to be a reactive component to disability, and to the daily discomfort and to despairing thoughts about an uncertain future. There is no suspected CNS involvement. As a reactive depression it is not expected to be particularly anhedonic, but to retain pleasure responsiveness (Wells et al. 1988). Similarly, if the superimposed mood disorder among sufferers of the post-viral fatigue syndrome is a reactive depression, the responses on the Pleasure scale would be expected to approximate those of the arthritis sufferers.

There was a significant overall group difference in the Pleasure scores (Kruskal-Wallis H=20.7, df2, p<0.0001). The post-viral group responded to the items with significantly higher anticipated pleasure than reported by the depressed group (Mann-Whitney U=45, df1. p<0.0001). Their reported pleasure score was also significantly higher than that of the arthritis subjects (U=114, df1, p<0.05). А median score of 136 (SIR 144 - 133), compared to a median of 127 (SIR 140 - 123) in the arthritis group and a median of 90 (SIR 116 - 54) in the depressed group, is difficult to reconcile with the reports of 40 % of post-viral subjects in the PAS interview that they had largely lost interest in activities which they had found pleasurable in the past. The responses of the subjects suggest that the loss of interest corresponds to an unwillingness to engage in previously pursued activities because of the debilitating fatigue and deterioration in general health they would induce. The subjects often described this loss of interest as being unable to bother with such things and that

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they seemed no longer worth it. The loss of interest therefore reflected the expected consequences of task involvement. This cautiousness was evident in the majority of the post-viral subjects.

The Pleasure scale enabled subjects to reflect upon the possibility that the 36 imagined situations could take place regardless of their actual likelihood. For the post-viral and the arthritis sufferers the task was understood in terms of imagining themselves free from the physical restrictions of their conditions. Whilst the enjoyment of one's children and the intimacy of a close relationship were currently meaningful to these subjects, many of the situations were not. It was apparent that the life-styles of many of the post-viral and arthritis sufferers excluded the possibilities of these situations occurring. Tasks involving physical or mental exertion were not possible. These tasks were often referred to as those which would be expected to give the most pleasure if they were possible. The way in which a pervasive depressive and anhedonic mood could interfere with the imagining of pleasurable situations was apparent in the depressed group; some of the subjects were unable to imagine the stated situations giving them any pleasure, judging the task in itself to be tedious and meaningless.

The situations which were rated as the most pleasurable in all of the subjects involved witnessing the success and happiness of one's children (item 8), being loved by one's spouse (item 9), experiencing the achievement of successfully completing a task (item 23) or mastering a new skill (item 10) and discovering an unexpected financial gain (item 12). These items were rated as giving at least moderate pleasure in all three of the groups. Relaxation in peaceful

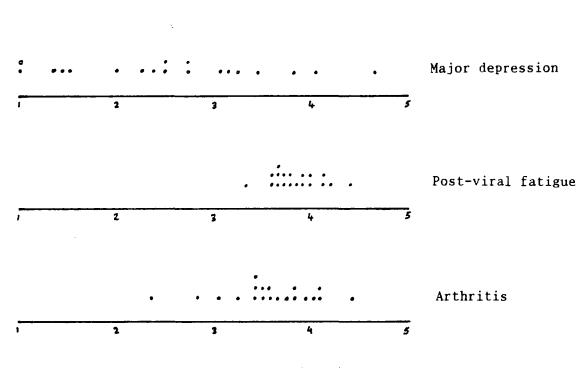
surroundings (item 4) was highly rated by the post-viral and arthritis subjects but not the depressed group. Additional items reported as giving the most pleasure in the post-viral group involved the expected pleasure from physical exertion (item 28: travelling and item 18: skillfully flying an aeroplane), whereas those additional items reported as giving the most pleasure in the arthritis group, (item 20: a quiet walk along the seashore, and item 1: watching a sunset) did not. The indication is that the arthritis subjects are better in tune with their capabilities, as they will perhaps never recover to this extent, whereas the post-viral subjects still perhaps place much hope upon ambitiously active ways of life.

Correlations were calculated between the pleasure scores and the indicators of psychiatric severity: the total PAS score, the HAD depression score and the HAD anxiety score. The distribution of pleasure scores are plotted by subject group (Figure 8). Seven of the depressed subjects and one arthritis subject had mean pleasure scores which were at least one standard deviation below the pooled mean score from all of the subjects. The arthritis subject was a young mother with a high anxiety rating of 12 who was currently receiving treatment for depression.

It was only in the depressed group that the pleasure scores were associated with psychiatric severity, correlating negatively with the PAS score (rho=-.41, p<0.05), and the HADS rating of depression (rho=-.61, p<0.005). There was also an association between the pleasure score and the rating of hopelessness rho=-.55, p<0.01). The correlations between anhedonia and psychiatric severity were not statistically significant in the post-viral and the arthritis groups.

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Figure 8



THE ASSESSMENT OF PLEASURE REACTIVITY (Pleasure Scale)

Individual pleasure scores (mean)

The seven anhedonic depressed subjects were compared to those depressed subjects who showed a normal response on the Pleasure Scale. Psychiatric symptom severity was only marginally higher in the anhedonic subjects, reaching borderline significance (U=35, dfl, p<0.1). There were very small, non-significant differences on the HAD measures of depression and anxiety. There was no difference between the groups on the duration of illness or in the age of the patients.

The ease with which the post-viral fatigue sufferers appeared to achieve separation from their current distress and the fetters of their illness, and their clear sense of enjoyment in the completion of the task suggests that their feelings of dysphoria are not pervasive. The post-viral subjects often commented that their depression was closely tied to the vagaries of the illness and that it expressed the utter frustration and despair which they experienced because of the restrictions to their lives. There was no close identification with feelings of depression in most cases. Those receiving psychiatric treatment for a major depression were often unable to disengage from their current state to enable them to complete the task, and often could not imagine themselves free from their depressive predicament.

#### (b) Outlook: the measurement of hopelessness

Hopelessness is a major cognitive component of a depressive illness. However, in the case of a chronic medical condition, a lack of hope about a healthy future and a feeling that nothing can be done to personally improve one's plight may in fact be a realistic interpretation of a personal situation. Clark, in his latent trait study with medically ill subjects, found that hopelessness was a symptom that discriminated poorly between depressed and non-depressed medical patients (Clark et al. 1983); but suicidal thoughts, which are closely related to expressions of hopelessness, discriminated between them well.

This investigation is aimed at clarifying the relationship between hopelessness and psychiatric disorder in the physically ill. Feeling that the future can offer no happiness, that there is nothing within a person's control to determine that future, and a consequential feeling of wanting to give up trying indicates an inadequate coping response to illness, and such an outlook could be improved with basic cognitive therapeutic work. Forty percent of the post-viral group had reported that their futures seemed bleak and hopeless on the Psychiatric Assessment Schedule (PAS). This was only marginally less than those reporting feelings of hopelessness in the depressed group. The Hopelessness Scale permits the subjects to reflect more upon this negative perception of the future.

The three groups were compared on their reactions to 20 statements designed to pick up expressions of hopelessness. A significant between group difference in the total hopelessness score was detected (Kruskal-Wallis H=18.8, df2, p<0.0001). The post-viral subjects gave responses depicting hopelessness for a median of 3 of the 20 items (SIR 7 - 1), which represents a significantly less hopeless outlook in comparison to the depressed-treatment group (U=87.5, df1, p<0.005). The depressed group reported a median score of 11 hopelessness items (SIR 14.5 - 8). There was no significant difference in the recording of hopelessness between the post-viral and the arthritis subjects

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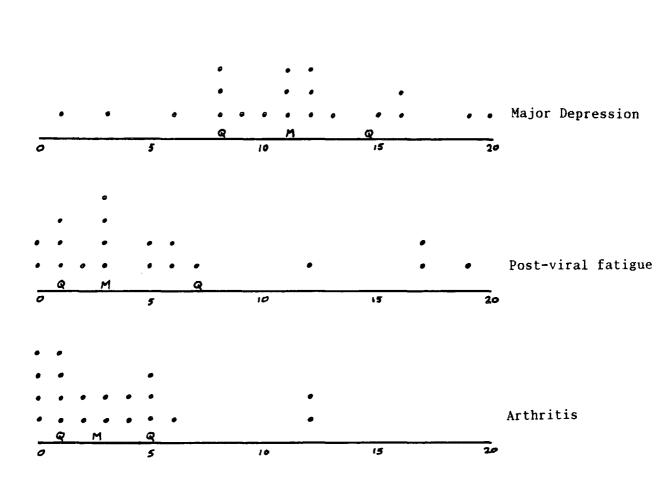
(U=142, df1, p=0.18). Both describe surprisingly positive future outlooks, with four of the arthritis subjects and two of the post-viral group scoring 0 on the hopelessness scale (Figure 9).

The individual items were assessed firstly for their contributions to the total score of hopelessness. In line with the testing of internal scale consistency in item-analysis, the items were tested against the median-split total hopelessness score. The phi-statistic is reported. The items with the highest phi-statistic are those items which, when rated negatively, correspond the most to an overall hopeless outlook. A phi-statistic of 0.5 or over was taken as an indication that the item was highly associated with such an outlook. It was expected that the medically ill groups would rate different items as expressions of hopelessness and that whilst some responses could be understood in the light of their physical condition they would not always correspond to a pervasive sense of hopelessness about the future and sense of futility about one's present plight.

Secondly, each hopelessness item was correlated with a measure of psychiatric severity. The total symptom severity score from the PAS was used. Spearman correlation coefficients were calculated for the item-criterion correlations for each of the groups. Those items which are strongly associated with the independent rating of psychiatric severity are judged to be expressions which reflect a depressive outlook.

There were four items on the hopelessness scale which made a significant contribution to the total score in the depressed group but which did not reflect a general feeling of hopelessness in either the

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# THE ASSESSMENT OF HOPELESSNESS (BECK'S HOPELESSNESS SCALE)

Individual hopelessness scores (sum of items)

M = median
Q = quartiles

post-viral or the arthritis subjects. These four items correspond to Beck's underlying factor, "Loss of Motivation" (Beck et al. 1974). The feeling of wanting to give up and of not expecting to get anything from life because of an inability to make things better for oneself (items 2 & 16), a feeling that there is only unpleasantness and little satisfaction in store in the future (items 11 & 17), are expressed in between 10 and 20 % of the post-viral subjects, but such expressions of loss of motivation do not reflect an overall feeling of hopelessness. Of those items contributing little to the overall feelings of hopelessness in the post-viral and arthritis groups, it is the motivational items which are most frequently presented (items 2, 3, 11, 16, 17, 20). Thus, the medically ill may experience a loss of motivation without an all pervading sense of hopelessness. The realisation that there is little they can do to affect their futures in terms of real satisfaction, and the underlying feeling that things can get worse than they are currently may be in line with a realistic response to ill health.

Items corresponding more closely to the overall score in the post-viral group fit in with Beck's factor focusing on "Feelings about the Future". These items revolve around negative responses to affectively toned associations such as hope and enthusiasm (item 1), future success (item 6), and faith in a future which will bring more good times than bad ones (items 15 & 19). One item with a significant contribution to an overall hopeless outlook in the post-viral group is a feeling that the future is dark (item 7). This relects Beck's cognitive factor, "Future Expectations". Two further items associated with hopelessness correspond more closely with the type of outlook encountered in the depressed-treatment group. These reflect thoughts

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centred around a loss of motivation, not expecting to get what you really want (item 12) and feeling fatalistic about expectations of breaks from misery in the future (item 9).

The item correlations with psychiatric symptom severity fell between .04 and .64 (Spearman rank) in the post-viral group. The items which were most closely associated with psychiatric severity concerned feelings of a dark future (item 7), where there was no reason to believe there would be any breaks from the misery (item 9). Seven items correlating with the severity score between .45 and .60 reflect a general loss of motivation. It was the affective aspects of feelings about the future which were most closely related to psychiatric severity in the arthritis and depressed groups, correlating between .41 and .78 in the depressed group, and between .40 and .62 in the arthritis group.

Using the pooled cases from all three of the groups and the HADS to identify cases or non-cases on the basis of ratings on either or both of the depression and anxiety subscales (a threshold of 9 was taken), the close relationship between hopelessness and psychiatric disorder was demonstrated. With 32 identified cases and 27 non-cases overall, there was a significant difference in the total hopelessness scores (U=93, df1, p<0.0001). The psychiatric cases recorded a median of 11 hopelessness items (SIR 14.5 - 5.25), and the non-cases a median of 2 (SIR 5 - 1). There were 17 recorded cases overall who had expressed no thoughts of dying in the past month and 16 who had. Of those non-cases, only 1 had had thoughts of dying. The difference is statistically different (chi-square=12.5, df1, p<0.001). Eleven of the cases had actually considered or attempted suicide, and 22 had

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None of the non-cases had made a suicide plan or attempt in the not. past month (Chi-square=8.9, df1, p<0.005). Suicidal ideation was recoded on a 4 point scale, with 1=no serious thoughts of suicide; 2=deliberately considered but no attempt made; 3=suicidal attempt but not designed to end in death; 4=suicidal attempt seriously considered to end life. Suicidal ideation was found to correlate significantly with the hopelessness score (rho=.56, p<0.001). Whilst those in the post-viral group who had contemplated suicide had higher hopelessness scores than those subjects who had not, the differences in hopelessness only reached borderline statistical significance (U=9, df1, p=0.1). The relationship in the depressed group was more clear cut (U=5.5, df1, p<0.005). The results suggest than in spite of a few quite significant ratings on the hopelessness scale the post-viral and the arthritis groups were less at risk for suicide.

Many of the post-viral fatigue subjects experienced difficulty completing the Hopelessness Scale. Many expressed an inability to think about the future in a condition which forced them to live one day at a time, and sometimes hour by hour. The biggest frustration which was continually mentioned was the frustration of being unable to make plans and provisions for a future, even from one day to the next. Secondly, the mental confusion and concentration difficulties frequently seemed to interfere with the understanding of the items. The greatest difficulty was encountered with the "true / false" responses to the negatively worded statements.

## 3.9 Somatic symptoms: the assessment of fatigue and activity levels

The assessment of motor retardation (facial expression, gestures,

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bodily movement and gait), verbal retardation (verbal output, conversational inertia and pausing), intellectual retardation (concentration and memory, conversational engagement) and tiredness and pains (peripheral muscular fatigue and diffuse pains) are based upon observations rated on criteria taken from the Bech-Rafaelson Depression Scale (Bech, 1986). The assessment concerns the extent to which the symptoms have influenced or interfered with the interview. They are coded at the end of the meeting.

The retardation and fatigue items were correlated with a number of psychiatric measures: the self-reported ratings of depression and anxiety from the HADS, the total severity score and the broken down somatic and non-somatic subscale severity scores of the PAS. The items were also correlated with age, duration of illness and a measure of activity (Activity Schedule).

#### Motor Retardation

The ratings of motor retardation were not significantly different between groups (Kruskal-Wallis H=2.5, df2, p=0.29). The post-viral syndrome is characterised by subjective reports of fatigue and anergia on the PAS (95 % of the subjects in this study), and the current rating of the retardation of motor activity demonstrates that this subjective feeling is backed up by observational measures. Five of the post-viral subjects displayed clear retardation in their reduced gestures and slow pace, and 12 subjects appeared to be retarded in all of their movements. Motor retardation was evident among those subjects receiving treatment for major depression, although the trend was towards higher ratings in the post-viral group. The arthritis

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subjects produced almost identical ratings to the post-viral group.

For the post-viral sufferers, the extent to which motor activity was retarded was related to the severity of HADS depression (rho=.47, p<0.05), HADS anxiety (rho=.37, p<0.05) and the psychiatric severity rating from the PAS (rho=.55, p<0.01). The severity rating is made up of somatic or bodily symptoms and non-somatic or cognitive symptoms and the correlation is significant for both of these (rho=.39, p<0.05) and rho=.49, p<0.01 respectively).

It is of some interest that there were no significant correlations between this item and the psychiatric measures in either the arthritis or the depression groups. The implication is that in the arthritic disorders a degree of motor retardation will occur irrespective of psychiatric disorder and this is essentially symptomatic of the physical changes in the condition. The correlation demonstrates a positive relationship with age (rho=.43, p<0.05). However, because of the very low psychiatric ratings in this group there was little opportunity for any relationship with psychiatric severity to emerge. The explanation in the depressed group is in line with Clark's latent trait study which demonstrated the relatively low discriminatory power of fatigue. In his study fatigue and retardation tend to occur at medium levels of severity of depression (Clark et al 1985). In the group studied here, the subjects all had fairly severe psychiatric disorders, obscuring the increase in retardative severity with increasingly severe disorder. The results however do indicate a clear relationship between retardation and psychiatric symptoms in the post-viral fatigue syndrome. The subjects appear to display similar degrees of motor retardation to the subjects in the depression group of subjects, albeit at lower degree of psychiatric severity.

#### Verbal Retardation

A significant between group difference was demonstrated for the assessment of verbal retardation (slow speech) during the course of the interview (Kruskal-Wallis H=2.5, df2, p<0.001). The post-viral group demonstrated more pronounced verbal retardation in comparison to the arthritis subjects (U=78, df1, p<0.001). Eight of the post-viral subjects were rated as displaying pronounced retardation in speech, and 3 to such an extent so as to prolong the interview. In one subject the verbal retardation resulted in marked difficulties in completing the interview. Only 3 of the arthritis subjects showed a degree of verbal retardation and in none of these cases was the interview unduly affected. There was no significant difference in the ratings of verbal retardation between the depressed and the post-viral groups (U=175, df1, p<0.67).

The majority of the arthritis group showed no verbal retardation but for the group as a whole, a clear association was found with the rating of depression (rho=.39, p<0.05). For the post-viral subjects verbal retardation was not clearly associated with depression or anxiety but the item correlated positively with the psychiatric severity rating of the PAS (rho=.38, p<0.05). This was largely explained by the somatic and physical-symptom components of this scale and less so by the non-somatic symptoms. Verbal retardation was varied in the depressed subjects but was not clearly connected to the severity of the psychiatric disorder on the HAD or PAS scales. There was no relationships between verbal retardation and age, duration of illness or a measure of activity.

#### Intellectual Retardation

A significant between group difference was demonstrated on the measure of memory, concentration and decision-making difficulties (H=23.7, df2, p<0.0001). The arthritis and post-viral groups are rated differently with more intellectual difficulties evident in the post-viral group (U=19.5, df1, p<0.0001). Whilst 18 of the arthritis subjects show no or doubtful difficulties with concentration or memory, 19 of the post-viral subjects are rated at least 2 on the scale. Eleven of these subjects experienced pronounced mental difficulties and 3 to such an extent so as to influence their performance during the interview. The post-viral group displayed and reported memory and concentration difficulties to the same degree as those subjects suffering from major depression. In fact, whilst in the depressed group 5 of the subjects experienced no or doubtful problems, all but one of the post-viral group were affected intellectually to some significant degree. The differences between these two groups did not however reach statistical significance (U=152.5, df1, p<0.3).

For the depressed subjects intellectual retardation of the type measured in this study was closely associated with psychiatric severity with high and significant correlations with the HADS depression (rho=.71, p<0.001), HADS anxiety (rho=.44, p<0.05), and the PAS symptom severity (rho=.58, p<0.005), particularly so for the non-somatic ratings of this scale (rho=.62, p<0.005). The same association was found among the arthritis subjects with the HAD depression scale (rho=.64, p<0.001) and the PAS severity scale

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(rho=.42, p<0.05), in spite of the small numbers with significant psychiatric symptomatology.

No such relationship was found for the ratings in the post-viral group (for HAD depression, rho=.13, p=.29; for HAD anxiety, rho=-.06, p=.41; for PAS, rho=.24, p=.15). It appears that whilst the post-viral group experience retardation of intellectual abilities to a similar extent to those subjects with major depression, here the difficulties are not correlated with psychiatric difficulties.

For the post-viral subjects intellectual retardation tended to become more severe with increases in age (rho=.37, p<0.05), perhaps more so than would be generally expected, since there is no association with age in the other two groups. In the arthritis group, a strong and negative association between intellectual retardation and a measure of activity (assessed on the basis of an account of the day before the interview) was found (rho=.73, p<0.001). This is difficult to explain and could have resulted from idiosyncrasies in this sample of data, but the indication is that arthritis sufferers with memory and concentration difficulties are less active (and perhaps less mobile) than those whose mental capabilities remain unaffected.

#### Peripheral tiredness and muscular pain

The groups were significantly different from one another on their reports of this item (Kruskal-Wallis H=18.2, df2, p<0.0001).

The post-viral subjects experienced peripheral tiredness and muscular pain significantly more often than the depressed subjects (U=51, df1,

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p<0.0001). The depressed subjects did not experience such peripheral tiredness in spite of their reports of a general sense of tiredness and exhaustion (80 % of subjects on the PAS interview). In the depressed group there were 8 subjects who did not suffer from such peripheral fatigue to any noticeable extent. In the post-viral group 6 reported degrees of peripheral fatigue and pain which caused occasional daily interference and 14 reported that this symptom caused severe distress and markedly affecting their day to day functioning. The peripheral fatigue and pain experienced among the arthritis sufferers was considerable, 5 without interference of functioning, 8 with occasional interference and 7 with daily and continual disruption. However, the ratings are marginally less than those in the post-viral group (U=115, df1, p<0.05).

In the arthritis group, peripheral tiredness and muscular pain was associated with severity ratings of depression (rho=.53, p<0.01) and overall psychiatric severity (rho=.53, p<0.01). The correlation with overall severity was accounted for mainly by the somatic symptom Whilst it appears that mood disorder can accentuate the component. subjective report of muscular tiredness and pain in this group, the relationship was not found in the post-viral or in the same depressed-treatment group. A measure of the extent to which pain and muscular fatigue had affected daily functioning is closely and negatively associated with the activity level of the post-viral subjects (rho=-.57, p<0.005). It is this measure of peripheral tiredness and discomfort which appears to be most restrictive to daily The same negative relationship with the level of functioning. activity from the previous day was found in the arthritis group (rho=-.37, p<0.5).

#### The measurement of activity levels

The Activity Schedule is the self-reported account of the previous day's activities coded on 5 activity categories, graded 1 to 5. Each successive category requires more energy and increasingly sustained effort. Inability to sustain activity in these successively graded categories points to the restricting nature of the underlying fatigue. The analysis below will incorporate a total activity score of the amount of time spent in the graded activities for a 24 hour period on the day before the interview. Additionally, the individual time periods in minutes will be presented.

The total activity score is significantly different between the three groups (Kruskal-Wallis H=13, df2, p<0.001). The arthritis group was the most active on the previous day, with a mean total activity score of 38. The depressed group were marginally less active, with a mean total activity score of 33, and the post-viral group with a mean score of 19. The post-viral subjects spent their time in significantly less active behavioural categories than the arthritis subjects (Mann-Whitney U=72, df1, p<0.001). The difference between activity scores in the post-viral and depressed groups is not as large but still significantly different with the post-viral subjects leading less active life-styles (U=99, df1, p<0.01).</pre>

Sleeping patterns are known to be affected in the post-viral syndrome, with reports of reduced sleep in some and hypersomnia in others (Behan & Behan, 1988). The pain resulting from remaining for too long in one position is one contributory factor to the sleeping problems of

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arthritis sufferers. The individual may experience a disturbed night with middle insomnia and early morning waking. Reduced sleep is also common in the major depressive disorders. Delayed initial sleep and early morning waking have been used as identifying markers of different depressive subtypes (Kiloh & Garside, 1976).

There was no significant group difference in the reported amount of time spent asleep on the previous day (H=3.1, df2, p=0.2), but the median scores indicate a slight increase in sleeping time in the post-viral group, 480 minutes (SIR 516 - 315), with a median of 397 minutes (SIR 450 - 335) in the depressed group and 360 minutes (SIR 460 - 240) in the arthritis group. The accounts indicate that the post-viral group are more likely to have increasingly delayed sleep. This is in line with the hypotheses of the reversal of sleeping They report a median of 75 minutes before sleep (SIR 116 cycles. 30). The arthritis group report a median delay of 30 minutes (SIR 98 - 15), and the depressed group a median delay of 30 minutes (SIR 75 -15). The group difference reaches only borderline significance (H=3.6, df2, p=0.1). There was no reported difference in the amount of time in which sleep was disturbed during the night (H=1.1, df2, p=0.6), but 12 of the post-viral group had awoken at least once during the night; 4 had woken at least four times. Disturbed sleep was also common among the arthritis subjects, 14 waking at least once. Only 8 of the depressed group had woken up during the night.

The post-viral subjects had spent a median of 138 minutes (364 - 56) in bed during their waking day. This represents a median of 14 % (SIR 31 - 6 %). A median of 10 % of the waking day was spent in bed in the depression group (SIR 16 - 4 %), and a median of 9 % (SIR 17 - 6 %)

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among the arthritis sufferers. Time spent resting was very small in all three of the groups inspite of the recommendations from medical practitioners and the M.E. Association that rest, relaxation and avoidance of "stress" must be the mainstay of any therapeutic strategy.

The majority of the waking day was spent in the home: A median of 34 % of the waking day in the post-viral subjects (SIR 48 - 32 %), 43 % of the waking day in the arthritis subjects (SIR 50 - 35 %) and 51 % in the depressed group (SIR 58 - 38 %). The largest group difference in time allocations in the activity categories was the amount of time spent out of the house by the subjects (H=6.5, df2, p<0.05). The post-viral group with a median of 78 minutes spent out of the home for the 24 hour period (SIR 303 - 0) and the depressed group with a median of 150 minutes spent out of the home (SIR 270 - 0) do not differ significantly from one another (U=171, df1, p=0.6). The post-viral subjects, however, spent significantly less time out of the house than the arthritis subjects (U=115, dfl, p<0.01). The arthritis subjects had spent a median of 265 minutes out of their homes (SIR 480 - 180) and only 2 subjects had failed to leave their homes on the day before Eight of the post-viral group had been retricted to the interview. their homes because of fatigue and anergia. Many said that they were unable to leave their homes unaccompanied. Six of the depressed subjects had not left home or hospital on the day before the interview.

It is hoped that the reported activity of the subjects on the day before the interview reflect to some extent their normal life-styles, and the restricting nature of the fatigue, anergia and retardation.

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Lack of activity, especially in terms of reduced time spent out of the house and more time spent in less ambulatory behaviours was expected to be representative of many of the depressive conditions, in which anhedonia, situational anxiety and social withdrawal may play a contributory part over and above the effects of fatigue. Whilst the results indicate that the arthritis sufferers, in spite of their disabilities, lead more active lives than the depressed or the post-viral subjects, the indicators used here can reveal little about the different reasons for the levels of activity, and indeed, whether it is the fatique itself which has resulted in the reductions of activity. Additionally, as to the representative nature of the and more importantly to the accuracy of the preceding day self-reported accounts, there remains considerable doubt. However, it is apparent that all three groups experience to some large extent a limited way of life with restricted functioning. Only two subjects in the post-viral group, two of the arthritis subjects and three depressed subjects were currently in employment.

#### 3.10 Summary and discussion

Significant psychiatric morbidity was identified in the post-viral fatigue syndrome subjects during the course of their illness. Eleven subjects (55 %) achieved criteria for "caseness" on the basis of self-reported depression and anxiety, using a conservative measure which is designed for use in the physically ill (HADS). Over half of these reached a clinical threshold of severity on both depression and anxiety ratings, suggesting an increased prevalence of mixed "neurotic" disorders in this group. Psychiatric diagnoses according to ICD-9 (PAS-CATEGO), were allocated in 60 % of the post-viral group,

significantly higher than the frequency of classifiable psychiatric disorder in the arthritis condition, which was of a comparable disabling status. The diagnoses of the post-viral group conformed largely to a neurotic depression (with retarded, neurotic and simple depression and phobic neuroses), and did not substantially differ in type from the diagnoses given to the group of patients receiving psychiatric treatment for a major depressive episode.

The profile of psychiatric symptomatology in the post-viral fatigue syndrome was dominated by symptoms of tiredness, exhaustion, anergia, retardation and reduced motor activity, which is not surprising given that these are often cited as the cardinal features of the syndrome. Subjective ratings were made irrespective of a coexisting diagnosis of depressive disorder, but would be reported as increasingly intense alongside more severe depression. Of the observer ratings, observed slowness / underactivity and motor retardation were particularly the depressed post-viral subjects. characteristic of Observed slowness also proved to be a reliable predictor of the post-viral fatigue syndrome and succeeded in distinguishing between these subjects and those with a primary depressive disorder.

The results of this study have highlighted the qualitatively different type of fatigue expressed in the post-viral fatigue group in comparison to the group with a depressive disorder. Ratings of peripheral tiredness with painful muscles was reported by all of the post-viral subjects, but rarely in the depressed group. This symptom was not affected by depressive severity, but was reported to induce the most severe disruption to daily functioning and to cause the most distress to the post-viral subjects. Retardation of speech and

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cognitive functioning were common among the post-viral subjects, but unlike the psychiatric depressed group, they were not related to the concurrent psychiatric dysfunction.

The post-viral subjects were found to be the least active of all the subjects. They spent significantly more of their waking day in bed and significantly less time out of the house than the depressed or the arthritis sufferers. Many had reported that they felt unable to leave The arthritis sufferers led more active the house unaccompanied. lives than the post-viral sufferers, in spite of comparable degrees of disability. The post-viral sufferers had, on the whole, not endured their physical conditions for as long as the arthritis group. Either they had had less opportunity to adjust their life-styles to the limitations imposed by the condition, or their poorer psychological adjustment was contributing to their less active way of life. Alternatively, it is likely to be something about the nature of the post-viral condition which makes it differ from the experience of arthritic disorder. It was not common for the arthritis sufferers to report that they actively "felt ill". However, almost all of the post-viral subjects described a sense of anergia, lassitude and prostration such as is characteristic of an ongoing febrile condition. It was this sense of feeling constantly unwell which was found to be one of the most disabling features of the syndrome.

Observed agitation in movement and speech was a common presentation among the depressed psychiatric subjects. Retardation of movement would more often occur among those who were severely depressed. This is in line with the symptom-severity threshold levels found in Clark et al.'s (1983) latent trait studies. The observed slowness of gait,

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movement and facial expression was prominent in the post-viral fatigue group, rated significantly more often than in either of the other two samples. The significance of these differences suggests that a study rating videos of patient interviews blind may be of substantial value.

Concentration difficulties, subjective sleep problems and loss of libido are also common presenting features of the post-viral fatigue syndrome. However, unlike the major depressive disorders, symptoms of pathological guilt, self-depreciation and anxious-foreboding are relatively uncommon. A dysphoric mood is reported in only 50 % of the post-viral group whilst this was a dominant feature of major depression. Similarly, loss of interest was expressed by only 40 % of the post-viral subjects, and as the pleasure scale indicated, they are significantly less anhedonic than both the depressed and the arthritis Such reactivity to illness related and environmental subjects. circumstances supports further the hypothesis that the psychological symptomatology is largely indicative of despair and reactive disorder. Whilst the post-viral subjects often reported difficulties thinking about a future in a condition which enforced day by day living, very few reported the hopeless outlooks so often seen in the major depression group.

The estimated prevalence of past life-time psychiatric disorder (treated or untreated) was 80 % in this sample of post-viral fatigue syndrome sufferers; 12 overall were treated, 5 in an inpatient setting, and 4 untreated. Many of these episodes had occurred since the self-reported onset of the fatigue condition. It proved to be too difficult to distinguish pre-morbid and post-morbid onset of past psychiatric disorder, owing to often prolonged periods of diagnostic

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uncertainty and the difficulties of relying upon self-reported symptom onset. Because of the crude estimate of psychiatric disorder, it was also not possible to clarify that a disorder of clinical severity had occurred. This was perhaps clearer when a suicide attempt or psychiatric hospitalisation had been reported. However, many subjects were convinced that the psychiatric diagnoses they had been given were symptomatic of the initial problems of diagnosing a post-viral condition. Either they reflected the despair of not knowing what was wrong with them, whilst failing to get better, or they reflected the confusions of the medical profession, faced with a medley of symptoms which would not fall into any recognisable category of disorder. All too often, it seemed, the post-viral subjects were keen to explain all past episodes of illness or psychopathology in terms of the post-viral fatigue syndrome. Given the plethora of diagnostic investigations these subjects had received and the scepticism of many of the practitioners they had come into contact with, such a rejection of psychological interpretations for their illness or past episodes of distress, is not surprising.

In spite of such reservations, it seems probable that more of the post-viral subjects do report life-time psychiatric episodes than of the arthritis subjects (six treated episodes, including two hospital admissions, and three untreated episodes), and perhaps as many as reported in the depressed group (nine treated episodes, including seven hospital admissions, and three untreated episodes). A past episode of psychiatric disorder was associated with more severe current psychiatric symptoms in all three of the groups, but the relationship was weakest among the post-viral subjects, suggesting further differences between the depressive and the post-viral syndromes, and helping to disprove Taerk's (1987) psychiatric vulnerability hypothesis. A study which more systematically assesses the symptom profile and timing of the life-time episodes may throw some more light upon this controversy.

Finally, the logistic analysis successfully discriminated clinically depressed and post-viral subjects on the basis of psychiatric symptom profiles, with only a marginal degree of error in making the predictions. Eighty percent of the post-viral group were predicted into the correct diagnostic group with at least 67 % certainty. Sixty-five percent of the depressed group were predicted to have only two chances in a hundred of being cases of post-viral fatigue. The three parameter model derived from this analysis demonstrated that a patient presenting with an observed slowness of gait and movement, but without anxious foreboding or pathological guilt was most likely to be suffering from the post-viral fatigue syndrome, in spite of other similarities of presentation to a primary depressive illness.

Psychiatric features are indeed common to the post-viral fatigue syndrome and may in themselves be equally as disabling to the sufferer as the organic features, but there is evidence from this study to suggest that there are distinct differences in presentation such that the post-viral condition cannot be subsumed under a diagnosis of depressive disorder. Whilst there is much to suggest that the psychological presentation is a consequence of or reaction to chronic ill-health, it seems more than probable that there is a significant "endogenous" contribution to psychiatric morbidity. Viral contagion of the brain-stem and central nervous system, and the abnormal production of interferon released in response to viral infection, have

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been postulated as potential contributors to psychiatric morbidity. Future research only can provide the answers.

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Illness in the family: an investigation into the children of sick mothers

#### 4.1 Introduction

Illness of a physical or psychological nature occurs within the context of a unique microculture, the family system. As this chapter will illustrate, the onset of disorder in a person has repercussions for all members of a family and causes reverberations which spread well beyond the family sphere. The perspective of the family is increasingly being adopted in the investigation of psychological disorder or chronic physical illness. The study of family adversity resulting from illness has focussed upon the ensuing crisis and resulting disequilibrium in family functioning, and upon the burden experienced by other family members through caring for that person.

It is the nature of the family system, the pre-illness family relationships and problem-solving strategies which will determine how a particular family will respond to disorder. Many families will display extraordinary resilience, the illness serving to enhance the quality of relationships within the family, deepening feelings of empathy and understanding, whilst encouraging positive values such as sharing and caring (Orford, 1987). Such steeling effects of family adversity have been reported among carers of the dementing elderly (Gilhooly, 1987), parents of handicapped children (Pahl & Quine,

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1987), families where a member is depressed (Kuipers, 1987), or anorexic (Eiser, 1987), all explored in Orford's book.

There is, as yet, no well-validated or generally accepted taxonomy of family systems which can be utilised in the study of families beset with illness. Disorder is still largely described in individual terms even though it is understood to interact on a systems basis, altering relationships and patterns of interaction, which will have a reciprocal effect upon the course of the illness. Early studies have offered useful clinical impressions, although they are lacking in empirical support and they fail to provide a standardised means of describing families.

Koos (1946) describes the resulting family disequilibrium when one member becomes ill, most significantly when it is a parent who adopts the sick role. Other family members may suffer from disruption in the complementarity of roles within the family, changes in dominance patterns, and the changing strength and direction of feelings between members. Koos describes the withdrawal of the family from active contact with the outside world and changes in system functioning which may outlast the recovery and rehabilitation of the sick member.

Sturge (1978) has explored the role changes within the families of parents with psychiatric illnesses, and the "parentification" of children who have been forced to adopt the role of caretaker or supporter. Temporary and potentially adaptive role changes can become fixed, resulting in enduring and damaging changes in a child's personality and cognitive devlopment. Anthony (1970) talks of the "narcissistic invalidism" of other family members, often with

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increased hypocondriacal and psycho-somatic complaints and undue bodily preoccupation, in families where a member suffers from a physical or psychiatric condition.

Such disequilibrium and disturbance of family functioning has been described further in the family systems crisis theory of Moos and Tsu (1977). They describe how habitual restorative problem-solving mechanisms can fail to restore a family to psycho-social and physiological homeostasis. Such restorative mechanisms can fail for a number of reasons. Moos and Tsu cite the patient who fails to get better, and the patient with disorder which may not fall easily into the sick role because of its stigmatising or alienating nature. In assessing the family reaction to disorder, cognitive appraisal of the altered behaviour of the patient as signalling "illness" is crucial. Where changes are attributed to personality constructs, such as "laziness", or "intentional provocation", or where it is felt that there is secondary gain from the adoption of a sick role, the reaction of family members may be less than adaptive.

The most extensive area of research assessing the impact of mental and physical disorder, which has received considerable interest in the research literature because of its more systematic approach and the use of largely standardised measures of individual and family outcome, has been the study of children in those families where a parent becomes ill. The research discussed in this chapter thows light upon the impact of illness upon child and family adjustment, and upon specific role relationships and interactions between family members. It specifically assesses the impact of illness from the point of view of the child, for whom the family system assumes the utmost importance for cognitive, personality and social development.

#### 4.2 Family mechanisms in the transmission of depression

The work of Brown and Harris (1978) was seminal in demonstrating the high risk of depression among mothers with young children. They demonstrated that working class women with children living at home had a four-fold increased risk of developing depression than a comparable middle-class group. This class effect was restricted to women with children: single women with no children displayed very low prevalence rates regardless of social class. The risk for depression was found to be particularly great in urban areas. In a working class area of London, they found a 40 % risk of depression, as diagnosed by a psychiatrist, for women with children under the age of 6 years. A similar risk was reported by Richman et al. (1982), in a study of mothers of pre-schoolers in working class London.

Recent studies have given support to the hypothesis that past adversities in the lives of parents will exert recognisable effects in the present difficulties in parenting behaviour and the relations between a mother and her children. These effects have been shown to operate partly independently of a parental depression, but such that the association between maternal depression and behaviour problems in a child will be strongest in those mothers with histories of severe adversity in their own lives (Cox, Puckering, Pound & Mills, 1987).

In terms of their own experiences of parenting, the depressed mothers in the above study (Cox et al. 1987) were more likely than matched controls to report that their mothers had been "indifferent" or "poor

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parents", with less warmth and more punitive discipline shown to them. They were more likely to report prolonged periods of separation from parents, through death, desertion or turmoil, or significantly unhappy parental marriages. These mothers were also more likely to report more emotional difficulties during their own childhoods, with 38 % reporting that they had truanted regularly during adolescence (Cox et al. 1987).

The link between past adversity and present deprivation was also apparent. These mothers were living in poor housing conditions on low They tended to have married very young (82 % of the incomes. depressed group had married under the age of 21; 43 % of the controls had done so). They tended to have had their first child at a very early age (62 % of the depressed mothers were under 21 at the time of birth of their first child; only 19 % of the controls fell into this category). Current marriages were also more likely to be marked by constant quarrelling and conflict. Adversities of the past were seemingly repreating themselves. Adverse factors in the physical environment, maternal confidence and experience in parenting and current adversity in family life all appear to be linked with a risk for emotional and behavioural disturbance in the children of the current generation. Links with the past seem to be mediated through current maternal mental state.

# 4.3 Adversity transmitted through maternal mental state

It is well established that a depressive disorder in a parent, and especially the mother (Keller et al. 1986), can have a detrimental effect upon the children in a family. The risk has been seen to

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operate in terms of increasing the current symptomatology and behavioural problems of the child, in placing the child's social and cognitive development at risk, and in making the child more vulnerable to adversity later in life. Although maternal depression may lead to severe disorder in only a small proportion of children, it appears to be linked with impairment in a number of areas of functioning: physical and emotional complaints have been reported, behaviour and school problems, attentional and cognitive disturbances and interpersonal problems.

A recent comprehensive study of 125 children of depressed parents and 95 children from other families, aged between 6 and 23 years, identified a three-fold increased risk for psychopathology in a child whose mother was depressed (Weissman et al. 1987). The major diagnosis was childhood major depression (DSM-III), a life-time incidence rate of almost 40 %. There was also a considerably increased risk for alcohol and drug abuse, and multiple diagnoses, including trends towards increased conduct and anxiety problems. Diagnoses were based upon child psychiatric assessments from direct interviews with a parent and the child. Best-estimate diagnoses represented the sum of these two informant reports. The increased risk to these children was evident regardless of the informant and irrespective of the strictness of the diagnostic criteria.

No significant IQ differences were found (Wechsler Intelligence Scale-Revised and Peabody Picture Vocabulary Test-Revised), but the children of depressed parents were more likely to attend special classes for attention problems and teachers were more likely to rate these children as having learning problems (Weissman et al, 1987).

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The Children at Risk for Affective Disorders study (Keller et al. 1986), assessed 72 children from 37 families in which either the mother or the father suffered from a depressive illness (DSM-III). Sixty-five percent of the children, who were aged between 6 and 19, received at least one DSM-III life-time diagnosis; 46 % received two or more diagnoses. The most common disorder was major depression (24 %) and oppositional syndrome (18 %). Diagnoses were once again reached via a consensus rating by independent interviewers of the mother and the children. The current adaptive functioning of the child, assessed by means of child and parental reports on a number of inventories, was based upon the expected level of functioning according to the age of the child. It is the extent to which symptoms behavioural problems interfere with relationships, school or performance or family functioning which is of importance, and not the presence of the symptoms themselves. Eight percent of the children were judged to have serious disturbance problems in adjustment seen to be sufficient to require clinical help. A further 38 % were regarded as moderately to intermediately impaired in adjustment such that they were having difficulties facing the demands of growing-up. Such moderate difficulties include sub-clinical levels of disturbance.

Kashani et al. (1985) studied 50 children between 7 and 17 years of age, with a parental depressive illness. Fourteen percent met diagnostic criteria for a major depressive disorder (child report, DSM-III). Those children identified as depressed showed significantly more symptoms of attention-deficit disorder, oppositional disorder, mania, over-anxious disorder, phobia and bulimic eating problems. It also became apparent from parental interview that the depressed children were more likely to have been victims of abuse (where beatings had resulted in marking or bruising).

The following figures (Table 1), are taken from a study of 133 children of depressed parents receiving treatment at a psychiatric clinic, and 135 children from families taken from census tract data, socio-demographically matched to the patient group (Billings & Moos, 1983). The parents of the latter group were psychiatrically well. The ratings of child adjustment were taken from parent interviews on child health and functioning.

Thus, the children of depressed mothers were rated as having significantly more physical and psychological problems, including more depression and anxiety. Academic and discipline problems were noted at school, as well as problems of peer interaction. There was a tendency for more of the children of depressed parents to abuse alcohol and drugs.

Ratings of impairment have been taken from a non-standardised interview with a proband parent. There are obvious problems in using a depressed informant to report upon the impairment of their children, with risks of depressive cognitive bias and systematic negative distortion (Billings & Moos, 1982). However, spouses' assessments on aspects of the family environment did not differ substantially from the reports of the depressed parents. For a small sample of the proband families, ratings of child functioning were obtained from both parents. No evidence was found for more negative ratings in the depressed as opposed to the non-depressed spouses. Diagnoses of depression (DSM-III) assessed by a child psychiatrist from structured

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Table 1

# IMPAIRMENT IN THE CHILDEN OF DEPRESSED AND NORMAL PARENTS

	Depressed parent	Non-depressed parent	l
Child problems on parental report			
Academic problems	34.7 %	17.0 %	p<.01
School discipline problems	23.0	14.1	p<.05
Peer interaction problems	18.1	7.4	p<.01
Depression	49.2	32.3	p<.01
Anxiety	44.4	19.4	p<.01
Physical problems	17.8	12.2	p<.01

(Billings & Moos, 1983)

interviews with the child and the mother, and medical records, reported an incidence of 38 % for the children of depressed mothers (N=125), and 25 % for the children of non-depressed matched controls (N=95).

A point worthy of comment in this study, is the high rate of reported problems among the children of healthy parents. This community comparison group was carefully selected from census tract data, each family located to within a 12-square-block area or "neighbourhood", to the home of a depressed parent. Such a well matched comparison group is of considerable importance in estimating the incremental effects on child adjustment of having a parent with a depressive disorder.

The discussion above has established the link between depression in a parent and a number of functional and developmental impairments in a child. A number of alternatives have been considered in understanding the methods of transmission, or the pathways through which disorder in a parent may lead to problematic adjustment in a child.

Rutter and Quinton (1984) considered four likely mechanisms of familial transmission:

(i) a link between parental and child disorder which could be explained by genetic influences;

(ii) the influence of direct environmental exposure to symptoms of the parental disorder;

(iii) those correlates of parental mental illness such as family atmosphere or marital disharmony, which may indirectly predispose to child disorder; and

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(iv) the indirect effects of parental disorder, such as episodes of interrupted child-care and separation from the parents.

The association between parental disorder and impairment in the development of their children is not a straight forward transmission of risk. There is reason to believe that each of these broad sets of mechanisms operate in a complex accumulation of vulnerability and risk factors. Causal-chain models (Fergusson et al. 1985), multivariate risk models (Stiffman et al. 1986; Billings & Moos, 1983; Hammen et al. 1987), and accumulative adversity index models (Rutter & Quinton, 1984) have been developed in order to separate out the independent of these factors. Additionally, prospective effects of some longitudinal studies have uncovered the potential longer-term outcome in the child, and particular periods of vulnerability, of having a parent who is suffering from depression (Ghodsian et al. 1984; Richman et al. 1982).

In order to make sense of the means through which adversity is passed on to the children, and to understand what it is about the depressed parent that affects the functioning of their offspring, four areas of investigation will be covered in this chapter. Initially, an overview of the risks of genetic transmission is covered. Secondly, the literature will be examined for the discussion of differential effects in child adjustment according to the parental diagnosis, and the level of exposure the child has to depressive or other symptoms. The discussion will assess the impact of parental "disability", over and above that of the diagnosis per se, and will therefore include a review of the impact of parental physical disorder upon the children. Thirdly, the transmission of adversity will be assessed in terms of

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the social adjustment of depressed parents and the effects upon the quality of parenting. Studies assessing the ways in which a depressed mother interacts with her children on a micro-level will be analysed. Finally, the discussion will centre around the transmission of risk through ongoing family difficulties and the structural and functional features of the family environment.

#### 1. The genetic risk

The separation of genetic and family environmental influences in the transmission of psychiatric disorder is beset with difficulties. It is clear that the biological offspring of a depressed parent, not only share genes with that parent, but also share a psycho-social environment. Psychosocial adversities, as well as depression, have been shown to aggregate in families. It is likely that a familial loading for depression reflects both genetic and environmental mediation, with evidence of interaction between the two factors (Rutter et al. 1990).

It is difficult to say a lot with authority about the genetic transmission of depressive disorders and a certain degree of caution must be exercised in interpreting the results of genetic studies. A cautious approach is recommended because, (i) in the study of depressed children with concurrently depressed parents, the disorder of the child poorly matched that of the parent in terms of the presentation of symptoms or clinical course (Cox, 1988); disorder in a parent may be associated with a wide variety of impairments which are not syndrome-specific; comorbidity also frequently presents (Weissman et al. 1987); (ii) if we are accepting the possibility of genetic risk to explain concurrent disorder of parent and offspring, then we require an understanding of transmission from an adult psychiatric condition to one of childhood. To explain that the offspring of mentally ill parents have a genetically increased risk for the same conditions in their own adult life, is less problematic given our understanding of genetic factors, than an understanding of why such disorders should occur earlier in life in the offspring. As Rutter and Quinton (1984) assert, our knowledge is largely lacking in these areas.

Evidence for a genetic basis for major depressive disorders has been located from both twin and cross-fostering studies. A study of twins reared together showed a 76 % concordance rate for depression among a mono-zygotic pair and a 19 % concordance rate for di-zygotic twins (Tsuang, 1978). The same study found a 67 % concordance rate for mono-zygotic twins who had been reared separately. The adoption studies of Mendelowicz and Rainer (1977) similarly find evidence to support a genetic transmission factor. The findings are largely restricted to bipolar disorder.

There is well replicated evidence of a very significant heritability factor for manic-depressive illness (Katz & McGuffin, 1987). However, the estimate for genetic contribution in the transmission of milder depressive illnesses, such as the out-patient treated unipolar depressions with "neurotic" features, has been quoted to be as low as 8 % (Katz & McGuffin, 1987). The findings of earlier adoption and twin studies are contradictory for these milder psychiatric disorders, suggesting the importance of environmental features (Rutter et al. 1990).

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Weissman et al. (1984) investigated the children of depressed and normal parents, identifying a three-fold increased risk for anv DSM-III diagnosis in the children of the depressed parents. The increased linear-risk where both parents were psychiatrically ill, and the identification of the early onset of parental depression (before 20 years of age), along with increased number of depressed first-degree relatives, as significant predictors of child depression, are all suggestive of a genetic risk. The rate of disturbance in the children was found to be unrelated to a number of environmental variables which could have followed on from the parental illness. Tn a follow-up study (Weissman et al. 1987), it was found that the age of onset of depressive illness in the children of depressed parents was significantly younger (12-13 years) than peak age of onset in children of non-depressed parents (16-17 years). It has been shown that earlier age of onset predisposes towards a more protracted illness at follow-up (Kovacs et al. 1984).

Additionally, the risk to the children was particularly great when the parental depression had been of early onset. What is implicated in these findings is that where depression arises in childhood there is need for a greater genetic predisposition to bring it about.

The findings point to the importance of genes as one factor in explaining familial transmission of depression from a mother to her child. What they fail to clarify, however, is the unique contribution which is made by genetic and environmental influences. The question is one which is perhaps impossible to answer, especially given the current paucity of systematic investigation in these areas. The issue

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may also be insoluable because of the possibility of gene-environment interactions and suggestions that genetic effect may operate largely through its influences on temperament and personality variables (Rutter & Quinton, 1984).

### 2. The risk attributable to diagnosis and symptomatology in the parent

A number of studies have attempted to systematically assess the differential contribution to risk according to the diagnosis of the proband parent. There is little uniformity in the studies in the ways in which this has been achieved. Diagnoses have been made on the basis of current symptoms identified on self-report; on the basis of psychiatric diagnoses given on admission, taken from medical records, often with no evaluation of current psychiatric status; others have more systematically utilised standardised methods of psychiatric assessment (such as the Schedule of Affective Disorders and Schizophrenia, Spitzer & Endicott, 1978).

A wide range of parental psychiatric disorders have been covered, from severe psychopathology, schizophrenia and personality disorders, to unipolar and bipolar affective disorders. The studies differ in their use of inpatient or out-patient samples, in their assessment of current or life-time disorders, in the degree to which patients have been previously hospitalised, illness duration and the timing of onset. Descriptions of the course of the disorder or psychiatric treatment effects are rarely found.

For example, Rutter & Quinton (1984) select a sample of patients with disorders of recent onset (with no evidence of previous referral in

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the past 12 months). The subjects chosen by Hammen et al. (1988), however, include parents whose depressive illnesses predate the birth of their children, or began in the child's infancy. The former study reflects upon the effects of a recent adversity or life-change, whereas Hammen's study is concerned with the detrimental effects upon the formulation of relationships, where child development issues may be far more at stake.

Kashani (1985) stressed the importance of separating the effects of unipolar and bipolar depressive disorder in the parents. Kashani's groups of children from bipolar and unipolar depressive parents showed few differences in adjustment. There were suggestions, however, that bipolar disorder in a parent can predispose a child to more "acting-out" behaviours, perhaps accounting for the significantly increased incidence of alcohol dependence in this group. Unipolar disorder in a parent was more closely correlated with "acting-in" behaviours in the children, such as expressed anxiety and somatisation. Kashani explains the differences in child outcome by means of differential coping styles which have been learnt from sick parents.

A study by Conners (1979) also directly compares parental unipolar and bipolar disorders. He found that it was the unipolar depression in a parent which was associated with the most current impairment in the children. These children showed significantly higher rates of conduct disorder, anxiety disorder, impulsivity and hyperactivity than the children of parents with bipolar disorder. It was the female children in this group who appeared to be most at risk. Some reservations could be made in the acceptance of Conner's findings, given the

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absence of a comparison group of children with well parents, and given the fact that all child assessments were taken from the self-reports of the depressed parents. Beardslee et al. (1983), in a review of the literature, were unable to come to any conclusions about the differential effects of unipolar or bipolarity in the parental depressive illness due to the methodological study differences.

Rutter and Quinton (1984) identify only a weak link between the form of the parental disorder and the concurrent problems in the child. The strongest specific effect according to parental diagnosis was found for personality disorder (systematically evaluated on an assessment interview which was to be the precursor to the Present State Examination, Wing et al. 1967). A significantly increased risk reported child disturbance and psychiatric disorder for (by standardised interview) was found in children where at least one parent suffered from a personality disorder. Three-quarters of the child problems were related to conduct problems. The association of risk was found irrespective of whether the personality disorder was of anti-social or non-anti-social features. They conclude that it was aspects of parental impaired social and interpersonal functioning that was putting the children at risk.

There were also suggestions in their study of a diagnosis-specific link between parental and child concurrent depression. Twenty-six children were diagnosed as having some form of psychiatric disorder. Of these, 18 % suffered from a depressive illness; whereas of 7 psychiatrically ill children whose parents had a major depressive illness, 57 % were also rated as depressed.

In order to assess the differential effect of parental disability as opposed to the specific effect of a diagnosis of depression, various have used groups of parents with physically disabling studies conditions, for comparative purposes. Cowie, (1961) used a group of unselected medical inpatients to control for features of hospitalisation in a comparison of the children of psychotic patients. No group differences were found in the degrees of impairment to the children. Janes et al. (1983), assessed the school behaviour of the adolescent children of parents with psychiatric disorders. Parents hospitalised for tuberculosis or diabetes mellitus formed a comparison The children of both groups showed evidence of disorder group. although no between-group comparison was made in this study. An earlier study by Worland and Hesselbrock (1980) compared four groups. Parent probands were identified on the basis of diagnoses of schizophrenic, manic-depressive disorder, mixed medical conditions and parents free from disturbance. All three groups with parental disorder displayed child impairment on a number of assessments. The children of parents with medical conditions achieved the lowest scores on a measure of IQ.

An important study by Hirsch and coworkers from Illinois (1985) studied the adolescents of depressed (Research Diagnostic Criteria for major or minor depression), arthritic (diagnosed as suffering from rheumatoid arthritis by a consultant rheumatologist), and normal parents (taken from census tract data). The group with arthritis were selected in order to control for the level of general disability evinced in depressive illnesses. The sufferers of arthritis were seen to be similar to those with depression in the decreased levels of activity and in their emotional expression. The degree of impairment

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in the children (self-reported symptoms and self-esteem), was significantly different from the children of well parents in both the depressed and the arthritic groups, with the children of arthritic parents falling somewhere between the two. The children of arthritic parents were significantly more impaired than community controls, but not significantly different from the children of depressed parents.

The authors conclude that "the principal risk factor is the presence of parental disability or distress rather than a specific parental diagnostic category". However, high incidences of reactive depression have been found in sufferers of rheumatoid arthritis, along with other debilitating physical conditions (Wells et al. 1988). Given that the psychiatric status of the arthritis patients was not assessed in Hirsch's study, it remains inconclusive whether the differences between children are attributable to the presence of depressive illness or to the effects of general disability.

Their general conclusion was, however, corroborated in a study of children referred to the Maudsley psychiatric clinic and children attending dental and paediatric clinics (Rutter, 1966). Twenty percent of the disturbed Maudsley children had a parent with a diagnosable mental illness (a rate which was three times higher than that of the matched dental and paediatric controls). The Maudsley group also displayed a two-times increased chance of having a parent with a chronic or recurrent physical illness in comparison to the controls. It was the disturbed Maudsley children only who showed this increased risk.

Rutter makes the point that it does not appear to be the diagnosis of

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the parent which is of importance in determining risk. "The finding that the association with disorder in the child is not restricted to mental illness in the parent but includes all chronic or recurrent illnesses is important and suggests that considerations of the effects of parental illness on the children should extend beyond the direct effects of parental morbid behaviour or attitudes".

Hammen et al. (1987), include a medical comparison group (14 mothers suffering from either arthritis or insulin-dependent diabetes), in an assessment of psychopathology in the chidren of unipolar and bipolar depressed parents. A community comparison group was also included. The psychiatric status of the mothers with medical conditions was assessed (DSM-III), and the women were excluded from the study if there was evidence to suggest that the psychiatric conditions predated the onset of medical illness. Those with signs of reactive / adjustment problems, and those without disorder were not distinguished. The children from this group showed moderate rates of psychiatric diagnosis (50 %), which were significantly higher than the rates in the normal comparison group (29 %), but not as high as the 92 % and 74 % life-time rates of psychopathology found in the children of bipolar and unipolar mothers respectively.

This intermediate position for the children of parents with medical illnesses (including those with reactive depression or adjustment disorders), in comparison to the children of depressed and normal parents is similar to that found in the studies by Hirsch et al. It establishes that there is a considerable risk to child adjustment in having a parent with a chronic or recurring physical condition.

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The importance of disability as opposed to a diagnosis of depression per se, as a significant risk factor for child adjustment, was addressed further in a recent study by Lee and Gotlib (1989). In a group comparison of 16 clinically depressed psychiatric out-patients (DSM-III), 10 non-depressed psychiatric out-patients (manifesting symptoms of anxiety disorder, personality disorder and adjustment disorder without depressed mood), 8 non-depressed medical out-patients (receiving treatment for rheumatoid arthritis), and 27 non-patient subjects with no reported psychiatric or medical difficulties, the following three hypotheses were evaluated:

(i) The depression-specificity hypothesis, predicting that it is the specific diagosis of depression which is the risk factor.

(ii) The psychological distress hypothesis, predicting that maternal psychopathology and distress in general are associated with child adjustment problems. Their hypothesis predicts that the two psychiatric groups (depressed and non-depressed) would both show poorer child adjustment than the two non-psychiatric groups (medical and disorder-free).

(iii) The general disability hypothesis, predicting that child problems would occur in all three patient groups (psychiatric and medical).

The children of the depressed mothers were found to be the most impaired (on standardised child adjustment measures taken from the mother and child), although no significant differences emerged between these children and the children of the non-depressed psychiatric patients (supporting the psychological distress hypothesis). The

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medical subjects in this group were excluded on the basis of accompanying depressive disorder, past or current treatment for any psychiatric illness, and therefore were unlike the arthritis subjects in Hirsch et al.'s (1985) study. Lee and Gotlib's subjects suffered from a physically disabling condition, uncontaminated by psychological impairment. The general disability hypothesis was not supported in this study. The children of these parents were no more impaired than the children of community controls.

On the basis of their findings, physical illness in a parent with accompanying good psychological adjustment does not appear to be detrimental to the adjustment of their children. However, the sample sizes in this study are small and no attempts have been made to compare the groups on measures of disability or impairment of functioning (assessed across psychiatric and physical disorders). It is feasible that those physically ill parents without adjustment or reactive depressive disorders are less disabled or restricted by their conditions than medically depressed subjects who would have been excluded from this study. Alternatively, a finding emerging from this study, and corroborated by other researchers, suggests that it is the presentation of distress which is the primary risk generation factor. This cuts across diagnosis and the psychiatric / medical illness distinction. It involves the current symptomatic status of the parental condition and the way in which the parent expresses and communicates her distress to significant others (Cox, 1988).

Rutter and Quinton (1984) assessed the child's exposure to psychotic and bizarre behaviour, hostile and irritable behaviour and behaviour characteristic of anxious, depressive and emotionally labile outlooks.

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The effects of symptom exposure were assessed across diagnostic groupings. Exposure to parental hostility and aggression accounted for a significant proportion of variance in ratings of child behaviour problems. No child of parents with disordered personalities displayed problems if they were not exposed to such symptoms. Most damage to the children occurred when the parents involved them in their psychotic symptoms (as targets of hostility, violent behaviour or neglect, or as central to the parent's pathological guilt, anxiety, bizarre preoccupations or delusions).

The exposure to anxious and depressive behaviour is largely the same across diagnostic groups. In a sample of 72 families, where the mother had a diagnosed psychiatric disorder, it was the mother's affective symptomatology which was most significantly related to measures of child competence (Kokes et al. 1980). The other symptom groups, corresponding to psychotic, schizophrenic, paranoid and neurotic disorders contributed significantly less to child problems. It was the depressive symptoms which appeared to impart the most risk to child adjustment. Kokes describes this influence to be not so much the exposure of the child to symptoms, but the emotional unavailability of the mother suffering from affective disorder. The study also identified positive symptoms of a presenting psychotic disorder which appeared to exert a protective effect upon the children:

"It would appear that the mother who exhibits lability of affect during an acute episode of psychotic illness will continue to interact with her environment and presumably with her [child], albeit erratically, even during times of crisis. In this way, lability of affect in a mother remains a positive prognostic sign for her child. On the other hand, depressive, incongruous affect and withdrawal are signs suggesting that affective symptomatology in psychiatric patient mothers has a definite and specific

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It is suggested by Lee and Gotlib (1988) that it is the "prolonged self-focus", which is characteristic of a depressive illness which is a central mechanism in the transmission of disorder from a mother to her child. In such a heightened state of self-preoccupation, the mother is unlikely to be responsive to the emotional needs of her children. Through a pathway such as this, it becomes more understandable that depressive symptoms in a parent are perhaps the most aversive and damaging to a child. The damage may occur through a whereby a child may internalise a parental symbiotic process depressive mode of thinking and attritution. The resulting low self-esteem and feelings of worthlessness will impede a child's coping style and problem-solving abilities. Lee and Gotlib (1988) comment that the altered pattern of exchanges between family members may disrupt a child's mastery of appropriate conflict-resolution and affect-regulation skills. Perhaps it is also the tangibility of a parent's depressive symptoms which is at issue. Sad affect and withdrawal are easily understandable to young children; perhaps they are somewhat closer to something a child may have experienced him/herself. Such affective states in the parents are easily attributable, by the children, to circumstances they may have generated themselves. The potential for self-attribution, self-blame and guilt is perhaps greater for the child of a depressed parent, whereas more bizarre psychotic behaviour allows for a greater protective response of distancing and disassociation.

Two further hypotheses addressed by Lee and Gotlib (1988), assess the temporality of the child and parental disorders. The direct effects on

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the child of the symptomatic status of a mother would tend to suggest that the generation of disturbance is in the patterns of interaction between mother and child, and will therefore be transient.

(iv) The transient disturbance hypothesis, predicts that child disturbance will only show when mothers are symptomatic. The removal of depressive symptomatology would mean a return of general responsiveness and interactional engagement. Child adjustment problems would therefore be expected to disappear.

(v) The prolonged disturbance hypothesis, derived from the findings of Billings and Moos (1986), that remitted depressed parents continued to describe adjustment problems in their children. They found an incidence of "serious child dysfunction" in 52 % of the children with mothers with on-going depression, and 26 % in the children of mothers whose depression had remitted. The suggestion is that there are longer term deleterious consequences to the children, which go beyond the current symptomatic presentation of the mother.

The authors found that an improvement in maternal depression on a 6-8 week follow-up was not paralleled by changes in child adjustment measures (Lee & Gotlib, 1988). It is clear that there may be a substantial delayed effect between fluctuations in maternal symptoms and changes in child functioning. The introduction of concepts of sequence and timing will add considerably to our understanding of the impact of parental disorder through extensive longitudinal studies. Such research will allow for more definitive claims to be made concerning issues of causality.

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Other features of a parental illness which may be protective of associated child problems concern the degree of impairment in multiple areas of functioning. Parental disorders have been assessed in terms their current severity, their chronicity, the frequency of of hospitalisation, treatment status and possible suicidal attempts. Keller et al. (1986), addressed the impact of these indices upon impaired adaptive functioning and psychopathology in the children of depression. Child adaptive functioning parents with and psychopathology was significantly related to the duration of the parental depression (and thereby the extent of the child's life-time exposure to the depression), the number of depressive episodes, the number of suicidal attempts, times treated and hospitalised and overall depressive severity. The indices were more successful at predicting child disorder than the parental diagnosis itself.

Keller reported that the first episode of major depression in a child (DSM-III criteria) followed the onset of a parental disorder in 79 % of cases. Harder et al. (1980) introduce the dimension of time into their assessments of parental disorder, to determine the effects of illness course and associated impairment. The onset of the disorder was dated at the time of hospitalisation. Current impairment was measured on average 4 years later. It was during the non-acute episodes of disorder and not during periods of hospitalisation that the impact upon the child was greatest. The level of impairment resulting from parental illness and the degree of recovery of levels of functioning attained prior to hospitalisation were closely related to child adjustment. It would seem that it is through aspects of the parent-child interaction and changes in the quality of parental care that adversity is being generated.

# Social adjustment and quality of parenting in the transmission of risk

The preceding discussion suggested that it was the prolonged self-focus and depressive preoccupation of the parent, with poor responsiveness and emotional unavailability, which explained the particular risk to the child associated with a depressive illness in a parent. Thus the child is responding to more than merely the effects of possible separation through parental hospitalisation.

The following discussion will focus upon the social adjustment and parental role performance of the depressed mother. A substantial amount of work has investigated aspects of maternal competence and ways in which it may be disrupted by depression. Observational work tends to focus upon changes in the mother-infant / toddler relationship, as this is regarded as a crucial period for emotional and cognitive development. The aim of the review is to identify something about the interaction which may be transmitting ill effects from the maternal depression to the child.

It is to be expected that there will be changes in the way in which a mother interacts with her children, and generally with any significant others. A depressed mother is likely to experience irritability, poor concentration, dysphoria and a lack of energy. There may be overriding feelings of worthlessness and loss of pleasure. These are obviously not exclusive to depression, but they will clearly involve the children in most cases.

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The typical depressed women depicted by Weissman and Paykel (1974), is of a woman living at home, functioning, albeit marginally, on a daily basis and still interacting as far as she can in her usual family roles. These depressed mothers have reported difficulties relating to and communicating to their children, reacting to them with increased hostility and resentment and often lacking in affection towards them. They felt only moderately involved in their children's lives and reported more incidents of friction between them.

These problems were seen to persist even after recovery of the maternal depression (Weissman & Paykel, 1974). Moreover, the children continued to show significant problems themselves, long after their mother's recovery (Weissman et al. 1972).

The adaptive performance of mother and child were found to be impaired at each successive stage in the family life-cycle. Acute depression was seen to impair parental ability to be involved in their children's lives. Younger children were deprived of parental involvement in physical care and play. All of the childen studied by Weissman exhibited some developmental disturbance (eg. "tyrannical behaviour" or separation anxiety), (Weissman et al. 1972). Older children were affected by parental lack of interest and involvement in their lives outside of the home environment - their school progress, their friendships and their social and leisure activities. During adolescence, impaired communication and friction between mother and child were associated with deviant behaviour, rebelliousness and withdrawal. With needs for affection and attention not being met, the children were found to be less inclined to confide in their depressed mothers, thus permitting the build up of potential worries and

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The observation of interpersonal relationships and interactions between mothers and their children has enhanced our understanding of inappropriate maternal behaviour and child distress. It has been shown that infants are sensitive to subtle changes in maternal communications, such as facial expression, speech and motor activity (Murray, 1988). Observational studies of depressed mothers have shown that their infants fret more, are more drowsy, more distressed and fussy and engage in significantly less eye contact (see Cox, 1988). The interactions are punctuated with more controlling communications on the part of the mother and more distress of the child. There is evidence to suggest that these mothers are discouraging responsiveness in their children by timing their interventions wrongly (Browne, 1987), and failing to mesh the quality of interactions with their children (Mills et al. 1985).

A small scale epidemiological study was carried out from the Institute of Psychiatry, in a working-class district of South London (Mills et al. 1985). Health visitors approached all the mothers of 2-3 year old children who were screened for disorder on Rutter's Malaise Inventory. A structured interview administered to those high-scorers identified clinical cases of depression in the mothers. Observations were conducted on two morning visits. From three hours of videoed observational data for each of the 39 depressed mother-child dyads, and 21 control dyads (low scorers on Rutter's scale), one hour was extracted when mother and child were "doing something together". Such reciprocal activities included engagement in a game or household task. Playful interactions emerged where mothers involved the children in

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household task, for example: peeling the potatoes together, watching things out of the window or watering the plants.

An important finding emerging from the observations was that the depressed and non-depressed mothers did not differ in the amount of time they spent interacting with their children. There were also no differences between the groups in the language comprehension or cognitive development of the children. However, there were more child problems in the group with depressed mothers, particularly in those depressed mothers with personality problems or a prolonged history of chronic depression. It was something about the depressed mother-child interactions which was found to distinguish them from the controls.

The observation identified more negative interactions, such as physical smacking and negative verbal criticisms, in the depressed mothers versus controls (Dowdney et al. 1984). The depressed couples also seemed to be low on mutual affect, that is, they appeared to have less fun together.

In their analysis of reciprocal activities, the authors identified a particular type of interaction they called a "link". This was considered to be indicative of a dimension of mutual responsiveness. It was measured whenever the contribution of one of the dyad added to or commented upon the activity or talk of the other. A CONTEXT link was identified where the contribution was seen to be relevant to the ongoing behaviour of the other; a CONTENT link was identified where the contribution introduced or expanded upon conceptual material.

The depressed mothers are not making fewer links overall in comparison

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to the non-depressed mothers, but the group difference is in the number of links which the child responds to. The children of depressed mothers appear to be responding less, irrespective of whether they have behavioural problems or not. It is the maternal depression which is predictive of the number of links responded to. Depressed mothers with significant behavioural problems in their children also made fewer world-links, a link which situates the child in his own family and social context.

It seems that perhaps the depressed mothers are getting the timing of their interventions wrong, and are therefore failing to recruit, sustain and expand the child's attention. These mothers spend more time staring into space and losing attention and they often appeared to be intervening too soon. Interventions were often not relevant to the child and thus, there were fewer opportunities for reciprocal patterns of normative and adaptive behaviour.

Similar patterns of interaction have been reported in a study of interactions between abusing mothers and their children (Browne & Parr, 1980; Browne 1982). The sequential analysis of video data from 23 abusing and 23 matched non-abusing mother-infant pairs, suggested that abusing mothers were more intrusive in interacting with their infants and adopted a more coercive style in comparison to the non-abusing mothers. A lack of sensitivity was shown by the abusing mothers, often inducing distress because of their untimely and inappropriate interventions which interrupted exploratory play (for example, the abusing mother obtrusively adjusts a child's clothing whilst the child plays; the non-abusing mother interacts with the child showing an interest in the toys being played with). The

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interventions of the mothers were cutting short potential interactions. Opportunities to learn from the turn-taking pattern of parent-infant interactions was therefore reduced.

Similarly, such poorly meshed responsiveness, ineffective control and expressions of negative effect were typical of the interactions of mothers whose children were failing to thrive (Heptinstall et al. 1988). The mothers in these families were seen to be unconcerned and overinvolved.

It must be stressed that what could be seen here as indicative of poor parenting style is not characteristic of depressive disorder per se. One subgroup of depressed women identified by Mills et al. (1985) were described as sensitive to their children's verbal and non-verbal cues, scored highly on all measures of interaction links, and clearly met the emotional and cognitive needs of their children. It is suggested that it may be the more profound personality disturbances in some of the depressed mothers which are promoting transactional problems. Clearly, there many factors in the current are circumstances of these mothers and in their past experiences which may help to explain differences in parenting abilities.

Poor experiences of parenting in their own childhoods, a history of insecurities in early social relationships and current life events and difficulties have all been shown to influence maternal competence (Brown et al. 1986). The depressed mothers in Mills study often reported poor relationships with their own mothers and had often had their child at a much younger age than mothers who were not depressed. Past adversities can clearly have links to the present, perhaps

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through reduced confidence or a lowering of self-esteem (Brown et al. 1986).

Wolkind and Kruk (1985), identify areas of influence which may help to explain competence in mothering. Firstly, there are the factors in the woman's past, such as adversity in the families of origin, coming from larger homes, and having parents in unskilled or semi-skilled work. Secondly, there are those factors such as current low levels of emotional support, and relationships with parents involving poor support, low contact and frequent disputes. The role of poor intimate and confiding relationships has been shown to play a part in the social causation of depression in women (Brown & Harris, 1978), and it is possible that it may too adversely affect the competence these mothers bestow upon their parenting role.

Finally, Hammen et al. (1987), in their study of the children of depressed mothers found that a measure of "chronic strain", seen to be a concomitant of depressive illness, but not specific to it, contributed significantly to impairment in the children, over and above the effect attributable to the depression alone.

A measure of chronic strain was designed to incorporate the externally caused environmental events (the life strains of Pearlin & Johnson, 1977), and internally caused difficulties relating to role dysfunction and social adjustment. It was expected that chronic strain would relate to a woman's level of functioning. A number of role-content areas were considered for degrees of strain: marital / social roles; employment and finances; relationships with children and with family members. The measure was found to correlate with socio-economic and

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educational status. Unemployed or single mothers were more likely to report higher chronic strain. Substantial correlations were reported with measures of marital happiness (Dyadic Adjustment Scale, Spanier 1976), and with social adjustment (Weissman & Bothwell, 1976).

Thus, there are correlates of maternal depression which have clear links with child problems which may coexist with and precede the psychiatric illness. Impaired maternal adjustment and parenting problems may be more likely to occur in mothers who are depressed, but may not be attributable to the depression. Furthermore, as indicated in the Hammen study, adversities which exist beyond the personal qualities of the parent can lead to child impairment. The final section in this discussion will concentrate upon the transmission of risk through adversity in the family.

# 5. The family environment and ongoing adversity in the transmission of risk

Anthony (1969), in his study of the children of schizophrenic parents describes the child's exposure to a

"depressogenic, or reactive environment [...] characterised by its inconsistency, chaotic management, contradictory communications, highly ambivalent but powerful intrusiveness into the lives of the children. This environment of irrationality envelops the family and makes for unprecedented storms and crises that hover over the lives of the children".

The description of such an environment is likely to apply across parental psychiatric diagnoses and to be related more generally to family adversity and emotional turmoil. Environmental factors such as stressors and family social resources are among potential determinants

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of a child's health. Negative life-events involving the family (divorce, death, financial problems), and chronic strains (marital disharmony, parental work stress) can have adverse effects upon a child's adjustment (Moos & Billings, 1982). Family environments also differ in their coping and problem-solving strategies and in their provision of supportive resources for maintaining the healthy adjustment of the children (Billings and Moos, 1983). Adults receiving treatment for a depressive illness frequently report negative childhood family environments (Crook et al. 1981) and it has been seen that depressed mothers report less affection, more resentment and more communication problems between family members in comparison to healthy mothers (Weissman et al. 1972).

Much research has been conducted into the impaired communication patterns associated with a depressed patient and the aversive impact they induce in others. The depressed person is said to produce slow and more negative speech with reduced eye contact and less humour (Hinchliffe et al 1978). The interaction studies of Coyne et al (1973; 1976), using depressed confederates, illustrate how a depressed person may elicit aversive reactions and withdrawal from others. Howes and Hokanson (1979) found more frequent silences, more directly negative comments and less overall verbal responses in a group of depressed subjects. Overall, there was a lower rate of smiling, lower arousal and less pleasantness in their interactions when compared to the interactions of non-depressed subjects.

The ways in which such negativity of affect are transmitted within a family environment have been demonstrated in the observation of family group discussions with a depressed parent (Alexander, 1973), in the

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observation of family meals (Walker et al. 1984), or in the coding of the ways in which family members speak of others during interviews (Brown & Rutter, 1966). The latter approach operationalised a measure of the amount of emotion, positive or negative, and the number of critical comments which were expressed during the course of a factual interview about the patient. Such a measure, taken from an interview with family members at the time of hospitalisation of a depressed parent, was found to significantly predict relapse within months of discharge (Vaughn & Leff, 1976). High expressed emotion in a family is associated with a degree of isolation from social support systems (Brown et al. 1972), and is closely related to the patients' disturbed behaviour. It is suggestive of a "visible" sign of family disturbance and coping failure (Birchwood, 1983). The presence of a depressed person in a family has a directly adverse effect upon other family members, thereby resulting in a negative and highly charged family environment. The changes in family atmosphere and the quality of interactions play a part in the recovery and rehabilitation of the depressed member and it has been shown that the reactions of family members can sustain a depressive episode or trigger a relapse (Cronkite & Moos, 1980).

The Family Environment Scale (Moos & Moos, 1981) was developed in an attempt to make some standard representation of a family. Billings and Moos (1983) compared the family environments of 133 families with a depressed parent and 135 families with a non-depressed parent matched from census tract data. The depressed parent families were found to be less cohesive, less expressive and more conflictual than controls. Less emphasis was placed upon the pursuit of the independence of family members and fewer joint recreational activities

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were conducted. Moral and religious values also assumed less importance in these families. The depressed families were less organised with poorer allocation of individual responsibilities. A measure of family support was taken from three subscales of the Family Environment Scale (cohesion, expressiveness and the absence of stress factors). A supportive and more active family environment was found to be protective of child health in the face of family stressors and chronic strain.

There is a significant association of child impairment and psychiatric disorder with chronic stresses and acute life events (Goodyer, 1990). The effects of such adversities will be mediated through the family environment, its support systems and coping strategies (Billings & Moos, 1983), and mediated through maternal affective state (Fergusson et al. 1985). Life-events and ongoing stresses are correlates of parental mental disorder. For example, psychiatric state is closely associated with marital discord, often anteceding the psychiatric condition (see Rutter & Quinton, 1984). In Fergusson et al.'s five year longitudinal study, maternal depression was significantly correlated with both long-term (ongoing) and short-term (acute) life events. When the effects of maternal depression were taken account of (using multiple regression methods), the independent contribution to child adjustment problems (on maternal report) was small. Using measures of child adjustment independent of maternal report, liable as it is to depressive bias, it was shown that family life-events were making a significant and independent contribution to variability in child behaviour. The long-term stressors occurring throughout a child's pre-school years were far more predictive of child behaviour than events which had taken place in the previous 12 months. Thus, a

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consistent history of adversity has more marked effects on child adjustment.

It is apparent that family adversities, of both the chronic and acute kind, tend to potentiate each other. Rutter's "family adversity index" (Rutter & Quinton, 1984), looked for the presence of the following 6 variables: psychiatric disorder or criminality in the mother, the same in the father, marked marital discord or disruption, fostering or admission of children to a children's home, the presence of more than four children at home, an overcrowding index of 1.1 or more persons to a room, or head of household in semi or unskilled occupation. The adversity index was administered to 137 psychiatric patients with children under the age of 15, living at home, in a four year prospective study.

The presence of only one of these adversity factors was associated with no reported child disorder (on parental or teacher report). If 2 to 3 of these factors were present, a significant number of the children were seen to have emotional or behavioural problems (20 % on parental report; 11 % on teacher questionnaire). After controlling for the effects of these family adversities, the children of patients failed to show any increase in emotional / behavioural disturbance. It would seen that the presence of parental psychiatric disorder is but one of several psychosocial risk factors which are more damaging to the children in combination than in isolation.

These findings are confirmed in a risk factor analysis conducted in the study by Billings and Moos (1983). Three classes of risk were identified: parental depression; family stresses (those families

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scoring above the grand mean for a composite of a) negative life events, such as job loss, death of spouse, marital separations, b) personal physical illness, c) spouse illness, d) negative physical home environment, such as comfort or cleanliness, e) family arguments, f) work stress); and lack of family support.

Table 2 is taken from Billing and Moos's (1983) study. It illustrates the proportions of families with child problems (emotional and physical health and behavioural disturbances) according to the presence of risk factors.

In a stepwise regression analysis, parental depression was entered first, accounting for 25 % of the variance in child disturbance. The acute versus chronic status of the parental depression incrementally added to the prediction of child disturbance (F=8.0, p<.001) when it was entered. Thirdly, stress was entered, adding a significant proportion to the prediction (F=11.5, p<.001). Finally, family support was found to contribute an additional and independent effect (F=7.1, p<.01).

The role of low family stress and a supportive family environment as "protective" factors, is stressed. Whilst 26.2 % of the children with depressed parents had considerable emotional, health and behavioural problems, only 22 % were found to be disturbed in families with low stress. In spite of having a depressed parent, among families with both low stress and high support, only 10.7 % of the children were disturbed. Whilst these results indicate the potential for adequate functioning and parenting in adults with depressive illnesses, they also highlight the protective and sensitising effects of family

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# RISK FACTORS IN THE FAMILIES OF DISTURBED CHILDREN

	Percentage of 1	families
	with disturbed children	
Risk factor(s)		
No risk fators present	2.7 %	(N=74)
Depressed parent	26.2	(N=133)
Acutely depressed parent	32.9	(N=79)
Acutely depressed parent & high family stress	38.1	(N=42)
Acutely depressed parent, high family stress &		- ,
low family support	41.2	(N=34)

(Billings & Moos, 1983)

environment variables upon a child's mental health and adjustment.

Stiffman et al. (1986) introduced child-specific competencies into their mutivariate risk model of the transmission of disorder to the children of parents with mental illness (DSM-III). Forty percent of the variance in child behavioural problems was explained by two risk factors (the proportion of family members with mental health problems and discord in the mother-child relationship), and two aspects of child competence (a competence in activities, particularly sports and involvement in clubs, and academic abilities). In this study, competence was seen to interact with environmental factors in determining the risk status of a child.

So far, the discussion of the transmission of risk has been concerned largely with factors outwith the child - factors which involve features of a parental illness and the impaired functioning and parenting style resulting from it, and factors in the family environment, as correlates of parental disorder or secondary developments of it. However, children are not passive recipients of environmental stimuli. Their problems also do not simply vanish when family circumstances improve. In the multiple adversity models, a substantial amount of variation in child disorder is yet to be accounted for. What the discussion has yet failed to address, is the reciprocal pattern of influence between child and family adjustment, and the resources and coping skills unique to a child which help to determine which children will suffer adversity and which children will remain resilient.

In many of the "high-risk" outcome studies discussed above, mentions

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were made of individual differences in child vulnerability. These are not clearly understood but the fact that they exist is not in doubt. In the study of adult depression following acute life events, the question of individual differences has resulted in a search for "vulnerability factors" that increase a person's susceptibility to stressors, and for "protective factors" that buffer a person's resilience (Brown & Harris, 1978). In accounting for individual differences in children, discussions have largely centred upon constitutional, temperamental and developmental factors. However, the degree of resistance is not a fixed quality, it is relative and not absolute, and the bases of resistance are environmental as well as constitutional (Rutter, 1985). In the adult literature, attention has focussed upon cognitive appraisal and attributional style (Lazarus & Launier, 1978), coping strategies (Hirsch, 1981; Folkman et al. 1986), and supportive social networks (Henderson et al. 1981; Brown & Harris, 1978; Hirsch, 1979). Personal qualities such as self-concept, attributions of self-control and self-efficacy are also of importance in improving individual resistance.

The best predictors of a child's later functioning are measures of adaptation rather than psychopathology (Beardslee & Podorefsky 1988; Keller et al. 1986). In order to understand the longer term effects of life stressors and family adversities, it is important to know how they impinge upon the child's adaptive skills and competencies. Garmezy (1983) assesses child adjustment, in the face of life stressors, in the light of age-appropriate competency skills on broadly-based developmental stages. The effects of adversity upon a child can thus be addressed in terms of the developmental challenge they are currently facing and the skills which have already been

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mastered. The impact of an event is dependent upon the child's capacity to understand it, the extent to which it reflects upon a child's belief-system and self-concept, the child's stage of emotional development and the strategies developed for dealing with it.

What is clear, moreover, is that family adversities and life stressors may have positive effects which enhance child development and adaptive Rutter (1985) speaks of the potential "steeling" skills. and "sensitising" effects of unpleasant events. The experience of adversity may serve to "toughen" an individual. For example, the neuroendocrine response of an experienced parachute jumper is different from that of a novice. The steeling effects of the first jump produce resistance against the first acute stress reaction (see Rutter, 1985). The sensitising effect of early separation experiences, however, has been shown to predispose to depressive illness in adulthood (Bowlby, 1980).

Other studies have commented upon the "health-enhancing" effects of stress associated with a child's own illness (Parmalee , 1984), or of positive developmental changes resulting from the birth of a sibling (Dunn & Kendrick, 1982). Similarly, a parental psychiatric illness has been linked to positive signs of adaptation in the children if the stresses are manageable, and if they produce tasks which are found fulfilling (Garmezy et al. 1985). What seems to be of importance is a child's feelings of self-worth and self-efficacy and the extent to which they believe themselves to be in control of their stressors.

A child's sense of individual esteem is a strong component part of their response to adversity. Feelings of positive self-worth

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contribute to the development of new situation-specific problem-solving strategies. A child with a good sense of personal self-worth will not feel responsible for a parental psychiatric or physical illness and may cope effectively by avoiding excessive emotional involvement and seeking release of their anxieties and frustrations elsewhere. A child, alternatively, may develop a feeling of responsibility in a care-giving role resulting in a heightened sense of morale, and a belief in one's own self-efficacy in effecting change (Rutter, 1985).

Beardslee and Podorefsky (1988) investigated 18 adolescent children of parents with major affective disorders and other accompanying psychiatric problems. They were selected for the purposes of this study because of evidence of good adaptive functioning and absense of current psychiatric disorder. A follow-up interview, on average two and a half years later, identified that 3 of the subjects had had depressive episodes. The remaining 15 showed no evidence of disorder.

An indepth interview conducted with the adolescents centred around issues relating to their experience of the parental illness. An index of self-understanding was developed on the basis of their awareness of the illness, their responses and their capacity to reflect upon their experiences.

All of the adolescents reported awareness of their parents' illness. Observed changes included the apparent sadness, irritability and lack of energy of their parents. A few commented upon their extreme isolation and loneliness. Their sense of loss was most apparent in the reported lack of parental involvement in their lives and the loss

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of a role model. The adolescents commented upon their own experiences of confusion and helplessness.

All of those coping well had made an accurate cognitive appraisal of their parents' illness. Whilst recognising that something was wrong, they had come to the conclusion that they were not the cause. This understanding was seen to crucial to their capacity to deal with the experience of having a sick parent. Those who were not coping had a tendency to blame themselves for what had happened. They had also failed to successfully separate from their parents.

Also important for successful coping was the realistic assessment of one's capacity to act and a realistic expectation of what could be achieved. The "resilient" adolescents were able to talk about their parents' difficulties with empathy but without emotional over-involvement. They were able to reflect upon their experiences with sufficient distance in order to delineate what they were and were not responsible for and what they were capable of changing. They spoke of the development of self-understanding as an ongoing process.

The adolescents coping well were said to be competent in their academic and occupational pursuits, involved in extensive and varied activities outside of the work / school environment and to have close and confiding relationships with other family members and friends. Their psychological and constitutional strengths included courage, motivation and a strong sense of personal integrity (Beardslee & Podorefsky, 1988).

A number of important points are raised in this study. Firstly, it

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shows the importance of the ways in which events are understood in determining coping style. Secondly, it stresses how involvements and activities out of the home are crucial for the maintenance of an adequate sense of personal esteem and efficacy. At the same time, these adolescents were heavily involved in care-taking and house-hold management. However, unlike the three who were not functioning well at the second assessment, the coping adolescents did not regard themselves as their sick parent's life-line. Thirdly, the study highlights the protective effects of close and confiding relationships. The parental depressive illness has potential for seriously impairing relationships within the family and thus, extra-family friendships and support networks assume even more importance as protective factors in these childrens' lives.

#### 4.4 Individual differences in child outcome

The remaining discussion in this chapter will focus upon constitutional, cognitive and experiential features which contribute to vulnerability or resilience in the face of parental illness or family adversity.

# 1. The role of temperament

Evidence seems to suggest the presence of a risk factor for psychiatric and behavioural problems which is explicable in terms of temperament. Thomas, Birch and Chess, in their New York studies were in the forefront in standardising the measurement of temperament. They identified nine temperamental traits which consistently appeared in mother's descriptions of their children: activity level; regularity

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of sleeping, eating and toileting patterns; adaptability to altered circumstances; tendency to approach or withdraw from novel situations or strangers; threshold of sensory responsiveness; quality of mood; intensity of emotional expression; attention span, and distractibility (Thomas et al. 1968; Thomas, Chess & Birch, 1977).

It is not possible simply to view temperament as a constitutional, and therefore given attribute. It is not an absolute quality and it appears that it is partially determined by the informant who is reporting upon it. Temperament needs to be understood in an interpersonal dimension. It has been suggested that one parent may respond positively to an attribute of a child's character which another parent may find difficult to cope with (Chess & Thomas, 1984). Similarly, some temperamental attributes are more appropriate in certain contexts. Schaffer (1966) identified that infants characterised by highly active temperaments were more likely to thrive in poor quality institutions by means of encouraging more stimulating interactions with staff. Such temperamental attributes were not found to benefit adaptation with the family context (Dunn & Kendrick, 1982). It appears that features of the child's temperament will interact with those of a parent. A mismatch can result in a series of mutually unrewarding interactions. In effect, it has been argued that temperamental characteristics may set in motion trains of events and experiences that impinge upon developmental factors. In such a way, temperament itself may be modified (Rutter, 1983).

Nevertheless, temperamental attributes, however stable, appear to determine how a child may experience and suffer from adversities such as a parental mental illness; they appear to be important in

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determining coping styles, and have been shown to be predictive of psychiatric status for as long as five years into the future.

To start with, it has been shown that those children with difficult temperaments (low adaptability, low distractibility, negative mood, withdrawal from new situations, intensity of emotional reactions), are more likely to suffer from the adversities of parental mental They are more likely to be the targets of parental disorder. criticism and hostility when the families are in discord (Rutter & Maladaptive patterns of parent-child interactions 1984). Quinton, resulting from such focusing, are expected to persist long after the removal of discord or adversity. The study showed that children at temperamental risk, by virtue of their displaying of "difficult" temperamental characteristics, were twice as likely as temperamentally easy children to be subject to maternal criticism. Criticism from a parent was strongly linked to emotional / behavioural problems in the children four years later, particularly so for the temperamentally at risk.

Temperamental differences are associated with a child's different ways of coping with stressful occurrences. Those children rated as unmalleable, negative in mood and with intensity of emotional expression responded to the birth of a sibling with more disturbed behaviour, making them more difficult to handle and culminating in tenser exchanges with the mother (Dunn & Kendrick, 1980). There is not much understanding of the factors which underlie resistance to stress and individual differences in vulnerability and coping style, but it appears that temperament has a considerable part to play. The children who are more likely to become clinical cases in the face of

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family adversity were those whose behavioural styles were markedly consistent (Rutter et al. 1964). A child can become entrenched in certain problematic behaviours and appears, over time, to become less strongly reactive to environmental change (Rutter & Quinton, 1984).

Thus, the child's behavioural disturbance may persist even after the improvement of family stressors, as demonstrated in the studies of Billings and Moos (1983), and Rutter and Quinton (1984). Such persistence may account for the excess of ongoing disorders in the children of psychiatric patients in comparison to controls. It also explains the occurrence of difficulties across settings - in the home, the school and within the peer group.

It is possible that those children who succomb to stress in one sphere of their lives, will do so across others because of their lower thresholds of responsiveness to stress generally, and the lack of personal resouces to successfully cope. Thus, a low malleability and intensity of style, predisposing towards constancy does not augur well for healthy adaptation.

Temperamental characteristics are also significantly associated with the later development of behavioural disorders. What is more, such characteristics have been shown to antedate the onset of symptoms. In the four year prospective study by Rutter and Quinton (1984), a temperamental risk index was identified on the basis of those attributes which appeared to be related to later disorder. Children, interviewed initially between the ages of 3 and 8, who were reported to have sleeping, eating and toileting problems, unmalleable behaviour, and who appeared more tolerant of dirt than most children,

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were those most likely to show emotional and behavioural problems on the next annual assessment. The important factors appeared to be behavioural irregularity, low malleability, low fastidiousness and negative mood. The temperamental risk factor predicted which of the children rated as non-disturbed on a teacher's rating scale on the first assessment, would develop problems on a later assessment.

Maziade et al. (1987) demonstrated how family functioning and parenting style can interact with a child's temperament in the prediction of child impairment. Difficult temperament was identified according to Thomas and Chess' criteria (1977). А difficult temperament at age 7 was predictive of psychiatric disorder at age 12. The high risk temperamental attributes only appeared to predispose to child disorder where parental consensus was lacking and where there was little consistency and firmness of parental style. Additionally, poor clarity of family rules and dysfunctional behaviour control increased the risk of child disorder in children with difficult temperaments. Where parenting was consistent, with good behavioural control and clear rules and demands, there appeared to be a consistent protective effect against the risk associated with difficult temperament (Maziade et al. 1987; 1989).

## 2. The role of gender

The gender or sex of a child also appears to exert an influential effect in terms of risk status. It is not clearly understood although it seems possible that the effect may operate through temperamental differences associated with sex (Maccoby & Jacklin, 1975), and through differences in parental behaviour towards children of different sexes.

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Over and above this, there are suggestions of an innate vulnerability to physical stresses in boys, from conception onwards. Evidence also points to a possible male vulnerability for many psychosocial adversities. It is the male first-borns who show most withdrawn behaviour at the birth of a sib (Dunn & Kendrick, 1982); boys are more likely to show aggressive behaviour in the face of parental discord (Rutter, 1981); they show a more severe and prolonged disturbance after parental divorce (Hetherington et al. 1985); boys also appear to be at greater risk from parental mental disorder (Rutter, 1982).

It does not appear to be constitutional resilience as such, which appears to protect female children. It seems that girls are less likely to elicit damaging and abusive behaviour from others. Hetherington (1985) has shown that parents are more likely to display marital discord in front of their sons, and are rather less likely to do so in front of girls. In exposure towards hostile behaviour, there appears to be a tendency towards a same-sex parent-child link (Rutter & Quinton, 1984). If a mother expresses hostility, 36 % of the children will show disturbed behaviour on the basis of a teacher's assessment. None of the girls displayed problems where hostility came from the father. Similarly, a hostile father was associated with disturbance in 71 % of boys; 40 % were disturbed where the mother was hostile. These results show the greater risk for boys associated with parental psychiatric illness presenting with hostile behaviour and the interaction between sex of the child and sex of the sick parent.

It is feasible that there are greater opportunities for symbiotic relationships to occur between a mother and her daughter and between a father and his son. The loss of role models for the children when

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their parents become ill is likely to assume greater importance when the functioning of the same sex parent becomes disordered as a result of illness. Different expectations are also made of girls and boys with respect to their reactions to adversities. Parents appear to be less supportive of boys in aiding adjustment to life circumstances. They are more likely to respond negatively to their distress reactions when faced with family discord (Hetherington et al. 1980).

#### 3. The role of developmental stage

Rutter (1985) locates six reasons why it matters when adversity occurs in a child's life:

(i) Developmental stage will influence the impact an experience has upon a child. Thus, infants up to the age of about 6-18 months will not suffer the ill-effects of maternal separation, having not yet developed the capacity for enduring selective attachments.

(ii) Without cognitive appraisal of events and the development of self-concepts, experiences can have no lasting effects. Thus, very early experiences will not result in any long-term disturbance.

(iii) Children have changing ideations of themselves and acquire more complex emotions with age. Thus, responses to stressful events will have different meanings depending upon the age of the child. During the middle years of childhood, unhappiness may be accompanied by a sense of rejection and negative self-image. Low self-esteem, feelings of self-blame and ideas of hopelessness begin to emerge during early adolescence. The developmental changes in the understanding of

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emotion and self-concept are evident in the age specific differences in responsiveness to parental divorce (Hetherington et al. 1985).

(iv) There appear to be timing differences according to when adversity in the life of a child exerts the most damage. Rutter stresses that during rapid maturation, a child may be less susceptible because of the canalisation of development. The growing child faces major developmental hurdles and the type of problems emerging in response to a stressor appear to depend upon the age and developmental stage of the child at the time of exposure. The first two years of a child's life appear to be critical for cognitive abilities, attention and language development which are placed at risk if a parent is critically ill during this period. Poor mutual responsiveness between a mother and child at 2 years is associated with poorer expressive language (Mills et al. 1985). Such a language deficiency may provide the basis for later educational problems. Thus, a maternal depression during a child's first year is associated with low scores on the McCarthy scale of child ability at 4 years of age (Caplan, 1974). A maternal depression at 3 years of age is also predictive of educational failure at 8 years, a finding which was irrespective of IQ level (Richman et al. 1982).

(v) With increasing age, a child's understanding of events and of strategies to deal with them improves. Whereas younger children (aged 5 and 6) were more likely to attribute maternal emotional changes to themselves, older children were more likely to refer to other family members or intra-family events as causes of maternal anger or happiness (Covell & Abramowitch, 1987). With attributions of sadness, a developmental progression of the understanding of interpersonal and

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abstract events, in addition to personal events, was apparent. The effects of divorce on children shows that the form of expression of difficulties, appraisal and coping style vary with developmental level (Hetherington et al. 1985). For pre-school and early school-aged children, there is likely to be personal attribution for the parental separation. The older child is more likely to focus blame outside of themselves. Such different attributions determined the vulnerability or resilience of the adolescents of depressed mothers in Beardslee's study (Beardslee & Podorefsky, 1988).

(vi) An event is imbued with different meaning according to the time at which it occurs. Thus, more child disturbance was found when stressful changes accumulated at the same times. A mother starting employment at the same time as divorce would exert a negative effect after controlling for the divorce effect, even though maternal employment is not associated with child adjustment generally.

It is hypothesised that there may be different pathways through which adversities such as parental illness affect a child's cognitive, language, emotional or personality development respectively (Cox, 1988). It is not, however, clear at this stage, which aspects of the altered relationships, parenting or family environment are of the most importance in the different component parts of a child's development. The longer-term consequences to a child will be more pronounced where behaviour patterns concurring with the adverse circumstances are most developmentally atypical (Rutter, 1972).

### 4. The role of cognitive factors and coping style

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A child's concept of self, sense of self-efficacy and repertoire of problem-solving strategies are essential in the understanding of individual differences in vulnerability and resilience. A child witnesses parental responses to family adversity and life stresses. The association with child coping strategies appears to be via both direct and indirect pathways. There are some feelings among researchers that the child of a depressed parent picks up depressive styles of thought, such as the internal, stable and global attributions of a depressive outlook, with belief in one's inability to exert influence or change (Gizynski, 1985). The child can develop a low self-esteem, feelings of worthlessness and guilt through a symbiotic relationship with a depressed mother (Eisenbruch, 1983). Such event-attribution renders a child vulnerable to depressive disorder.

Hammen and Adrian (1984) explored this relationship between negative attributional style and subsequent depression at a follow-up interview 6 months later, with the 8-16 year old children of depressed, medically ill or healthy mothers. The children had been exposed to maternal affective or medical illness for most if not all of their lives. The child's attribution of events, interacting with stress levels, was predictive of child disorder, especially those non-depressive diagnoses. The absence of association with depression was surprising, but it is likely that the cognitive vulnerability effect was obscured because of the high-risk status of these children. Alternatively, cognitive vulnerability attributes, such as negative views of the self, did predict changes in depression over time in a similar high risk group (Hammen et al. 1987). A parallel report by Jaenicke et al. (1985) demonstrated that the children of depressed

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mothers showed evidence of more negative explanatory styles than the children of medically ill or healthy mothers. Cognitive bias can shape future problem-solving and produce damaging changes to self-esteem.

Rutter (1985) spoke of the "transduction of experiences through incorporation into a child's self-system". In exploring the family and school influences on cognitive development, he stresses the importance of several psychosocial influences in determining how environmental influences operate. A child's self-esteem and concept of self, future aspirations, attitudes to learning and the style of interaction with parents and teachers, assumed greater importance than the specifics of what is taught. The transduction of experiences of parental illness, through self-concept was clearly demonstrated in the resilient adolescents of Beardslee and Podorefsky's study (1988). The protective effects of scholastic attainment appeared to operate through its influence on self-esteem, although a more direct contribution to problem-solving skills may also have been possible. Achieving emotional distance from a situation which cannot be escaped from, also emerged as a substantial protective attribute.

Coping skills play an important role in the effectiveness of an individual's response to stressors. They have two major functions: dealing with the problem that is causing the distress (problem-focussed coping), and regulating emotional adaptation (emotion-focussed coping) (Folkman et al. 1986). Both forms of coping have been demonstrated in a vast variety of stressful encounters. Problem-focussed coping includes the taking of specific action, including aggressive interpersonal efforts to alter a situation, as

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well as the cool, deliberate efforts to problem solve. Emotion-focussed forms of coping include distancing, self-control, the seeking of social support, escape-avoidance, accepting responsibility and positive reappraisal (Folkman et al. 1986). Both cognitive appraisal and coping are transactional variables, referring to the interaction between a person and their environment.

Billings et al. (1981; 1983) identified the styles of coping among the children of depressed and normal parents. It appeared that the children of depressed parents were less likely to use problem-focussed coping, but displayed more information-seeking. Emotion-focussed coping was largely based upon emotional discharge. Differences in coping skills accounted for 9 % of the variance between depressed and non-depressed children. A further 2.5 % was explained by the negative life events, 2.8 % by ongoing strains, and 7 % by the extent of social resouces.

Stiffman et al. (1986) identify coping skills according to parental reports of social competence (Achenbach Child Behaviour Checklist). This included the ability to sustain friendships and mobilise peer support, the ability to communicate needs to others and to benefit from advice and social resources. It involved participation in active pursuits and performance in academic subjects. The strongest predictors of good child adjustment of children deemed "at risk", on account of maternal mental state, were school achievement and a high participation level in a variety of hobbies, clubs and sports.

High satisfaction and success in school life and strong peer group allegiances were two successful coping strategies reported in some

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case-study examples by Hirsch (1985), of children with family problems. They were the children of a depressed mother and an arthritic mother, and their successful adaptation points to the importance of cultivating rewarding activities and relationships outside of the family sphere, such that they could not be focussed predominantly upon family events and topics. Such coping strategies would encourage the development of extra-family identities allowing for the healthy separation of family and non-family roles and activities.

Coping is a transactional process that involves the integration of resources in several personal and environmental domains. As the previous research study has indicated, it is the accumulation of resources in spheres other than those in which adversity resides, and the spread of resources across family, school and peer groups, which lends towards healthy adaptation in the face of stressful life circumstances.

The interaction of coping style with social resources is also evident. Both have been shown to attenuate the relationship between stressful life events and personal functioning (Billings & Moos, 1981). A person with a limited social network is likely to have fewer resources of potential social support, and is therefore more likely to use coping strategies based upon avoidance (keeping feelings to oneself, reducing tension through eating / smoking). A person with a supportive network of friends, with some separation from life-domains characterised by adversity, is able to utilise coping strategies which involve seeking support and making adaptive use of such friendships.

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There must be some understanding of the interrelationships between the variables predisposing towards resilience or adversity which have been discussed here. The understanding must extend to an awareness of the linkages between social systems - for the child, the linkages between the family, the school and the peer group. Bronfenbrenner (1979) has stressed the developmental and adaptive potential of such linkages, interactional spheres which have become known as "mesosystems". A child who perceives such linkages, such that his / her parents display interest and involvement in the child's school life, or such that a child's friends spend time among the child's family, will develop a more positive orientation and an adaptive personal identity in which family, school and friendship life can be satisfactorily integrated.

What has developed from such research has been a ecological conception of developmental impairment which contains an understanding of coping and support mechanisms across multiple social domains. The analysis of peer relationships and social networks is crucial to the understanding to these mesosystems. A social network is not only a source of support and builder of coping skills, it is also the mediating domain which maintains such family / school / peer links. Understandings of these areas have also proved to be of importance in the development of therapeutic intervention and preventative strategies for children faced with stressors in the family or school domain (Hirsch, 1985; Dowling & Osborne, 1985).

# 4.5 Peer relations and social network analysis in children at risk for psychopathology

In the study of a child's peer relationships, there is an awareness of

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the system interdependencies between the different social worlds of the child. Correlational studies have pointed to the importance of warm and secure relationships with family members for the development of competence and success in peer relations (see Hartup, 1986). The effect would appear to operate through the enhancement of a child's self-confidence and esteem.

The mother-child relationship provides an affective and instrumental base upon which competencies in peer relationships will emerge. Α study by Lieberman (1976) demonstrated how secure attachments between mothers and three year olds (defined according to Ainsworth's strange assessment), predisposed towards more positive and situations responsive social interactions with other children. The mothers of securely attached children were also more likely to provide experiences involving engagement with other children. A prospective study by Waters et al. (1979), found that mother-child interaction patterns assessed at 15 months, predicted patterns of interaction with peers at nursery school up to 2 year later. The securely attached children were more socially active, participarting in activities more often than onlooking; they they were more sympathetic to peer distress and sought out peer leaders more often than the children identified as poorly attached to their mothers.

Parenting style, parental affection and satisfaction with children have also been linked with a child's peer relations and popularity at school. Parental affection has been shown to correlate positively with a child's self-confidence, assertiveness and effective peer interaction skills. Those children who are well liked by their peers, report more satisfaction with their home lives, describing their

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families as more cohesive and less conflictual than those children who are unpopular in their peer groups (see Hartup, 1986).

Parental social networks are also of significant importance for child development. They provide access to alternative adult role models, and provide additional cognitive and social stimulation, teaching varied interactional styles and providing different activities and settings for the development of important network-building skills (Cochran & Brassard, 1979).

Children's friendships have been shown to have important consequences for healthy development. Positive peer relationships are associated with social competence, school achievement and general adjustment in childhood (Hartup, 1979). In later childhood, peer relationships are necessary in order to achieve emancipation from the family and to build alternative social identities. Relationships with peers are also some of the best predictors of later disorder and successfully distinguish children in need of emotional treatment from controls.

life Stressful circumstances also have impact upon child relationships. Hetherington et al. (1985), examined the peer interactions of 48 children from divorced families and matched children from nuclear families. Both girls and boys showed evidence of antagonistic and aggressive behaviour towards peers two months after the divorce. Whilst the girls showed improvement with time, there were still signs of increased hostility to peers from the boys of divorced parents, two years on. Observations revealed group differences in child play with peers which could be explained by the parental separation. Both sexes showed signs of less imaginative, less

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cooperative and constructive play with peers. The disturbances were again more persistent in the boys of the divorced parents. The assessment two years post-divorce, showed that these children played in a less cooperative, constructive and imaginative way, when compared to the control children, with more solitary or onlooking behaviour, and increased contact over time with girls and children younger than themselves.

Achenbach and Edelbrock (1981) in a national study of children and adolescents referred to child guidance clinics, with matched non-referred children, found that disturbances in peer relations (on maternal and teacher reports), most clearly differentiated the groups. A retrospective study also indicated that those children, at risk on account of a parental mental illness, who later went on to develop emotional or behavioural adjustment problems were also those who could be identified early on, on the basis of existing peer relationship problems (Mednick & Schulsinger, 1968).

Peer ratings have been used in studies of children at risk for later maladjustment, and it appears that children are very perceptive observers of one another. Peer ratings of popularity are important predictors of child adjustment. Classroom peers have been shown to be more accurate predictors of later adversity than both parental and teacher ratings (Rolf, 1976; Cowen et al. 1973).

Cowen et al.'s (1973) long-term follow-up study of early detected vulnerable children, indicates that those children rated negatively by peers at 8 years of age, are more likely to end up on the psychiatric register in early adulthood (11-13 years later). Peer ratings are

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made according to Bower's class-play inventory (1969), in which each child in a class is requested to allocate children to one of 17 roles, including a variety of positive roles (eg. a good loyal friend; the most helpful and well-liked), negative externalising roles (eg. tough bad guy; class-bully), negative internalising roles (eg. a very shy person who doesn't have many friends), plus other negative choices (eg. class pest; very lazy person). Self-evaluations include the choice of two roles the child felt that he himself could play and the two roles most likely to be chosen for himself by his class-mates. The children who had been "red-tagged" at 8, on the basis of having schizophrenic or depressed mothers, were allocated to more negative roles in comparison to controls, and selected more negative roles for themselves.

In a study by Rolf (1976), children from 37 elementary schools with defined behavioural problems (attending clinics for externalising or internalising behaviour) or family problems (a depressive or schizophrenic condition in a parent), were rated by peers using the class-play technique. The children of schizophrenic mothers received significantly more negative externalising roles, and the internalising children more negative internalising roles, in comparison to controls. The clinic children showed very negative self-concepts and appeared to have established peer reputations for negative social traits. Rolf describes the findings as suggesting that these children are "locked-in at an early age to a self-fulfilling prophecy of social incompetence".

Weintraub et al. (1975), used the Pupil Evaluation Inventory (Pekarik et al. 1976), in order to assess the children of schizophrenic,

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depressed and healthy mothers. The children of schizophrenic mothers were viewed more deviantly than controls - they scored more highly on peer ratings of aggression, unhappiness and withdrawal. Similar peer ratings were found for the children of depressed mothers. Aggressive children are unpopular and particularly more likely to be rejected by peers (Patterson, 1982). Children engaged in physical aggression and hostile verbalisations in organised play sessions were more likely to receive rejecting and negative evaluations from peers. Those children who played more cooperatively with ongoing social conversation were more likely to receive positive social evaluations (Dodge 1983). Whilst those children neglected by peers (ie. not chosen for either positive or negative roles), had a possibility of moving towards a more positive social status in time, the longitudinal perspective of Dodge's study showed that the children allocated negative roles were less likely to improve and were more susceptible to later behavioural problems. The opportunities for peer to peer contact and for learning acceptable social skills are likely to be greatly reduced among these children.

A new growth area in the study of peer relationships is the social network approach to the study of adolescent supportive social contacts. The changing approach from the study of individual peer-peer relations to the analysis of relational ties and structural network components, goes some way in explaining the changing dimensions of social relations from childhood to adolescence. Conceptions of friendship, and the language used to describe them become more complex and well-differentiated with increasing age (Hartup, 1979). Notions of reciprocity and synchrony in social relations only begin to emerge in later childhood.

A social network is made up of significant members of family, friends and important affiliated professionals, who are connected in some way to the focal person. The network can be defined structurally in terms of the pattern and size of the complete network, and interactionally in terms of the types of link or relationships which exist and the pattern of their interconnections. The ties or links between network members and respondents can be seen as pathways through which there is a flow of practical or emotional support, services and information.

Most studies restrict their analysis of social networks to those members who share some depth-relationship with the respondent, either in terms of their field of origin (relatives, friends, club or activity), or with regard to some quality of the relationship (such as a measure of "intimacy"). Attempts have been made to define those people perceived by the focal person as "significant" or "important" in their lives. The criteria for inclusion will determine the size of the final network (eg. whether inclusion is based upon "knowing" as against "not-knowing", or upon frequency of contact, or perceived quality of interaction).

Considerable interest has recently been shown in the study of social networks. They are seen to play a role in the treatment of psychiatric patients (Tolsdorf, 1976), as a protection against psychiatric disorders in times of stress (Caplan, 1974), and as sources of buffering services, such as social support. Research into adult depressive illnesses stresses the role of social contacts and supportive / confiding relationships in protecting against adversity. The adult models of social supportive networks and relationships do

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not appear to be adequate for understanding children at risk for psychopathology. Their attempts at evaluating relationship dimensions are, however, of some interest.

The Camberwell and Islington studies of depressed women (Brown et al. 1975; Brown & Harris, 1978; Brown et al. 1986; Brown & Bifilco, 1983), assessed the roles of relationships in the face of coexisting adverse life events. Network members were identified according to the social support they provided. Their role was to exert a buffering (interaction) effect in the prevention of psychiatric disorder.

Interviewer-based ratings focussed upon the close, confiding relationships, or "core-ties" (usually with the spouse or best friend of the respondent). A type "a" relationship was identified where there was convincing evidence that the respondent had a close and confiding relationship with a person. A type "b" relationship was identified where the respondent lacked an intimate tie, but had a confiding relationship with someone seen at least weekly. Ratings "c" and "d" reflected women with confidants who were seen less frequently than weekly, or for whom no confidants were mentioned. This somewhat crude rating had substantial power, interacting with the provoking agent to predict depression. The type "a" relationship showed a strong protective effect, but "b" and "c" relationships failed to provide even marginal protection. It appears that the existance of any kind of confidant and the frequency of social contact cannot modify the impact of adverse events. Once intimacy is controlled for, no relationship remained between frequency of contact and depression. The support provided from a general network of ties did not appear to have any protective effect over and above that of the core

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relationship.

A prospective study by Brown et al. (1986) suggests that the mere presence of a confiding relationship prior to a life event has little association with the onset of adult depression. It is the ability of that person to mobilise crisis support following the event which appears to reduce the risk of depression.

The research by Henderson et al. (1980; 1981) attempts to determine a minimum requirement of social interaction for healthy adjustment, and to identify those qualities of relationships which are relevant for psychological and physical well-being. Their findings suggest a model for the protective main-effect of social relationships, occurring independently of adversity.

The sophisticated instrument designed for these studies aimed to assess certain qualities of relationships and social contacts. It encompasses notions of daily interaction involving service contacts and superficial contacts, contacts with whom the respondent shares interests, greets, speaks to, visits uninvited, experiences group reciprocity with, confides and ventilates feelings with, receives comfort from, or to whom the respondent looks for help and guidance. Indexes of availability and perceived adequacy are developed.

The availability index did not correlate with onset of clinical depression. An association was evident, however, for the perceived adequacy score. Thus, it is not the existence of social contacts, as such, which is protective, but how adequate they are perceived to be by the respondent. Such perceptions may be influenced by personal

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characteristics, such as self-esteem, or a depressive perceptual bias. Evidence seems to suggest that vulnerable or depressed persons are more likely to perceive available social resources as inadequate (Brown et al. 1986), and are likely to have impaired skills in extracting available support from their network members.

The research of Hirsch and colleagues (Hirsch, 1979; 1980; 1981; 1985; Hirsch, Moos & Reischl, 1985; Hirsch & Reischl, 1985; Hirsch et al. 1985), has contributed greatly to the study of social networks. Of particular relevance here are those studies which focus upon the 12-18 year old children at risk for psychopathology on account of a parental illness. Their studies included 16 adolescents with a parent receiving treatment for a depressive disorder (Research Diagnostic Criteria for major or minor depression), 16 adolescents with a parent suffering from rheumatoid arthritis (currently receiving treatment from a rheumatologist), and 16 adolescents with healthy parents.

Their use of structured interviews in conjunction with self-report questionnaires and daily diary forms completed during periods of ongoing stress, have removed some of the reliance upon retrospective or prospective self-reports, and mimimise problems of recall. The Social Network Questionnaire is concerned with up to 15 identified persons who are seen by the respondent to be "presently significant in their lives". These significant others were those with whom the respondent was likely to interact at least once during any 2-3 week period. Family and relatives, friends and non-family adults were recorded separately.

The Daily Interaction Rating Form represented a daily track of the

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amount of time spent interacting with network members. Overall satisfaction and the quality of interaction was rated according to the provision of social support (such as sharing feelings or personal Daily records were collected for up to 27 days during concerns). times of stress (eq. during final examinations or during time of major life changes according to Holmes-Rahe Social Readjustment Scale). A matrix format was used to develop specific network characteristics, such as density. Network density is an assesssment of the extent to which the significant network members know one It is a proportion, of actual to potential numbers of another. relationships which exist between the members included on the list. Thus, a network density of 1.0 shows that all 15 significant persons in the network are familiar with one another - the network is described as dense. Alternatively, a density of 0.3 would be described as a sparsely knit network.

1. Specific social support was assessed in the face of "the most problematic family and the most problematic school hassle", which the adolescent had experienced in the past several months. The index of support was calculated according to the number of individuals named who provided helpful cognitive guidance, emotional support, or tangible assistance. Codings made from taped discussions achieved 98 % agreement between independent raters.

2. Friendship variables included activities participated in with the network members, the degree of confidency, stress and reciprocity in the respondent-network member relationships. Scores were calculated for the respondent's best-friend and a mean-friendship score.

3. A measure of boundary density consisted of the proportion and quality of relationships between the adolescent's parents and friends. Relationships were said to exist where parents and friends of the adolescent were said to know one another. The density score was weighted according to the extent to which a relationship existed.

Three network dimensions appear to be of considerable importance in the determination of mental health outcome. The first of these is MULTIDIMENSIONALITY. A multi-dimensional relationship friendship occurs where at least two major activities or interests are shared by of the relationship. The friends may attend a both parties sports-club together and also go to the same church. The more multidimensional the contact between two people, the greater the opportunity for role variation and complexity. The existence of multidimensional relationships has been shown to be beneficial under conditions of major life change of stress. In the study of final year students during the time of examinations, it was the satisfaction with multidimensional relationships which was the most important predictor of overall social network satisfaction. The relationships were seen to encourage exploratory behaviour whilst providing a setting for mutual trust and the provision of emotional support (Hirsch, 1981). The existence of multidimensional relationships, among those undergoing major life changes, was found to correlate positively with ratings of self-esteem and perceived satisfaction of support (Hirsch, 1985).

NETWORK DENSITY is the second important network dimension which appears to have an impact upon physical and psychological health. Under normal circumstances, a high network density (where a large

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proportion of the network members know one another) provides a very satisfactory social life. However, in situations of adversity and stressful life events, a low network density appear to be protective (Hirsch, 1981). Network members may be called upon to serve different supportive functions. They allow for a greater diversity of feedback, the maintenance of a greater variety of norms, whilst ensuring the protection of other friendships (Billing & Moos, 1979). The stresses and adverse effects on self-esteem associated with with the seeking and receiving of help from confidants suggests that a low network density with greater segregation is most beneficial for persons undergoing major life changes.

Among college students approaching examinations and recently widowed or mature women returning to college, a high network density was associated with poorer satisfaction of support received and poorer mental health. Hirsch writes that,

"the greater diversity of interests and segregation of different spheres of activity characterising low density, multi-dimensional natural social supports can be seen to serve as an insurance policy. This policy may serve to protect individuals from having problematic changes in particular spheres of their lives become too encompassing, threatening and debilitating. The policy may provide rewarding alternative social identities and activities, facilitating a smoother reorganisation of one's life, at less psychic cost".

A similar differential effect, among persons faced with stressors and persons without, was demonstrated for the third dimension of networks discussed here. BOUNDARY-DENSITY looks at the relationship which exists across the different social spheres of a person. An adolescent may have developed three separate social worlds - the family, the school and the peer group, fostering different social identities and patterns of interaction. Previous discussions have already highlighted how adversity in one sphere may result in impaired adjustment in another. The permeability between spheres is likely to be a function of relationships which exist across these different areas of a person's life, resulting in informational and emotional transfer from one sphere to the next.

The research from the Illinois group (Billings & Moos, 1983; Hirsch & Reischl, 1985), addresses the importance of the NUCLEAR-FAMILY-FRIEND BOUNDARY DENSITY. Density is calculated on the basis of the actual to potential relationships existing between parents and the friends of the respondent. It concerns the extent to which children talk to their friends about their respective families, and the amount of contact with respective parents with visits to each other's houses, and outings with each other's families. It is basically a measure of how well parents and friends know one another and the involvement of parents in their children's lives outside of the home.

Low density or "segregated" networks allow for one segment of a network to serve as a source of support against stresses or adversities in another part of a network. They provide a resource for the necessary support of adaptive non-family involvements. The adolescent children of depressed or arthritic parents were better adjusted to family adversity, where there was little contact between parents and peer group.

Strong family-friend linkages, in terms of friends coming to the adolescent's house, going on outings with the friend's families, discussing family matters with their friends, and knowing their

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friends' parents, were associated with lower self-esteem, more severe psychological symptoms and less satisfaction with friendships. The association appeared to operate in the opposite direction for the children of normal parents. High family-friend boundary density was associated with better adjustment and a higher self-esteem.

This study points to an interesting paradox in the protective effects of peer networks. The degree of support received from peers for a family or school hassle, the number of activities problematic participated in with the adolescent's best-friend, and the boundary density between parents and friends, all correlated positively with self-esteem and psychological and physical health for the control group, but negatively for the childen with sick parents. Something very interesting is happening here. Some caution is required as sample sizes are small and the direction of causality is unknown; replication of the finding is strongly called for. There is a suggestion that adolescents are aware of the "differentness" of their sick parents. Contact with their friends' parents can only serve to enhance this understanding. The awareness that their parent is different from others and may act embarassingly and unpredictably, may make a child anxious about the security of their friendships. It may be more difficult for them to reciprocate - in having friends over to their house, and there may be anxieties about how they themselves will be perceived by their friends.

It is of some significance that similar findings were made for the children of arthritic parents. A parental physical as well as a psychological disability appears to have a negative impact on a child's ability to make adaptive use of peer friendships for support.

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It seems that adolescents, overall, have some difficulty asking for support. In the study, 35 % reported that they had received no support from family or peers for a family problem. Thirty-three percent reported that they had received no support for the most problematic school difficulty that had recently occurred. An impression emerged, that for these adolescents, the receipt of support was somewhat socially undesirable. It may be that the adolescents with sick parents already have lower self-esteems and more symptoms, rendering them more vulnerable in the face of more intimate and active friendships, more family-friend contact, and so on. It may be the greater need among these children to develop alternative social identities apart from the family, which has played a part in the fostering of damagingly low self-concepts.

The findings of the Illinois group contradict the main-effect or buffering (interaction) hypotheses of social support taken from the adult models of depression (Brown & Harris, 1978; Henderson, 1980). The existence of an adequate social network, a supportive and confiding relationship outside of the home, does not appear to be providing the expected protection for these adolescents with family difficulties. The findings from these studies, suggests something of the complexity of the reaction of children to parental illness, and of the importance of how they experience, perceive and understand it. The child's image of self and image of family are crucial in determining coping style and whether that child will be rendered vulnerable or resilient in the face of family disorder.

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# The Post-Viral Fatigue Syndrome from a family perspective: a comparative study of the children of sick mothers and healthy controls

#### 5.1 Introduction

The family has emerged as a major focus of enquiry for the investigation of mental and physical illness. The study of family processes and intra-familial relationships has typically developed because of an interest in the effect of the family upon the course and outcome of a disorder. The measurement of family social resources, coping strategies and the quality of important relationships in the family has become part of the assessment of treatment success in the rehabilitation of psychiatric patients. More recently, an interest in the deleterious consequences to the rest of the family of caring for a member with disordered mental or physical health, has resulted in the study of the "burden" of care and the process of adjustment which must take place in order to accomodate it.

A crisis in a family system, such as the onset of a physical or psychological disorder, requires the adjustment of habitual problem-solving mechanisms to achieve a new equilibrium (Moos & Tsu, 1977). The reverberations continue well outside of the family boundaries influencing social adjustment in the spheres of work, school, leisure activities and social networks.

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The family has a part to play as a precipitant, a predisposing or contributory factor in the aetiology of disorder and in the care and treatment of its sick members. The involvement of family dynamics in the onset, course and rehabilitation of chronic medical illness and psychiatric disorder has been investigated in a number of research areas.

Firstly, there is the observation that mental and physical illnesses often affect several family members at the same time. There appears to be some familial transmission which is over and above that which can be explained by genetics alone (Rutter, 1985). Multiple paths of transmission have been reported. The incidence of depressive disorders is found to be elevated in the spouses of depressed patients (Fadden et al, 1987); competing physical and emotional disturbances have been reported in the spouses of the chronically sick (Springer, 1985); significant numbers of mental and physical illnesses were found in the parents of children attending child guidance and psychiatric clinics (Rutter, 1966), and adult depression is associated with an increased risk for major depression, school problems and peer maladjustment in the children of the adult's families (Weissman, 1987).

Secondly, it has been found that family attitudes and relationships can influence the course and outcome of disorders. In a study of depressed patients, Vaughn and Leff (1976) found that the amount of criticism expressed towards the patient by family members at the time of hospitalisation could significantly predict the rate of relapse within months of discharge. A study by Feldman (1976) shows how a partner can maintain or trigger depressive symptomatology in a

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discharged psychiatric patient. Family resources and coping responses have been implicated in the post-treatment outcome of alcoholic and depressed patients (Cronkite & Moos, 1980). In another study, family environment factors predicted readmission of schizophrenic and depressed patients more adequately than base-line ratings of clinical status (Spiegel & Wissler, 1986).

Thirdly, it has been found that children are at emotional, behavioural and developmental risk from upbringing in families with sick parents. The preceding review investigated the pathways through which a disorder in a parent can lead to adverse emotional and behavioural adjustment in a child. The discussion was based primarily upon the children of mothers suffering from major depressive disorders. Investigations of the literature suggest that:

(i) the specific parental diagnosis does not matter as much as the degree of invalidity and the loss of ability to function adequately in the roles of parent, educator, provider, etc.

(ii) physical disability in a parent may be as damaging to a child's emotional, behavioural and social adjustment as a parental psychiatric disorder; and that

(iii) it is the milder depressive disorders, treated largely in primary-care or out-patient settings, such as those which may accompany a physical condition, which put a child at the most risk for adjustment problems, through increased exposure to the parent's symptoms and the increased perceived and realised burden upon the supporting family.

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The intention of the following study is to examine the consequence of the post-viral fatigue syndrome on the family unit. The impact of the illness will be assessed in terms of a) its effects on the mental status and coping strategies of the sufferer, b) its effects on family environment and interaction patterns and c) its effects upon the social networks of family members. The particular focus of this study is an investigation into the adverse effects upon school-aged children of having a mother who is suffering from the syndrome. Previous research findings indicate that depression in a mother may put a child an increased risk for current emotional, behavioural and peer at adjustment problems. It has been established that general parental disability and the ongoing family strains associated with chronic illness may be as potent a risk factor for a child as the depressive symptoms themselves. The children in these families have been exposed to the direct effects of the illness and the resulting changes in family life. As regards specific hypotheses:

1. It was expected that the children of mothers suffering from the post-viral fatigue syndrome would exhibit poorer adjustment and more problematic school behaviour that matched control children.

2. It was expected that the family social climate of the families with sick mothers would differ from that of the controls.

3. It was expected that the quality and type of interaction between child and family would differ between the two groups.

4. A specific test was made of the hypothesis emerging from the work

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of Hirsch et al (1985), that the degree of contact between a child's parents and friends would predict a child's adjustment to family stressors. In their study, increased contact between a sick parent and a child's peer social network was associated with poorer adjustment in the children of these families. However, a high level of contact between children's social networks and parents in healthy families was associated with better adjustment. This is an interesting paradox in the understanding of the protective effect of social networks in children and the link between social systems of families and peer groups. A specific replication of this finding was carried out in the present study.

# 5.2 Research Design

# Selection of subjects

Nine families with mothers suffering from the post-viral fatigue syndrome were recruited from the local self-help groups of the Myalgic Encephalomyelitis Association. Families were contacted following initial confirmation by the group leaders that they fulfilled the following criteria:

(i) a confirmed diagnosis of post-viral fatigue syndrome

(ii) at least one child living at home who fell within the 8-14 years age group.

Obtaining access

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The use of self-help groups for the selection of subjects has an advantage over G.P. or consultant lists in that the self-help populations are likely to have a much higher compliance rate in research projects. The group leaders provided access to families with a more personal introduction than could a medical practitioner approaching a referring patient with a protocol. One disadvantage in the use of such groups, and particularly so for a condition which has currently received so much media attention, is the problem of self-diagnosis. There are likely to be some individuals within such groups who are searching for legitimation for illness behaviour which has not received a diagnosis from the medical profession. For those others who have already received a psychiatric diagnosis which is perhaps unwelcomed, the easy access to the "M.E." label may be particularly attractive.

The problem is one which is well known and frequently identified by the group leaders. They are not able to preclude the membership of these people, nor are they easily identified. However, it is a policy of the N.E. England branch to advise prospective group members to contact a specialist doctor in order to receive confirmation of the M.E. diagnosis. Anti-body titres and viral protein tests are conducted by these doctors. They acknowledge the unreliabilities of these tests and accept that a "negative" result is not a disconfirmation of the syndrome. But alongside a characteristic clinical presentation and a full medical and psychiatric history, they are able to come closer to a "safe" diagnosis, minimising the false-positives.

I met members from these groups who expressed strong beliefs that they

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suffered from the syndrome but who had chosen not to have a diagnostic test. Amongst these were those who felt a strong desire to bring a long period of medical and psychiatric investigations to an end, and those who had been told that there was no evidence that they had a post-viral condition and for which a psychiatric diagnosis had been offerred, but who still believed themselves that they had the syndrome. Of course, there is nothing to say that these persons were not suffering from some post-viral debility or immunological dysfunction. However, caution was exercised in including these "uncertain" diagnosis subjects in the study.

# Confirming the diagnosis

Diagnosis was made by the G.P.s on the basis of significantly raised antibody titres to the Coxsackie B viruses found in the serum, alongside reports of an initial (acute) infectious onset, and characteristic profile of symptoms. Diagnoses were confirmed by six of the subjects with letters they had received from the specialists who had conducted the tests. In three of the subjects the medical status was checked with one of the two specialist G.P.s who were treating them.

The selected subjects met the following criteria: (i) mother aged between 25 and 60 at the time of investigation; (ii) symptoms characteristic of post-viral fatigue syndrome, with fatigue which had persisted for at least 3 months; (iii) a laboratory diagnosis of past or persistent infection with one of the Coxsackie B enteroviruses on the basis of specific anti-body titres and / or a positive viral protein test; (iv) diagnostic confirmation from one of the two local G.P.s specialising in the syndrome; (v) children between the ages of 8 and 14.

The subjects selected cannot be said to form a representative group of mothers with post-viral fatigue syndrome in the area. Because of the difficulties of access to these families it was not possible to obtain a random selection of sufferers. Group leaders were reluctant to allow contact with families known to be under a considerable amount of stress as a result of ill health. Families rejected for inclusion included those more severe sufferers who were almost totally bed-bound. Those with additional stressors, for example a child in the family with a mental handicap, or severe illness in the carers of the sufferers were also excluded from the selection. The group leaders were occasionally reluctant to select families on grounds of expected serious objections to being included.

A list of 18 families was drawn up. Initial contact was made by the group leaders who were familiar with the sufferers and a protocol which was sent to them by post. A follow-up phone call resulted in the selection of 13 families. Four were later withdrawn from the study because they felt that they were currently not well-enough to take part. Reasons for refusal included, current acute state of illness (N=7), additional family stresses (N=4), unwillingness of other family members (N=3), and suspicion of a study which suggested to some that the investigation was looking at faulty parenting skills of these mothers (N=2). The nine families which remained were willing volunteers who welcomed research in a very much neglected area.

Whilst it was not possible to obtain information on illness and

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psychiatric status of those who refused to take part, it was clear that seven out of the nine refusers did so because of subjective reports of severe ill health. However, within the selected group, there was a range of reported illness severity, some of whom had severe and disabling conditions. Self-reported illness durations ranged from 18 months to 14 years. Five had been ill from between 18 and 36 months, two had been ill from between 3 and 4 years and the remaining two subjects had been ill for 6 and 14 years.

## The target child

One child was selected from each family falling within the 8-14 year age group. Where more than one child fell into this category, the target child was chosen on a random basis. The target child serves as a focus for looking at the impact of maternal illness. This child will also provide the age and sex criteria for the matching of the control families.

# Selection of the control families

Nine control families were selected from the same neighbourhoods as the post-viral fatigue syndrome families. They represent an "opportunity" sample, chosen by the PVFS group themselves. The PVFS families were asked if they could recommend a family they knew in their local area with children the same age as the target child. It was felt that contact with such families would reduce the variability of family and socio-demographic factors. Three of the post-viral subjects were unable to recommend a family. They described considerable isolation from their neighbourhoods on account of the

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illness. Control families for these subjects were selected after referral from other control families in similar geographical areas.

Of these 9 provisional control families, two were unwilling to take part; time commitments and the unwillingness of other family members were mentioned. One family dropped out during the course of the study, and one failed to match on the age and sex of the target child. Four additional families with good matches on the age and sex of the target children were recommended by the post-viral families.

The families were selected when adequate matching was found on geographical location, housing type, sex of the child and age within 12 months. Three of the children were also successfully matched on the school they attended. Table 1 represents the matching of the two groups on socio-economic status (from paternal occupation, unless divorced), marital status, and maternal education. Group differences are compared using the Fisher exact probability test (Siegel, 1956).

There are no significant differences between the groups on socio-economic status or marital status. A comparison of maternal education divided at those with "O" Levels and higher and those below this showed no statistically significant difference but a trend for the control subjects to have a higher degree of education. Healthy mothers were significantly older than the sick mothers, with a mean age of 39.2 years, compared to a mean age of 36.2 years in the PVFS group (t=-2.3, dfl6, p<0.05). There were no significant differences in the numbers of children living in these families (a mean of 1.8 children in the PVFS families and a mean of 2.2 children in the controls.

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		PVFS	CONTROLS	FISHER
SOCIO-ECONOMIC STATUS	I-II	4	5	p > .05
	III-IV	5	4	-
MARITAL STATUS	Married	6	8	p > .05
	Divorced / Sep.	3	1	
MATERNAL EDUCATION	Higher	1	2	p > .05
	"A" Levels	1	3	r icc
	"O" Levels	2	3	
	"CSE"	1	0	
	None	4	1	

# COMPARISON OF POST-VIRAL AND CONTROL FAMILIES ON SES MARITAL STATUS AND MATERNAL EDUCATION

## 5.3 Family assessment

#### Maternal sickness dimensions (PVFS group only)

Information on the history of the condition was collected by semi-structured interviewing. The date of onset of symptoms was rated by self-report. It was the date on which the family doctor was first consulted or on which the subject reported enforced abdication from work, social or family roles.

A record was made of the number of specialists which had been contacted since the onset of ill health. They included medical specialists, psychiatric and psychological specialists and alternative practitioners.

Subjects reported any life-time episodes of psychiatric disorder, and presciptions of psychotropic medication issued by their general practitioners, during the course or their current illness or prior to the onset of PVFS. Any episodes which had resulted in periods of hospitalisation in psychiatric settings were reported. Subjects were asked if there was any immediate family history of severe medical or nervous problems. Finally, current medication was recorded.

#### Maternal coping style

The coping strategies of the sick member has predictive potential for the degree of distress which is experienced and for the long term prognosis of the condition. Rutter's (1984) study of mothers with

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depression, indicates that it is the way in which the mother expresses her distress and not her depressive symptoms as such, which predict adverse reactions in the children. It is likely that the communication of such distress is closely aligned to coping style.

Family members must not only seek ways of coping with the physical impact of an illness, but must be alert to the response the sick person makes to the event. The reaction of the sick member may prove a greater burden to the family than the illness itself. Reactions can range from depressive withdrawal or angry resistance to calm adjustment and acceptance of limitations imposed by the illness.

Moos and Tsu (1977) analyse the demands made by serious illness in terms of a set of adaptive tasks for the sick person and his or her close family. Failure to master these tasks can result in adverse psychological consequences and disrupted family functioning. The tasks can be achieved by means of the following seven major coping styles:

(i) denial or minimisation of the crisis; the ability to discuss the illness presentation with clinical detachment;

(ii) seeking of relevant information;

(iii) the requesting of reassurance and emotional support;

(iv) the learning of specific illness-related procedures and treatments;

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(v) the setting of concrete goals but within the limitations of illness;

(vi) the rehearsal of alternative outcomes; mental preparation;

(vii) finding a general purpose or pattern of meaning.

number of studies have attempted to identify adaptive and Α maladaptive coping styles which are able to predict psychological adjustment, long-term physical outcome and emotional strain on carers. Psychological disturbance has been found to be greatest where a patient's coping response to a diagnosis of cancer involved fatalism, displacement or projection (Katz et al. 1970). Stoical acceptance amongst women sufferers and helplessness / hopelessness in men were significantly associated with an unfavourable physical prognosis, whereas responses characterised by a fighting spirit or denial had a much better medical condition on a 10 year follow-up (Pettingale et al., 1985). In another study of women with breast cancer, an outlook based on a "fighting spirit" rather than one of "stoical acceptance" or giving up was associated with higher survival rates and reduced burden on the families (Greer et al. 1979).

A recent study of patients with the post-viral fatigue syndrome gives some indication of patient attitudes to illness and suggests patterns of coping which may be characteristic of this disorder. Hickie and colleagues (Hickie et al., 1990) administered the Illness Behaviour Questionnaire (Pilowsky & Spence, 1983) as a self-report inventory to 44 patients with the "chronic fatigue syndrome". Comparison was made with a sample of 147 general practice patients and 17 patients with a

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diagnosis of Briquet's hysteria. The chronic fatigue subjects expressed strong convictions of a physical-disease orientation and were reluctant to accept any psychological interpretations of their somatic symptoms, unlike the G.P. population. They did not present as hypochondriacal and were not inhibited in the expression of emotionally laden topics. There was no evidence of an inability to introspect or report on inner feelings, providing little proof for the assertion that this is a somatisation disorder.

There was a tendency in the chronic fatigue group to regard the chronic fatigue condition as the sole reason for psychosocial difficulties, believing that a physical cure would lead to complete problem-resolution. It is the firmness of their conviction in a physical interpretation of illness and a rejection of psychological aetiological or predisposing factors which can be seen as a motivational component in their involvement in self-help populations.

An assessment of illness attitudes and coping stragegies in this current study borrows from a newly developed self-rating scale which was designed to measure adjustment to a diagnosis of cancer (Watson et al. 1988). The Mental Adjustment to Cancer (MAC) scale was developed from clinical interviews with patients at various stages of the disease. The authors stress the importance of adapting the MAC scale to other serious illnesses. Four subscales of the inventory identify the following adjustment styles:

1. Fighting Spirit (14 items): a means of confronting illness, thinking positively and actively dealing with it. For example, "I believe that my positive attitude will benefit my health".

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2. Anxious-preoccupation (9 items): hypervigilence of bodily signs and seeking of information but with pessimistic interpretation. For example, "I feel that problems with my health prevent me from planning ahead".

3. Fatalistic (8 items): stoic acceptance of illness with a belief that things are out of their hands. For example, "I avoid finding out more about it".

4. Helpless / Hopeless (6 items): loading on a bi-polar dimension with "fighting spirit", this style suggests desires to give up with a feeling of hopelessness about the future.

The items are rated on a 4 point scale (Definitely does apply to me, applies to me, does not apply to me, definitely does not apply to me).

Investigations show the sub-scales to be internally consistent (alpha coefficients for the subscales range from .65 to .84). Validity, as demonstrated by correlations between reports of patients and spouses was found to be good for a population of cancer sufferers (Pearson coefficient ratings ranging from .66 to .76), although it cannot be said to have been validated for use with the PVFS group. It was utilised in this study, nevertheless, as an exploratory measure. Not only has it not been validated for use in this condition, but the implications of receiving these two diagnoses are clearly different. PVFS, unlike cancer, is not a potentially life-threatening condition and in spite of possible long-term illness and debility, there are hopes of complete remission. However, the scale is believed to have

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some potential use in the identification of important attitudes to PVFS which will reflect upon illness behaviour and coping style.

#### Maternal psychological adjustment

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was administered to sick and control mothers as a reliable instrument for the detection of states of depression and anxiety in community samples.

Each scale ranges from a self-reported score of 0 to 21. A score of 8-10 is identified as a borderline case, and scores of 10 and over will be regarded as definite cases of depressive or anxiety disorder. Mixed disorders are identified where high scores are obtained on both subscales. The psychometric properties and the development of the scale are discussed in detail in chapter 2.

#### Family psychosocial climate

The following inventories were completed by the mothers in both groups. The second scale was also completed by the fathers in the families (except those families which were divorced or separated) in order to assess incongruence in parental ratings.

a) The Family Routines Inventory (Jensen, 1983)

b) The Family Environment Scale (Moos & Moos, 1986).

The level of "organisation" in a family can be of critical importance in determining how individual members respond to the "disequilibrium"

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caused when a link in the family chain is weakened by illness. Illness can result in altered family functioning, changes in domination patterns and role boundaries, changes which may continue long after the illness. Such changes can have consequences for the health and adjustment of other family members. Children are particularly vulnerable.

Family rituals have been identified as critical factors in the prevention of the transmission of family problems, such as problem-drinking, to the children (Wolin et al., 1979), or adversity following parental separation (Wallerstein 1985). Organisational structure and parental control were found to be significantly related to the adjustment of the siblings of handicapped children, where the handicap had resulted in changes in family integrity and role tensions (Nihira et al., 1985).

Jensen's inventory is the only available instrument for the assessment of family routines. In designing the inventory, he was attempting to identify a critical variable in family life which could protect from or aggravate ill-health. A family routine was defined as "an observable, repetitive behaviour which involves two or more family members and which occurs with predictable regularity in the day to day and week to week life of the family". They represent behavioural units of family life, providing stability and structural continuity, buffering against the impact of stressful events and promoting strength and solidarity within the family.

The routines were selected from semi-structured family interviews with a wide-range of ethnic, social class and family life-stages. The

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final 28 routines which make up the inventory showed minimal correlations with race and social class and were judged by families to be of high importance in keeping their family strong. Ten areas of family life are covered;

Work day routines Weekend and leisure time routines Children's routines Parent's routines Bed-time routines Meal-time routines Extended family routines Leaving and home coming routines Disciplinary routines Household chores.

Psychometric properties were examined using families with at least one child under the age of 16, living at home. The inventories were completed by the mothers. Test-retest reliabilities, 30 days apart, showed continuity of responding (correlation coefficient for the frequency score .79). The Family Environment Scale (Moos & Moos, 1986) was used for the assessment of convergent and discriminant validity. The routines frequency score was found to correlate positively with family cohesion (Spearman rho .35, p<0.001), organisation (rho .36, p<0.001), and control (rho .20, p<0.001), and negatively with family conflict (rho -.18, p<0.001) as assessed on the Family Environment Scale. A positive correlation was also found for the age of the oldest child (rho .27, p<0.001) suggesting a change in the importance of family routines with different family stages.

A family's psychosocial climate has a critical impact upon the cognitive and social development of a child (Nihira et al., 1984), and has been shown to have a protective or buffering influence upon the impact of stressful life-events. It was found that in families with

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depressed parents, adolescents fared better (in terms of a higher level of self-esteem) in expressive and cohesive families that fostered the independence of individual members and which had less conflict. High self-esteem in non-depressed parental families was associated with increased cohesion and reduced conflict in the family climate with intellectual-cultural and active-recreational orientations (Hirsch et al., 1985).

A family's psycho-social climate has also been found to successfully predict the adjustment and rehospitalisation of psychiatric patients. Non-remitted depressives, one year later, show lower family cohesion, expressiveness and organisation and higher family conflict (Billings & Moos, 1985). Family environmental factors were also better predictors of rehospitalisation than baseline ratings of clinical status (Spiegel & Wissler, 1986). Better post-surgery adjustment for breast cancer was found in families identified as more expressive and lower in conflict (Bloom & Spiegel, 1984), and a cohesive family resulted in the maintenance of family functioning after dialysis for renal failure (Dimond, 1979). Psychosomatic and hypertensive conditions were found more often in families with high levels of organisation and control with low cohesion and expressiveness (McBurney & Baer, 1981; Waring & Russell, 1980).

The Family Environment Scale (Moos & Moos, 1986) was developed as a means of making a standard representation of a family and for facilitating family therapy interventions (Fuhr et al. 1981). It provides a picture of family psychosocial climate, family functioning and relationships, personal growth and system maintenance factors. A normative sample of some 1000 normal families and 500 families with

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psychiatric, substance abuse or adolescent management problems are used. The normal families are taken from census tract data and include families from different regions, different ethnic groups, varying marital, socio-economic and generational status. The distressed families were gathered from clinic and probation departments.

The 90 items of the FES cluster into 10 subscales which are described below:

1. COHESION: This is a measure of the degree to which family members are committed to one another and the extent to which they are helpful.

2. EXPRESSIVENESS: This is a measure of the degree to which family members are encouraged to openly express feelings and act in direct ways.

3. CONFLICT: This measures the extent to which the open expression of anger and aggression and conflictual interactions are characteristic of the family.

4. INDEPENDENCE: This assesses the extent to which family members are assertive and self-sufficient and able to make their own decisions.

5. ACHIEVEMENT-ORIENTATION: A measure of the extent to which school / work / other activities are cast into an achievement-oriented or competitive framework.

6. INTELLECTUAL-CULTURAL ORIENTATION: A measure of the degree of - 280 - interest in political, social, intellectual and cultural activities and the promotion of such activities within a family.

7. ACTIVE-RECREATIONAL ORIENTATION: This measures the level of family participation in social and recreational activities.

8. MORAL-RELIGIOUS EMPHASIS: This assesses the emphasis which the family places upon ethical and religious values.

9. ORGANISATION: This measures the importance of clear organisation and structure in the family and the importance placed upon family rules and responsibilities.

10. CONTROL: A measure of the extent to which the family is organised in a hierarchical fashion; the rigidity of family rules and procedures and the ways in which these run family life.

Each of these subscales is made up of 9 items self-reported in a true / false format. The scale range is therefore from 0 to 9 points. A family incongruence score is assessed by examining the difference score between the self-reports of 2 parents. This difference score ranges from 0 to 90 points. Family incongruence is a measure of family disagreement and is an important explanatory dimension of family dynamics.

Psychometric properties of the FES are good. The subscales are internally consistent. Cronbach's alphas demonstrate moderate reliabilities ranging from .64 for Independence to .78 for Cohesion (Moos & Moos, 1986). Intercorrelations between the subscales support

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the fact that they are measuring distinct although somewhat related aspects of a home environment. Test-retest reliabilities point to fairly stable family profiles for up to 12 months on retesting. Reliabilities vary from .68 for Independence to .86 for Cohesion (Moos et al. 1974).

Construct validity has been assessed using self-report scales, indices of family role and social functioning taken from family interviews, professional staff ratings from home visits and videotaped recordings of family interaction (Moos & Moos, 1986). Family cohesion was found to correlate with the Locke-Wallace Marital Adjustment Scale (Waring et al. 1981), and the Spanier Dyadic Adjustment Scale (Abbott & Brody, 1985). Jensen's Family Routines Inventory (Jensen, 1983) correlated with measures of cohesion, organisation, conflict and control. Levels of religious participation, joint family activities and the number of family arguments as assessed from semi-structured interview, correlated well with the FES respective subscales. Staff ratings and video recording also provided good construct validity for the scales (Spiegel & Wissler, 1983; Kosten et al. 1984).

# 5.4 Child adjustment measures

Although parental ill health may lead to severe psychiatric disorder in only a few children, it can result in impairment in other domains of functioning. It could be expressed in terms of physical and emotional complaints, behavioural and school problems, or attentional and cognitive disabilities. The aim of the assessment in this study is the uncovering of areas of competence as well as deficits within a wide gamut of adjustment including differing methods of collection and

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informants from different spheres.

The target child's psychological, behavioural, cognitive and social functioning were assessed on the following scales:

- 1. The Children's Depression Inventory (Lang & Tisher, 1978).
- 2. The Teacher-Child-Rating-Scale (Hightower et al., 1986).
- 3. The Child's Attitude to Mother Scale (Hudson, 1976).
- The Friendship Questionnaire: an assessment of child social networks (designed for the purposes of this study).

#### The Children's Depression Scale

The motivation behind the development of this scale was the current debate concerning childhood depressive disorders and presenting depressive equivalents. Since 1980, attempts have been made to demonstrate that the criteria for depression in adult life can be applied to children in an unmodified form espoused by DSM-III (American Psychiatric Association, 1980) and Feighner's criteria (Feighner et al., 1972). However, the reliable and valid use of these criteria with children have not been adequately or consistently evaluated (Shaffer, 1986). Individual and developmental differences have been identified in the presentation of childhood depression and dysfunction may be apparent in a variety of domains. In particular, symptoms such as somatic complaints and school refusal are not found in the adult criteria (Kashani et al., 1981), and other symptoms such as psycho-motor retardation / agitation or disturbed thinking are not often found in childhood. The Weinberg criteria (Weinberg et al., 1973) which preceded moves to diagnose childhood disorder in terms of adult psychopathology, developed child-specific features in descriptive terms. A multiplicity of symptoms and adjustment factors were used as evidence for depression. Many, such as dysphoria and self-depreciation were in common to adult criteria, and others, such as aggressive behaviour, change in attitude to and performance at school and somatic complaints could be regarded as child-specific in presentation or as symptoms which could be seen to "mask" depression.

This child self-report depression scale combines features of both of these developments. In particular, it is valued in terms of its breadth of coverage. Lang and Tisher report, "in terms of definition, we see depression as a range of behaviours, feelings and attitudes which varies in intensity and extent. We expect that childhood depression is present to varying degrees throughout the population as well as having a role in various specific groups such as bereaved children, underachieving children and psychiatric populations, particularly groups of children diagnosed as suffering from depression".

The Children's Depression Scale (CDS) was developed from careful examination of the clinical phenomenology of childhood depression and the evaluation of characteristics likely to occur with depression. In common with DSM-III-R criteria (American Psychiatric Association, 1987), the scale covers dysphoric mood, anhedonia and loss of interest in activities, self-depreciation and guilt, loss of energy or fatigue and changes in sleep patterns and suicidal ideation. It does not cover weight or appetite disturbances, the diminished ability to think

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or concentrate or psychomotor agitation or retardation. The need of another informant (than the child) to report upon these is paramount. Impairments in the cognitive arena and disturbances suggestive of over or under activity have not been proven to be defining characteristics of childhood depressive disorder although they may concur with such a diagnosis. In this study, they are covered in the teacher's assessment of classroom presentation.

Another major difference to the operational specifications for major depression in DSM-III-R is the absence of criteria for symptom duration in the CDS. The use of children's self-report of symptoms makes this approach impractical and thereby places paramount importance upon the applicability of cut-off criteria and successful validation in clinic and non-clinic populations. It is required, for the DSM criteria that at least five of the depressive symptoms must have been present throughout a two-week period. However, there is no empirical justification for the number of features required, nor of their duration (Shaffer, 1986). The importance of the criteria is a successful differentiation from concepts such as "demoralisation" (Frank, 1973) or "unhappiness" (Wing et al., 1977).

The CDS also incorporated items which may be correlates of depression but not defining characteristics of the syndrome. Thus, items of self-esteem, social interaction and thoughts relating to the child's own ill-health and death are included. The wide coverage of items, not specifically related to depression, does not invariably lead to a more comprehensive coverage of the syndrome, such as that defined by DSM-III (Kazdin & Petti, 1982). The problems identified with the Weinberg criteria, because of their broad coverage, included a

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tendency for them to meet the criteria for other psychaiatric diagnoses as well. Whilst the purpose of this present study is an assessment of child impairment and adjustment in a somewhat ecumenical sense, it is important that assessment on the CDS represents a measure of severity which can be understood alongside comparative data.

Another interesting feature of this scale, which recommends its much wider usage, is the inclusion of a scale corresponding to positive affect and pleasurable experiences. The value of this is that it is not simply at the other end of the depressive continuum. Correlations between the depression score and positive affect are in the low to moderate range (r=-.36 for child report and r=-.53 for adult report), (Kazdin, 1987).

The 5 subscales which make up the CDS are reported below with selected items taken from each of the 5 point scales.

- a) AFFECTIVE RESPONSE: This corresponds to the affect-state or mood of the child (eg. "I feel like crying often when I am at school").
- b) SOCIAL PROBLEMS: This reflects the child's difficulties in social interaction with corresponding feelings of isolation and loneliness (eg. "Often I feel lonely").
- c) SELF-ESTEEM: This reflects the child's feelings and attitudes of his own self-worth or value (eg. "I hate the way I look or the way I act").

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- d) PREOCCUPATION WITH OWN SICKNESS AND DEATH: Corresponding to fantasies, thoughts and dreams relating to ideas of death, illness and fatigue (eg. "I often imagine myself hurt or killed".
- e) GUILT: Feelings of self-blame (eg. "I feel as if I am letting my mother / father down").
- g) PLEASURE: This is a report of the experiences of happiness and fun in the child's life and his or her capacity to enjoy them (eg. "I'm always looking forward to the next day").

The card-sorting assessment format is an innovative feature of this scale. Each item is presented on a separate card thereby requiring individual contemplation without the influence of previous items or responses. The five boxes into which the items are posted correspond to a Likert-type scale ranging from "very wrong (unlike me)" to "very right (like me)". The format is particularly attractive to children, maintaining interest and helping to establish rapport. The "readability" of the passages (Fry, 1968), corresponding to syllable length and sentence complexity shows that it is appropriate for use from 8 years of age (Kazdin & Petti, 1982). The availability of the examiner to aid the reading of words and to check upon comprehension of the items where it is in doubt also enhances completion.

There are obvious limitations to the self-reporting of symptomatology which apply equally to adults and children. It is likely that age, cognitive development and degree of psychopathology could influence the accuracy of self-report in the discrimination of patients or non-patient subjects who meet diagnostic operational requirements.

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The value of self-report is, however, obvious when the characteristics of affective disorders are considered. The key symptoms reflect subjective feelings and self-perceptions which may not be objectively apparent in behavioural signs, and non-verbal manifestations of mood, which may be accessible to an observer, are difficult to assess. Thus there was an over-rating of depression by psychiatrists in the Isle of Wight study (Rutter et al. 1970).

It has been shown that children of clinic and non-clinic populations can give accurate accounts of how they are feeling (Cantwell & Carlson, 1983). Whilst they may report fewer overt behavioural signs than do parents or clinicians, and may be reluctant to report problematic behaviours that have drawn criticisms from others (Poznanski et al. 1979), they are often better reporters of symptoms relating to private or internal experiences. Information from the child on his or her subjective state has been validated in terms of suicidal attempts and independent assessments of suicidal ideation, negative attributional style, degrees of hopelessness and self-esteen and child-rearing practices (Kazdin, 1990).

Studies of childhood depression have pointed to the lack of correspondence of informant reports (Carlson & Cantwell, 1980; Weissman, 1980), raising questions as to the differential access to behavioural signs and subjective symptoms and the difficulties in the interpretation of childrens' statements. Feelings of hopelessness and despair towards the future require comprehensive cognitive skills along the lines of "formal" operational thinking, and young children may be incapable of expressing these (Shaffer, 1986). The self-blame which is commonly expressed in children following parental illness,

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death or separation often corresponds to a poor understanding of events and their causality and may not represent a depressive distortion.

These issues raise the important question of corroboration of a child's self-report. Parental corroboration was not sought in this study as it was felt that maternal perceptions of child adjustment could have been affected by the maternal illness. Parental perceptions of child behaviour have been found to be related to parental psychopathology, family and marital stressors and the level of social support (Kazdin, 1990). It was felt that the sick mothers of the sample of PVFS children may not be reliable reporters on their child's symptoms. The rating of school behaviour and adjustment by teacher-report, although reflecting observations and perceptions within a different ecological domain, provides some validation of the child's self-reported depression.

Test-retest reliability of the CDS was assessed by Tisher & Lang (1983), using a non-clinic sample of school children, repeated 7-10 days apart. It demonstrated a good level of stability across time (r=.74). An assessment of reliability should include a measure of the internal consistency of the measure, that is, the precision with which the individual items relate to a distinct concept of depression or positive affect. High degrees of internal consistency have been demonstrated with school-refusing, clinic population and control children (Tisher & Lang, 1983; Rotundo & Hensley, 1985; Kazdin, 1987). Using Cronbach's alpha (Cronbach, 1949), the mean of all possible correlated split-half reliabilities, figures of between .89 and .96 have been quoted for the total depression and pleasure scales with

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individual subscales ranging from .67 to .97. This represents a direct test of the unidimensionality of the scale (Nunnally, 1978). The depressive subscales were correlating in the moderate to high range, positively with total depression and negatively with the total pleasure scales.

The validation of measures of childhood depression is beset with problems. The issues of "masked" depressions, comorbidity and the overlap of symptoms among alternative childhood diagnostic groups have implications for such an exercise (Kazdin & Petti, 1982). Expansive attempts have been made, however, to report the validity of the CDS. The most important aspect of validation is a means of showing that the scale can successfully differentiate between independently assessed diagnostic groups. A test of criterion-validity aims to indicate that children diagnosed as depressed by other diagnostic means will score higher on a scale of depression than children with different or no diagnoses.

The selection of groups which are to represent the "gold-standard" is of particular importance. Lang & Tisher selected a group of school-refusing children, who may have been depressed although there is no reason to presume so. Their scores on the CDS could be differentiated from regular school attenders and clinic children with diagnoses other than school-refusal although this does not provide a strong test to validate the CDS as a measure of childhood depression. Rotundo & Hensley (1985) utilised DSM-III criteria to deliniate depressed from non-depressed groups, the latter independently assessed as "sad" or "not sad".

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The CDS successfully discriminated between clinic / non-clinic and depressed / non-depressed subjects. The child's self-report also adequately differentiated depressed from "sad". Kazdin (1987) tested criterion-validity using Research Diagnostic Criteria (Spitzer & Endicott, 1978) diagnoses of depression or other diagnoses in a clinic population. A multiple-analysis-of-variance indicated a significant difference between depressed and non-depressed patients [F (4, 158)=3.92, p<.005]. Further analysis showed that depressed children were significantly different to non-depressed on all subscales, except that for guilt.

Discriminant validity demonstrates the extent to which a measure correlates with other measures of similar or related constructs. It. usually represents a correlation of the instrument being validated with other measures. Because of problems concerning the validity of these other constructs and a strong method component where raters are the same, discriminant validity often shows weak results. Lang & Tisher (1978) demonstrated that the CDS correlated moderately with several factors on the Institute for Personality and Assessment Questionnaire (see Lang & Tisher, 1978), particularly factors of anxiety and neuroticism. This does not provide strong support that the CDS specifically measures depression as opposed to broader personality facets. A moderate-high correlation with Eysenck's neuroticism scale on the EPQ (Tisher & Lang, 1986), also provides little precise confirmatory information although the fault is likely to lie in the choice of the convergent measure; the neuroticism scale incorporates aspects of anxiety, worry, moodiness, sleep and psychosomatic problems as well as depression.

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Kazdin (1987) reports Pearson product-moment correlations between CDS depression / pleasure scores and independent measures of childhood depression (The Children's Depression Inventory, Kovacs, 1981; The Bellvue Index of Depression, Kazdin et al. 1983), in a patient sample of severely disturbed children. Correlation are moderately high for both child and adult report. Similar moderate-high correlations are found for measures of hopelessness and self-esteem (The Hopelessness Scale for Children, Kazdin et al. 1983; The Self-Esteem Inventory, Coopersmith, 1967). Similar correlations were reported in a mixed clinic and non-clinic group of children with the Children's Depression Inventory and Pier-Harris' self-concept scale (Pier & Harris, 1969).

Together, these results show acceptable levels of criterion and discriminant validity for the CDS.

Content validity has been maximised from the care given in the selection of scale-items from the evaluation of clinically depressed children. The consistency in judgement of depressed / anxious / neither depressed nor anxious by expert child psychiatrists also attests to a validation of scale content (Lang & Tisher, 1978). Factor analysis has not found much support for the content validity of the individual subscales. However, two distinct factors with homogeneous sets of items, corresponding to the total depression and total pleasure scales have been identified (Kazdin & Petti, 1982). It is advised that only the total depression and pleasures scales are used by researchers (Rotundo & Hensley, 1985).

The Teacher-Child Rating Scale (Hightower et al. 1986)

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The teacher who was most involved in the education of each target child was contacted in order to complete this scale. The teacher was sought as an independent source of information of child adjustment, apart from the parental perceptions and therefore not contaminated by the depressive outlook of the sick mothers.

The teacher is in a unique position to assess how a child copes with the demands of the school environment and is able to successfully relate any presenting difficulties to the readily available age-norm groups within the same classes. Teachers have been shown to be reliable and valid reporters of children's adjustment (Achenbach & Edelbrock, 1984; Rutter, 1967; Quay, 1979). They are reported to be better than clinicians in predicting later adaptation and clinical problems (Kellam & Schiff, 1967). They successfully identified 70 % of children rated independently as clinically disturbed (Kolvin et al. 1977) and have been shown to provide an effective screening method for the identification of vulnerable young children in the school setting.

The Teacher-Child-Rating Scale (TCRS) was developed from the Primary Mental Health Project, University of Rochester, New York, a programme for the early detection and prevention of children's adjustment problems (Cowen et al. 1973). The TCRS is a development from two extensively used scales in the school programmes of the PMHP which have been shown to clearly discriminate between referred and non-referred children. The scales, The Classroom Adjustment Rating Scale and The Health Resources Inventory have been used in assessment, consultation and programme evaluation studies. They were developed in collaboration with а number of teachers and mental health professionals. The scales reflect both problematic presentations of

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child school behaviour and classroom competencies. It was felt that teachers were far more comfortable enumerating negative aspects of a child's performance when they were able to report on things the child was good at.

The TCRS combines these two scales in a similar format whilst removing those items found to be redundant in terms of their contribution to the scale scores. The remaining 36 items retain internally consistent coefficients of near .90, with high loadings on factor analyses and the best discriminatory power (Hightower et al. 1986). Factor analyses of data gathered from programme and non-programme children revealled six meaningful clusters with the minimum of overlap.

The problem factors which emerged, Acting-Out (6 items), Shy-Anxious (6 items), Learning difficulties (6 items) explain 70 % of the variance of children's scores. The factor corresponding to the competence items broke down into three clusters, Frustration-Tolerance (11 items), Assertive Social Skills (7 items), Task-Orientation (8 items), explaining 75 % of the total variance.

The TCRS is a reliable instrument with recorded test-retest reliabilities of between .61 and .91, measured 10-20 weeks apart. A moderate to high negative correlation is reported between the problem and competence scales. Cronbach alpha figures of between .85 and .95 are reported for the associatio of individual items with the subscale scores.

Validatory investigation has shown that the overall and individual subscale scores can successfully discriminate between children who

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have been referred to the Primary Mental Health Programme and others who have not (Hightower et al. 1986). Positive tests of convergent and divergent validity have been conducted with varied measures of childhood adjustment and performance. The results of an achievement test of maths and reading abilities conducted by a teacher correlated highly with Learning problems, Task-Orientation and Assertive Social Skills as measured on the TCRS. Assessment of Acting-Out and Shy-Anxious orientation correlated inconsistently with the achievement test. All subscales with the exception of Acting-Out correlated significantly with the State-Trait Anxiety Inventory for Children (Spielberger, 1973). Moderate correlations with parental ratings of a child's school performance, peer and family relationships were recorded (Hightower et al. 1986). This represents a significant correspondence between two independent data sources.

## The Children's Attitude to Mother Scale (Hudson, 1982)

As Rutter's (1966) study illustrates, chronic physical or mental illness in a family can adversely affect the affectional relationships within the home and a good relationship with at least one parent can mitigate the deleterious repercussions upon the children. The effects of parental depressive illnesses upon their offspring have been shown to be mediated by the parent-child relationships. Depressed mothers increased discord with their children, report with poorer communication and less expressed affection (Weissman et al. 1971: 1972). The same relationship patterns have been expressed between depressed children and their mothers (Puig-Antich et al. 1985), depressed children perceiving family relationships as significantly more dysfunctional than non-depressed children (Kaslow et al. 1984).

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Depressed adults also frequently report poor relationships with their own parents as children (Raskin et al. 1971).

Psychological and physical illnesses may affect a mother-child relationship in three distinct ways. Firstly, of much importance is the level of exposure the child has to the mother's symptoms and the ways in which she expresses and communicates the affective components. Depressed mothers have been shown to be overtly hostile to their children (Weissman et al. 1971), and children may frequently respond with feelings of guilt (Eisenbruch, 1983). Secondly, the extent to which the quality of parenting has been affected will have some relationship repercussions, for example the role changes which are brought into effect and the disruptions of family routines. Such role reversals are often associated with later child adjustment problems (Rutter & Quinton, 1984). Thirdly, the relationship may be affected by changes in the daily interactions between mother and child. Chapter 4 investigated how depression in a mother can induce "chaotic" and unresponsive encounters with her children (Pound et al. 1985; Browne, 1986).

In this study, a child's assessment was made of the relationship between mother and child using a reliable and well validated questionnaire. The format was adapted to the card sorting assessment format as used in the Children's Depression Scale (Lang & Tisher, 1986). The five boxes were labelled in correspondence to the Likert-like scaling on the original questionnaire ( ranging from 1 "rarely or none of the time", to 5 "most or all of the time", Hudson, 1982).

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It was felt that the child's relationship with his or her sick mother could have a considerable potentiating or mitigating effect in terms of the consequences to the child of chronic illness in the family. The instrument draws upon elements of trust, embarrassment, reliance and interference within a relationship which may reflect upon the child's experience of the parental illness.

The adolescent studies of Hirsch et al. (1985), which have already been discussed extensively, provide some interesting and paradoxical results on the differential effects on child adjustment in the sick versus the well families of the amount of contact between parents and the child's peer networks. Hypotheses to explain these results have been raised in terms of parent-child relationships, the comparative awareness of difference in family atmospheres and possible embarrassment or ambivalence towards a sick parent, such that increased parent-peer group contact could pose a threat to friendships outside of the home. Guili and Hudson (1977) quote studies which regard children's perceptions of their parents to be of more importance to childhood adjustment and behaviour than other objective measures of parental behaviour (eg. Glidewell, 1961).

It was expected that the child in the Post-Viral Fatigue Syndrome families would report poorer relationships on the Child Attitude to Mother Scale compared to the control families. Good relationships in these families were expected to correspond to low levels of child adjustment problems and more overall family cohesion. While subject numbers are small, it was acknowledged that results may only give suggestions as to maternal relationship effects, but this variable was considered an important addition to child adjustment measures which

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may hold some suggestive explanatory status in the assessment of child social network and parent-frienship boundaries.

The Child's Attitude to Mother Scale (CAM) consists of 25 items which fall onto a scale ranging from 0 to 100. The scale was designed as a single-dimension characterisation of relationship problems between a mother and child. Positive and negatively worded statements are randomly ordered throughout the scale. With an alpha statistic of .94, the CAM scale was shown to have good internal consistency, and along with a factor-analysis the unidimensionality of the scale was demonstrated (Hudson et al. 1977). Individual scale items were less reliable (.40 or less) and it is recommended that the CAM is used as an overall measure of relationship problems. Reliability data was taken from a sample of 664 adolescent school children, which is not wholly appropriate for its use in this present study. However, as an explanatory and descriptive measure, it was selected for this study as the only available instrument of its kind. Test-retest data in a group of 36 adolescents, one week apart, provided a reliability coefficient of .95 (Guili & Hudson, 1977).

Validity was confirmed with an independent dichotomous response by the school students as to whether or not they were having problems with their parents (Guili & Hudson, 1977). The CAM scores were significantly different for these two groups. The mean CAM score of those who said there were relationship problems was 49.9, whilst the others reported a mean score of 20.8 (F=239; df=1, 616; p<.00001). The CAM scores, entered into a stepwise discriminant analysis, alongside independent measures of self-esteem and depression, had the greatest effect in discriminating the two criterion groups, as defined

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above (Hudson & Proctor, 1976). Similar discriminant validation was found for a small clinical sample of 38 children with a variety of referring problems. Those identified by the clinician as having relationship problems scored a mean of 54.8, whilst those regarded as not having significant relationship difficulties scored a mean of 14.7. The significant differences provide further evidence of the discriminatory power of the CAM (F=104; df=1,62; p<.0001).

## 5.5 The Children's Social-Network Interview

A social network has been described as a set of nodes (representing individual or group members) tied by specific types of relations. Those relationships may represent family ties or the associates of one's neighbourhood, work or school communities. As the discussion in chapter 4 illustrated, the existence of a tie within a network does not necessarily imply the passage of supportive or instrumental services to the focal person. The nature of the tie, or type of relationship could be explained in terms of a number of network dimensions, such as the quality or reciprocity of a relationship, or the multiplexity of the link (the number of roles and shared activities incorporated in the relationship between the focal person and the network member).

The study of social networks has become part of an exploration into the personal environmental contributors to health and psychological well-being (Cohen & Wills, 1985; Henderson et al. 1980). The previous chapter looked at research which explores the protective main effects and buffering (interaction) effects of social supportive relationships in the face of adverse life circumstances (Brown et al. 1986;

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Henderson et al. 1981), whilst acknowledging the potentially negative and non-supportive effects of some social contacts. Research has shown how various social network patterns can serve differing steeling or weakening effects on adjustment. Recently bereaved women and mature women returning to college were found to display better adjustment to life changes where networks were sparsely-knit and multi-stranded (Hirsch, 1980). It was found that networks involving non-family roles and activities called for less dramatic reorganisations of their life-styles. Increased segregation of network members increased the utility of selected members to serve as agents of support.

An important dimension descriptive of social networks which has been found to have a strong association with mental health is that of network density along with the density of relational links between the different social and family spheres of an individual. Network density is a measure of the proportion of actual to potential relationships within a social network. A high network density thus represents a situation in which a large number of network members know one another, either dependently or independently of the focal person. A low network density represents the situation where the focal person identifies a network of significant members where only a small number of relationships exist between them.

The influential work of the Illinois group into the social networks of the 16 adolescents of depressed, arthritic and well parents used network density and the boundary-density between parents and friends to explain the differential effects of family adversity. The studies illustrate an interesting paradox of the protective effect of social

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networks and parent-peer group contact in adolescence.

Bronfenbrenner (1979) asserts that the developmental potential of settings increases as a function of the links between settings that encourage the growth of mutual trust and a positive orientation. Boundaries exist between an individual's different social spheres. For a child, the linkages between the contexts of the family home and that of the peer group are of crucial importance. The social network of a child's parents provides access to alternative adult role models, linking the child to the outside world beyond the family occupational educational boundaries (Cochran & Brassard, 1979). and The involvement and interest of a child's parents in his or her school environment has also been shown to have beneficial effects in terms of cognitive and behavioural adjustment. In the Illinois studies, the degree of contact between parents and peer group was associated with child adjustment in contrary directions in the sick parent versus healthy parents.

The authors clarified aspects of peer identities on three measures, compiled from extensive interviewing with children on the 10 most important friendships on their network lists:

1. The support the child received from peers for a recent problematic school or family "hassle". Support received was coded according to whether it had provided cognitive guidance, emotional or tangible / instrumental support. Coders rating the taped interviews reached agreement on categories over 98 % of the time.

2. Friendship variables for the subject's best friend and mean peer

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friendships in the following areas:

- a) The number of activities the child took part in with friends. The semi-structured interview focussed upon joint activities of shopping, non-speculative sports, going to the cinema, parties and dances and dating between friends.
- b) A measure of friendship confidency. Adolescents were asked if they talked together about personal matters concerning the subject's family or of personal matters regarding the friend's family. They were asked if they confided in different friends about persons of the opposite sex, or about issues of very personal or private concerns.
- c) Network relationships were assessed in terms of the level of stress which existed. Questions asked focus upon issues of conflict, the degree of conflict and trust and separation by geographical distance.
- d) The reciprocity of the relationships was a measure of the extent to which friends spoke of personal matters regarding one another's families, whether they had been to each others houses and whether they took it in turns to initiate meetings.

3. The boundary-density between the adolescent's parents and friends. This was a measure of whether parents and friends knew one another. Adolescents rated each potential relationship (unweighted score) between parents and network members on a 4 point scale (weighted score) corresponding to how well the parents and friends knew one

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another. The boundary density represents a proportion, with the denominator demonstrating the sum of potential relationships (ie. number of parents x number of friends identified on network), and the numerator as a weighted or unweighted score of each parent-friend relationship.

It was noted that adolescents were somewhat unlikely to ask for support from their peer group, suggesting the social undesirability of so doing and the taboo nature of the family "hassles". However, results revealed that the adolescents of well parents were better adjusted where levels of social support were higher, but those of the depressed and arthritic parents were poorer adjusted where levels of social support were higher. Adjustment was measured as self-esteem and overall symptom scores.

To summarise, it was found that the level of social support, the strength of relationships and the parent-friend boundary density all correlated positively with healthy adjustment in the adolescents of the well parents, but negatively for the adolescents with depressed and arthritic parents. What these results suggest is that in families with sick mothers, increased support from the friends of the children will be associated with more problems in those children. Equally, a more intimate and more active relationship between a child and his or her friends can be associated with more problems in the child of a sick mother as opposed to the child of a healthy mother. The adolescents of the depressed parents showed higher levels of stress with their best friends than the group with healthy mothers, with the arthritis group intermediate between the two.

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Where there was more contact and more involvement of the psychiatric or physically ill parent in their children's lives, the children were more likely to be anxious and depressed with lower self-esteem. For the healthy families a parent involved in the child's peer network was seen to be a beneficial factor.

Significant associations of child mental health were found for variables concerning the extent to which the adolescent talked to their friends about their respective families and the degree of contact with respective parents concerning visits to each other's houses and outings with each other's families. The strongest negative effects for these friendship variables were found for the group with depressed parents. The arthritic group showed a similar profile but the relationship was weaker. For the normal group such contact was associated with fewer symptoms as long as some distance was retained between parents and peer groups.

Whilst sample sizes are small (N=16 in each of the groups) and the direction of causality unknown, these results pose some very interesting research questions. They suggest an awareness of "differentness" and possible ambivalence towards a depressed and arthritic parent, with anxiety about the security of friendships. Of particular importance is the finding that parental physical as well as psychological disability appears to have a negative impact upon a child's ability to make adaptive use of peer friendships for support. These results go against the adult models of social networks where supportive and confiding relationships outside of the family are expected to provide a protective role in the light of distress (Brown et al. 1986).

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The study reported in this thesis is an attempt to replicate those findings with the 9-14 year old children of mothers suffering from the post-viral fatigue syndrome and matched controls. In this study it was expected that:

1. The children of the PVFS mothers would display poorer relationships with their best friends than the children of healthy mothers, with higher friendship stress levels, lower levels of confidency and fewer joint activities participated in.

2. The social networks of the two groups of children will show different associations with child adjustment measures (total depression score on the CDS; total problem score on the TCRS; relationship with mother on the CAM) in the directions predicted by the Illinois studies.

3. The parent-friend boundary density will be associated with child adjustment measures, with high density networks correlating with worse child adversity scores in the PVFS group but with better adjustment in the well group.

The child's social-network interview was developed for the purposes of this study and was designed to cover the interview-based friendship variables described by Hirsch & Reischl (1985). The questionnaire items measure dimensions of relationships with the target child's 5 best friends. It was felt that a peer network of 5 would be adequate for the assessment of friendship dimensions, thus restricting the duration of the interview to about 20 minutes, and limiting its

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complexity for the accurate reporting of pre-adolescent children. Piloting of the instrument among 9 children aged between 9 and 14 suggested that all children were able to report a best friend and four other friends, but 33 % were unable to report more than this.

Names of the child's best friend and four other important friends are reported. The friendships are identified as school friends, class friends, neighbourhood friends or friends divided by geographical distance. The child is asked about any special interests, hobbies or outside school clubs which are attended and to specify if any of the network friends attend such activities or take part in such interests with them.

The 38 questions comprising the interview-based friendship assessment are asked for each of the 5 network members. Responses are coded on 3 point scales (3= "yes"; 2= any qualified response; 1= "no"). Six friendship dimensions are measured.

1. ACTIVITIES: The six questions which make up this dimension ask if the target child engages in certain activities with the network friends. The children are asked if they go into town / go shopping together; take part in non-speculative sports or games together (outside of school); attend clubs or take part in hobbies together; go out walking, cycling or playing together; help each other with their home work assignments for school.

2. CONFIDENCY: The six items which make up this friendship dimension concern the sharing of secrets and worries, talking about respective families or particular boys or girls they may like and sharing with

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one another happy thoughts when something good has happened.

3. STRESS: The dimension of stress is assessed with 12 questions. The questions focus upon issues of conflict (eg. "Do you sometimes quarrel, argue or fight about things?"; "Does N. sometimes annoy you or say things which upset you?"; "Does N. sometimes interfere with your activities?"), issues of contact (eg. "Do you sometimes find you would like to see more of N. but can't?"; "Is there anyone or anything that tries to stop you being friends?"; "Is it easy getting in touch with N. if you want to see / play with him / her?"), and issues of trust (eg. "Can you trust N. to keep secrets?"). Three items are included which are positively worded reflecting issues of mutual caring, patience and enjoying one another's company. The codings are reversed for inclusion in the stess composite.

4. NETWORK DENSITY: Relationships existing between the five network members were calculated. There are 10 possible relationships between members. Where all friends know one another, ie. the network is dense, a density score of 1.0 is reported (Figure 5.1). A sparsely knit network with a network density of 0.4 is displayed in Figure 5.2. There are 4 actual relationships out of a potential number of 10.

5. PARENT-FRIEND BOUNDARY DENSITY: A relationship is recorded between the target child's parents and network friends where the child stated that they knew one another. Each of the five friends is coded for a possible relationship with the child's mother and father. The possible number of relationships is 10. A boundary density of 1.0 (Figure 5.3) demonstrates that both parents know each of the child's five most important friends. Such relationships can be corroborated by the mother. A boundary density of 0.5 (Figure 5.4) shows a situation where both parents know friends 1 and 2 and the mother only knows friend 4.

6. PARENT-FRIEND CONTACT: The following 4 questions were asked so as to provide the possibility of a weighted score for the boundary density proportions.

(i) Does N. come back to your house after school or at the weekends?
(ii) Do you go to his / her house?
(iii) Do you go on outings with his / her family?
(iv) Does he / she come on outings with your family?

The questions are coded on a 3 point scale (3= "yes"; 2= any qualified response; 1= "no").

ACTIVITIES WITH PARENTS: Finally, the target children were asked 12 questions relating to the activities they took part in with their mothers and their fathers. The questions correspond to the activity questions for friends.

The children's social network interview was piloted on a group of nine children from professional families aged between 9 and 14. Test-retest reliability was assessed on a repeat interview 7 to 10 days apart. Difference scores were calculated for the mean sum of the activity, confidency, stress and contact scores. Each of the subscales demonstrated a good degree of stability over time (Pearson correlation coefficients). Mean activity scores r = .84 (p<.005); mean confidency scores r = .63 (p<.05); mean stress scores r = .96 (p<.001). The activity score for mother r = .83 (p<.005), and for father r = .96

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(p<.001). In 5 out of the 9 cases the choice of 5 friends remained the same on re-testing. Three children changed the name of 1 friend and 1 child named 2 different friends on the second interview. The friendship scores, however, remained relatively stable as is demonstrated by the test-retest reliability correlations. Friendship density ranged from 0.6 to 0.9. The retest reliability was good, r =.95 (p<.005).

#### 5.6 Family observation

Family observations have increasingly been used for the investigations of parent-child interactions in structured laboratory or clinic settings, simulated "natural environments" or in the family home. Observations have consequently moved from the dyadic interaction approach which is common to the mother-infant studies of attachment and language-development, to the more chaotic interactions which may occur between family members where the complexities of multiple interactions must be taken into account. Observational research has largely advanced from its early cognitive developmental outlook to looking at the emotional needs of children and how they are met in the affectual interactional sequences which make up the habitual patterns of everyday family life (Mills et al. 1986).

A family observation was designed and conducted in the present study in order to evaluate the differential patterns of interaction between family members and the target children in the PVFS and the control families. The focus of the observation is upon the activities of the target child during a weekday evening on return from school. The aim was to assess the amount of time the child spent with other family

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members, particularly the parents, and the time which the child spent alone. Activities participated in involved goal-directed and non-goal directed behaviours. An attempt was made to assess the amount and the quality of the verbal interactions involving the family members and the target child.

It was expected that the sick mothers would spend less time interacting with the target children in the home environment, being more physically and perhaps more emotionally absent to them. Thus, they were expected to be physically out of contact more often (ie. in a different room to the child, perhaps resting) and to engage in less overall and more negative interactions with the children. Poorer adjustment in the children was expected to be associated with increased time being spent in solitary and non-goal directed activities and less time interacting with other family members.

The family observation was primarily implemented as a means of providing an exploratory and more qualitative understanding of the impact of illness within the family system. It was intended as a supplement to the alternative measures of family environment and child adjustment. Along with the Teacher-Child Rating Scale, it provides a source of information which is independent of the mother.

The target child method is derived from focal animal observation techniques in ethology. It is particularly useful for group observation such as the study of child behaviour and interaction at nursery school (Sylva 1980). Its use in family settings is therefore recommended. Sylva used a combination of time and event recording in which focal subjects were randomly selected from those children

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attending the play group. The observer conducted consecutive 10 minute observations with each child, recording the behaviour of that child from pre-coded behavioural categories and all interactions which took place to and from that child.

The following study aimed to adapt the target-child method for observation within the family home. In this observation, the focus of the researcher is exclusively upon the selected child in each family. A record is made of the behaviour of the child from pre-coded behavioural categories and all interactions initiated by the child towards family members (or all those present during the observation), and interactions directed by others towards the child. Sylva's study was centred within the large activity room of a nursery school. This study involves the observation of behaviour and interactions within a less structured setting. Thus, the observation was conducted in a variety of rooms in the family home as well as settings outside of the house. The aim was to observe the child's family life in as representative a way as possible and this requires no restrictions to the movement of the child other than those imposed by family routines or other family members.

Individual behavioural and interaction categories were selected and developed in preliminary trial family observations, following a careful consideration of categories with proven good reliability properties from previous observational studies (Sylva et al. 1980; Dowdney et al. 1984; Kazdin et al. 1985; Lewinsohn & Shaffer, 1971).

The choice of the setting and time for the observation is of some considerable importance in establishing the representativeness of the

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behaviour observed and in an attempt to minimise observer effects. The aim was to select a time in which there was likely to be considerable interaction between family members but which was also likely to be fairly routinised, comparable across week-days within the same families and relatively "rich" in goings-on. It was presumed that there are likely to be a few critical hours between 16.00 and 20.00 hours in which similar routines would take place within and across families. The child will return home from school, the evening meal will be prepared, there will be some pattern of interaction in its consumption and in the leisure, domestic, educational and personal activities which take place thereafter. These few hours may reveal telling details of how a child behaves in the family and how family members respond to the target child. The child will have just spent some seven hours in school, mixing with peers. The after-school hours will show how the child interacting with parents and siblings, adapting to family routines and fulfilling leisure time interests.

The observation was conducted at the end of the study and consequently family members were familiar with the researcher and hopefully somewhat more comfortable with her presence. An evening was selected following mutual discussion of all family members. The aim was to select an evening which would be expected to be reasonably "typical", but in which it was to be expected that the target child would spent some considerable amount of time at home. Evenings were avoided if family members were expecting to be out or it the target child was to be attending clubs or activities away from the home. Maternal and target child presence for the majority of the observation was a condition for the selection of the day.

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The briefing given to the family members was that the observer's attention would be focussed upon the target child in order to come to some understanding of what that child usually does in the home environment after a school day. The family were told that the researcher would be following the target child and recording what they were doing and with whom they were interacting. They were asked to ignore the researcher as well as they could and to try not to direct conversation to her.

Behavioural categories and interactions with or from the target child were recorded on an event-sampling basis. This is appropriate given the nature of the behaviour being recorded and the length of the observation. On-going records were taken of the room the target child was in, who was present, what activity the child was engaged in and whether the television or radio was on. Time was recorded whenever there was a change of activity, a change of room, the entrance or exit of any of the family or extra-family members. Verbal interactions were categorised as initiations or replies judged upon contextual cues and the content of the material. Some qualitative assessements of these interactions were made on their functional or affectual value. An assessment was made of the time spent in verbal interaction, in which the target child is included at least minimally, and the time spent with no talk. Periods without talk were timed from 30 seconds after verbal interaction had ceased. In order to assess observer effects, all comments directed to or about the observer were recorded.

The following describes the format of the observation period and provides descriptions of the behavioural and interaction categories. The total observation time was four hours.

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1. A record is made of the room in which the child activity is taking place at the start of the observation period. Other family or extra-family members present are recorded.

2. Time is recorded with a digital watch which is attached to the left-hand side of the observation board. Hours and minutes are recorded in the first 4 columns of the coding sheet. The last minute is recorded each time someone enters or leaves the room, including the target child, each time the target child changes activities across behavioural categories and each time there is a cessation (after a pause of 30 seconds) or initiation of verbal exchanges between members present.

3. Activity categories are recorded. These refer directly to what the target child is doing, independently of the actions of other family members. A child's behaviour was placed into an activity category following direct observation by the researcher. There were two instances where direct observation was not possible. These referred to episodes with two 13 year old boys who shut themselves into their bedrooms in order to complete homework assignments and to listen to music, making it clear that the observer was not welcome. In these cases, behavioural categories were inferred from auditory cues, confirmed by direct questioning of the children on leaving their rooms.

There are six behavioural categories plus an additional category for when the child is "out of contact", or if the observer is not directly able to view what the child is actually doing. Although the

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observation method aimed to reduce time periods in which the child was not open to observation (eg. by following the child around, selecting an evening for the observation in which the child was expected to stay at home), this category was included in order to allow for those occasions in which direct observation is not possible. Out of contact periods reduce the validity of the observation but family consent to repeat a somewhat arduous and time-consuming period meant that for practical reasons out of contact periods were unavoidable.

#### The activity categories used were:

- a) PERSONAL: Any self-care activity which the child does for him/herself, including washing, grooming, toileting, dressing and eating.
- b) DOMESTIC: This involves any household or domestic task such as the preparation of food, household cleaning, answering the telephone, helping another family member with personal tasks, such as the feeding or dressing of younger siblings.
- c) LEISURE-ACTIVE: This includes any activities which are goal-oriented, structured, focussed or game-like in quality. It may include outdoor physical / ball games or sports activities, hobbies or craftwork, playing a musical instrument. Activities may be conducted alone or with others.
- d) LEISURE-PASSIVE (TV): This includes the viewing of television /video or listening to the radio / recorded music. It was a condition of coding this behaviour category that no other (more

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active) activity was concurrently taking place. Thus, a radio or television may have been transmitting with only the occasional attention being paid to it. In the absence of any other goal-directed behaviour, leisure-passive (TV) was recorded. If the radio or television was broadcasting whilst the child was engaged in other activities, such as laying the table or completing homework, domestic or educational activities were recorded respectively.

- e) LEISURE-PASSIVE (OTHER): The child was wandering aimlessly, staring out of the window, listening or watching on-going activity or conversation but with no contribution. The child is basically "doing nothing". This category is used if the child is not categorised under others.
- f) EDUCATIONAL-INTELLECTUAL: Any activity which is involved in the reading, writing, or learning of academic or educational material. It can take the form of school assignments, the exploration of educational materials, the discussion of academic matters. A child receiving a music lesson, taking a dictation from his mother for handwriting practice or reading a book for leisure are some examples of this category.

4. Entrances and exits. The intention is to provide a running account of the members who are present in the same room as the target child. These people are considered to be available to the child for interaction. Post-observation analysis categorises periods into target child solitary; target child and mother; target child and father; target child and sib(s) / others; whole family together

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(including parent figures and household members).

Time spent in verbal interaction was recorded. Time was recorded at the start of verbal exchange and any utterances to and from the child and other persons present. A silence lasting more than 30 seconds marked the end of the period of verbal exchange.

In order to evaluate some qualitative dimensions of the verbal utterances to or from the target child, a count was taken of a small number of selected speech categories. It was decided to focus upon the behavioural requests directed to the target child. The categories used were:

- a) POSITIVE-BEHAVIOUR-REQUEST are those utterances which issue a command or an instruction in the form of, "Do X!". They represent positive requests or utterances calling for task engagement or tangible assistance.
- b) NEGATIVE-BEHAVIOUR-REQUEST are those utterances which issue a command or instruction in the form of, "Don't do X!". They are concernced with control and the restoration of order.
- c) POSITIVE REPLIES, are responses to behaviour or verbal utterances which correspond to specific comments of praise, encouragement or positive displays of affection.
- d) NEGATIVE REPLIES, are responses which are personally critical or disparaging, displaying negative signs of affect (an argumentative tonality with raised voice, loss of temper,

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shouting, complaining, etc.).

The behavioural and interaction categories were developed and piloted in a succession of one hour observation periods with families who were not finally involved in the two group comparative study. The final categories were found to be easily codable with minimal ambiguity. The pilot observations enabled the tightening up of the defining characteristics of the mutually exclusive categories and provided examples of codings to aid classification of the non-exclusive ones.

An acknowledged weakness in this present study is the absence of reliability data of inter-observer ratings. The presence of another unfamiliar researcher in the home-setting of a family was felt to be unreasonably intrusive and inappropriate for target observations which involved following a child in often very cramped conditions. The lack of reliability data on these categories must be balanced against the careful refinement and improvement of categories during the pilot observations. However, it remains a weakness. The results are to be considered as exploratory and suggestive, and in need of confirmation.

In terms of validity, as Dowdney and Rutter assert, all observatory data has "an intrinsic face validity in that the behaviours have been seen to take place" (1984). The times chosen for these observations were such that family routines were in operation and the deferring of behaviours, or alterations in habitual interactions would not have gone unnoticed by the children. Children are particularly sensitive to changes in parental interaction or alterations in household regimes and it is somewhat unlikely that non-habitual behaviours could have been maintained. The presence of children tend by their sponteneity to

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provoke natural sequences of parent-child behaviour (Cox, 1975). All mothers at the end of the four-hour observation period commented that the interactions had been relatively "typical" of their week-day evenings.

#### 5.7 Summary of methodology and assessments

The post-viral fatigue syndrome subjects were selected from the M.E. Association membership lists in the N.E. of England. Local group leaders were contacted and names were selected of mothers suffering from the syndrome with 9-14 year old children living at home. A protocol was sent to the families and contact was initiated by phone seven days later.

The family assessments were collected on three visits with an additional visit to the target child's school. On the first visit of the PVFS family, parents were asked if they were in touch with another family in their neighbourhood with a child the same age as the target child, with healthy parents. Three of the PVFS sufferers reported such isolation because of their illness and estrangement from their neighbourhood that they were unable to contact anyone with a view to taking part in the project. Control families for these subjects were selected after referral from other control families.

Control families were selected where it was clear that there was a successful match of age and sex of the target children in the PVFS group. The families were compared on socio-economic status and housing type. The control families were selected from the same neighbourhoods as the PVFS families.

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The first interview collected family demographic details and a 1. personal medical history of the mother. Permission was sought from parents and the respective children to contact their schools and ask for an assessment from the teacher or tutor they had most contact Permission was not refused in any of the families. with. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was completed and the mothers suffering from the PVFS completed the Coping with PVFS questionnaire adapted from Watson's Mental Adjustment to Cancer Scale (Watson et al., 1986). In addition, the mother completed the Family Routines Inventory (Jensen, 1983), and the Family Environment Scale (Moos & Moos, 1986) was left with the family to be completed by both of the parents.

2. The second visit saw the completion of the Children's Depression Scale (Lang & Tisher, 1986), the Child's Attitude to Mother Scale (Hudson, 1982), and the children's friendship interview. All three were taken from the self-report of the target child. The parent-friend boundary densities (that is, the extent to which the target child's friends and parents know one another) was corroborated by the parents. The Family Environment Scales were collected.

3. The child's school was contacted and the Teacher-Child Rating Scale (Hightower et al., 1986) was completed by the teacher most involved in the teaching of the child, or most familiar with the child's behaviour and adjustment both in and out of the classroom. The head-teachers and classroom teachers were informed that this was a study investigating the school and family life of a selection of 9-14 year old children from a variety of different families. The teachers

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were not informed of the medical status of the mothers of the PVFS group.

4. Finally, a home observation was conducted one evening after the children had returned from school. Observations were conducted for four hours from 16.00 to 20.00 on an evening which had been pre-arranged with the family.

# Results of the family study into the children of mothers with the Post-Viral Fatigue Syndrome

## 6.1 Statistical procedures

The following analyses represent the comparisons of two independent subject groups. Where the variables being compared have reasonably symmetrical distributions in each of the samples, two-sample t-tests are used, to test for significant differences in population means. The pooled variance estimate is used if the variances of the two groups are approximately equal. Otherwise, the separate variance estimates are used.

Corresponding non-parametric Mann-Whitney U-tests are used in the place of the t-tests where distributions are skewed. Values without correcting for tied ranks are presented as a more conservative test of difference. For moderate sized samples, the power-efficiency of the U-test approaches 95 %, in comparison with the parametric t-test (Siegel, 1956). When hypotheses are tested with given directions of comparison, one-tailed tests are used. Otherwise, the significance figures are appropriate for two-tailed tests. For measurement of the degree of association between sets of scores, the Pearson product-moment correlation coefficient is used.

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It must be stressed that the analyses in this study are largely exploratory, and that given the small subject sizes and repeated tests of group significance, there are risks of type-1 errors. Substantial caution must therefore be exercised in the interpretation of these results. Attempts were made to restrict the number of statistical tests implemented, by grouping together variables, for example where there was a significant correlation between measures or where there were other reasons for grouping them. Where possible, pre-formulated hypotheses were tested. A significant part of the following analyses attempted a direct replication of research by Hirsch, et al. (1985) which looks at the children of depressed, arthritic and healthy mothers. This includes the regression analysis of social network dimensions and childhood depression, which was confirmatory, not exploratory.

### 6.2 Maternal psychiatric status

Self-reported measures of maternal depression and anxiety (Hospital Anxiety and Depression Scale) revealed a significant group difference with the mothers suffering from the post-viral fatigue syndome showing significantly higher scores than the mothers who were well. The depression and anxiety scores are displayed in stem and leaf plots in Figures 1 and 2. With a median depression score of 13 in the post-viral fatigue syndrome sufferers and 4 in the mothers from the control families the sick mothers are reporting significantly more severe depression than the well mothers (U=126.0, p<.0004). There is a trend towards group difference in the anxiety scores. The mean score reported in the post-viral fatigue syndrome sufferers is 12.6 (SD=5.5) and the mean score in the well mothers is 8.4 (SD=3.5). The group

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Figure 1

## STEM AND LEAF PLOT OF MATERNAL DEPRESSION SCORES (HADS)

 PVFS mothers
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 Control mothers

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Figure 2

STEM AND LEAF PLOT OF MATERNAL ANXIETY SCORES (HADS)

 PVFS mothers
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 Control mothers

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 |1|

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 |2|

difference reaches borderline significance (T=1.89, df=16, p<.08).

Using a HADS score of 10 as a stringent criterion of a "definite case" (in correspondence to the criteria used in chapter 2), six of the post-viral fatigue syndrome group satisfy the criteria for a "mixed" disorder (ie they are scoring over 10 on both the anxiety and the depression scales, Zigmond & Snaith, 1983). A further two mothers in this group satisfy the criteria for a depressive disorder only. Among the well mothers, none fulfill the conditions for a depressive disorder but three of the nine can be identified as suffering from an anxiety disorder.

In the post-viral group, five of the mothers have previously been treated for "nervous problems" by their General Practitioner or a psychiatrist (on maternal self-report). One of the mothers had been hospitalised during this past episode following an overdose. None of the control mothers reported a past episode of treated psychiatric "nervous" problems.

Of those mothers who had had a past history of nervous problems (separate from current episode) a significant difference was found in current depressive and current anxiety features in comparison to the mothers who reported no such episode. With a median depression score of 14.4 for those who reported a past episode and 7.6 for those who did not, it can be seen that past treatment for psychiatric / nervous problems is predictive of current depressive status (U=72.0, p<.01). Similarly, for the current anxiety scores, those who had had a past treated episode reported a median score of 15.2 and those without such an episode a median of 7.3. The difference is highly significant

(U=76.0, p<.005), with mothers who have had a past episode of psychiatric "nervous" problems more likely to have a current elevated anxiety score. Due to the small sample sizes this relationship cannot be explored separately for the 2 groups.

Two of the post-viral fatigue syndrome sufferers reported histories of psychiatric or "nervous" problems in their families (including agoraphobia, anxiety and post-natal depression). Four other mothers reported a history of physical problems in their families (including cancer and heart conditions). Among the control families, one mother referred to a "psychological breakdown" in one family member and another mother mentioned a family history of heart disease. There is a suggestion of more psychological and physical illnesses in the extended families of the sick mothers.

During the course of the current illness, the mothers suffering from the post viral fatigue syndrome had seen on average between 5 and 6 specialists. Five of the mothers had seen a psychologist or psychiatrist during the period before a clear diagnosis had been arrived at. Six of the mothers had seen a neurologist and one had seen a professional counsellor. All of the mothers were currently in contact with one of two specialist G.P.s who were treating them for their conditions. Two were also receiving treatment from a homeopathic doctor.

## 6.3 Maternal coping with illness

The coping scale was completed by the 9 mothers with post-viral fatigue syndrome. Using the sub-scale headings devised from Watson's

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(1982) original scale, no strong associations were found between coping styles and maternal depression or anxiety as measured on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). However, a borderline correlation was found between the anxiety rating and the "Helpless-Hopeless" orientation from the coping scale (Pearson r=.50, p=.08). Maternal coping style did not appear to be predictive of children's adjustment. However, a borderline negative correlation was found between childhood depression (Children's Depression Scale, Lang & Tisher, 1986), and "Fighting Spirit" (r=-.51, p=.08), and with teacher rated child problems (Teacher-Child Rating Scale, Hightower, 1986) and maternal "Anxious-Preoccupation"" (r=.50, P=.08).

The coping scale has not been validated for use on a post-viral condition and therefore strong faith cannot rest with the utility of the sub-scale totals. It is the individual scale items of the questionnaire which are of interest in the uncovering of maternal attitudes to the illness, which may be suggestive of coping style and the transmission of affect to other family members.

Overall, the items corresponding to a "Fighting Spirit" are scored highly by these subjects. There was evidence of strong beliefs in the benefits of positive attitudes (N=8), and positive states of mind (N=7). The metaphor of "fighting the illness" was expressed strongly by 7 of the subjects, with firm beliefs that they would get better in time (N=7). All of the post-viral subjects reported that they managed to retain a sense of humour about their condition and 7 reported that they saw the illness as a challenge. In spite of such positive attitudes to their illness, only 4 out the the 9 subjects were able to say that they had any plans for the future. The unpredictability and uncertain outcome of the illness seemed to preclude the making of any plans.

Of the items corresponding to a "Helpless-Hopeless" outlook, only 2-4 of the 9 subjects reported that these applied to them. Four subjects reported that they were not very hopeful about the future, that they were at a loss about what to do and that there was nothing they could do to cheer themselves up. Three reported feelings of wanting to give up, with feelings that their lives were hopeless. Strong feelings of helplessness and hopelessness expressed by only 2-3 of the subjects were not expressed by others who were of the opinion that there was something they could do to help themselves.

Similarly, very few of the subjects reported that they felt fatalistic about their conditions. Because of the nature of the post-viral fatigue syndrome subjects frequently reported that they took one day at a time (N=8), and that often they were unable to control their symptoms inspite of any actions which they took in order to do so (N=7). Only three reported that they felt fatalistic. None of the subjects had abdicated responsibility for their illness to their doctors. None avoided finding out about their conditions. Only 2 reported that there was nothing they could do to improve things, or that the best part of their lives was over. Four post-viral fatigue subjects, however, reported that they had put themselves in the hands of God.

The items making up the "Anxious-preoccupation" scale include those which clearly reflect anxieties about the illness and other items which appear to convey the ways in which the sufferers manage their

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conditions. All of the subjects reported avoidance of activities and substances known to aggravate their symptoms. All reported that they gathered a lot of information about the illness. Eight subjects reported that they had substantially changed their life-styles in order to accomodate the illness. Such items suggest a certain preoccupation with the illness but one which would be seen as necessary given the changing nature of the condition, its sensitivity to environmental and emotional change and the enduring and adverse effects of forgetting that the illness tends to "rule your life" (as quoted by a number of the sufferers). The sufferers, in such a way, must take sole responsibility for their conditions, teaching themselves methods of symptom control (Wookey, 1986).

Seven of the subjects reported that they felt angry about what had happened to them. Five suffered great anxieties about their conditions and 6 subjects expressed worries about their conditions getting worse in the future.

### 6.4 The maternal relationship with the target children

The two groups were compared on two aspects of mother-child relationship. They are both taken from the self-report of the target children. Firstly, an activities score provides an indication of what the child and his or her mother do together. Secondly, a qualitative dimension of the relationship with the mother is compared across groups using the Child's Attitude to Mother Scale (Hudson & Guili, 1986). The scores reflect problems in the mother-child relationships.

The children with sick mothers report significantly less active

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relationships with their mothers in comparison to the control children (U=48.5, p<.001). Activity scores with fathers were generally lower than maternal activity scores and there was a trend towards lower activity scores with the fathers in the families where the mothers were ill. The group difference did not however reach statistical significance (U=65.5, p=.1).

The relationship of a target child with his sick mother does not appear to be significantly more problematic than the relationships of the control children (T=1.35, df=16, p=.2). However, the mean scores suggest a trend towards more problematic relationships in the PVFS group as opposed to the controls (42.8 SD=7.8; 37.9 SD=7.6 respectively). A comparison by sex suggests that there is a trend towards more problematic maternal relationships reported by the male children (U=103, p=.1).

The scores on the Child's Attitude to Mother Scale (CAM) are presented in the stem and leaf plot in Figure 3. With a recommended cut-off of 50 on the mother-child relationship score (Guili & Hudson, 1977; Hudson & Proctor, 1976), it can be seen that 3 of the children in the post-viral group and only 1 of the control children have suspected relationship problems with their mothers.

A look at individual items shows that there is no difference in the extent to which target children view their mothers as irritating or embarrassing, in spite of illness in the mothers of the post-viral group. In fact, feelings of embarrassment about their mother was common to both of the groups, with reports of mothers frequently getting on their nerves. Three of the children of the sick mothers

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# STEM AND LEAF OF CHILD-MOTHER RELATIONSHIP PROBLEMS (CAM)

Control children

PVFS chil	.dren	
-----------	-------	--

		2   3	9		
	2	• •	2	2	
5	5	3	4	5	
		3			
		131	8		
	0	4			
	3	4			
	5	4	4	5	
		4			
		4			
	0	5			
3	2	5	2		

report that for some to most of the time they do not enjoy their mothers. More children in the post-viral group report that their mothers put too many limits upon them (N=4 post-viral; N=1 control), and reported that their mothers did not understand them. None of the control children reported this. Two of the post-viral group reported that they could not depend on their mothers. Again, this was not reported among the control children.

All of the children reported strong feelings of affection towards their mothers. All but one reported that they got on well together and enjoyed being together. Such good relationships existing between the sick mother and target child may serve to buffer against the ill effects of having a mother with such a debilitating condition. Impressions were often given of considerable intra-family supportiveness in the sick families and the involvement and cooperativeness of all family members in the care of the sick mothers. Children appeared to be sensitised to the effects of the illness and were well informed about the condition. With none of these mothers partaking in employment outside of the home and with their physical limitations, mothers often reported that they were able to spend more time with their children. It appears that such perceived increased contact had not compromised the quality of relationships with their There was no evidence of increased embarrassment or children. ambivalence towards the mothers as was suggested in the adolescent group of Hirsch's (1985) depressed mothers.

### 6.5 Child outcome measures

### The child's self-reported rating of depression

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It had been expected that the children of mothers suffering from the post-viral fatigue syndrome would show significantly worse adjustment on measures of affective disturbances. The analysis has shown that these children do not differ significantly in adjustment from children from a control sample. The groups cannot be differentiated on a self-reported measure of depression or on a measure of a child's capacity to experience pleasure (the total depression and total pleasure scales taken from the Children's Depression Scale, Lang & Tisher, 1986). Significance figures are both above p .25. The data is presented in the stem and leaf plots in Figures 4 and 5.

With respect to the normative guidelines derived from the validatory studies of the CDS (Table 1), it can be seen that the scores of the children of the sick mothers on the total depression score (mean=139, SD=38.4) resemble those non-depressed clinic attending children described by Lang and Tisher (19780, Rotundo and Hensley (1985) and Kazdin (1987). The control children (mean=122, SD=26.1) are scoring roughly the same on the total depression scores as the control children represented in Lang and Tisher's and Rotundo and Hensley's data.

If a total depression score of 150 is taken as a criterion for a major depressive disorder of clinical severity (given the Research Diagnostic Criteria scores of depression from Kazdin's study), individual scores indicate that three of the PVFS group and two of the control children could be regarded as clinically depressed.

The absense of any group difference in this study requires some

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STUDY

# CHILDRENS DEPRESSION SCORES (CDS) IN THREE VALIDATORY STUDIES

MEAN TOTAL DEPRESSION SCORES

Lang & Tisher (1978)		
"Normal" school attenders (N=37)	117	(SD 35.3)
"Depressed" school refusers (N=40)	157	(SD 28.3)
Clinical non-depressed (N=19)	135	(SD 23.9)
Rotundo & Hensley (1985)		
"Normal school attenders (N=24)	107	(SD 32.4)
Clinic depressed (N=22)	190	(SD 21.6)
Clinic / non-depressed (N=38)	148	(SD 48.2)
Sad / non-depressed (N=16)	162	(SD 30.3)
Not sad / non-depressed (N=22)	139	(SD 22.8)
Kazdin (1987)		
Clinic inpatients (N=185)	137	(SD 34.9)
RDC depressed (N=54)	151	
RDC non-depressed (N=131)	138	

# STEM AND LEAF PLOT OF CHILD TOTAL DEPRESSION SCORE (CDS)

PVFS children	1   <b>08 </b> 5	Control children
	091	
	1 <b>0</b> 0 0 2	
	1  11	
	2 0   <b>12</b>	
	50  <b>13</b>  037	
	14	
	<b>15</b>   1	
	9   <b>16</b>   1	
	6  17	
	18	
	19	
	7  20	

Figure 5

STEM AND LEAF PLOT OF CHLID TOTAL PLEASURE SCORE (CDS)

PVFS children	2  5	Control children
	151	
	76  5	
	5	
	2  6  2	
	4   6   4	
	<b>6</b>   7	
	8   <b>6</b>   9	
	1  7  0	
	<b> 7 </b> 2 2 2	
	54  <b>7</b>	
	<b>7</b>   7	

comment. Firstly, it is apparent that most of the children are achieving depression scores which are above those expected for the averages in the normative data studies. It is of some quite considerable significance that 5 of this overall group of 18 children were recording scores of depressive features which are of clinical severity. Secondly, it must be remembered that the two groups are matched not only upon the age and sex of the child but also the social status as identified by the parental occupation (Office of Population Census and Surveys, 1980) and a neighbourhood match. The absence of maternal illness in one of these groups (the expected predictive factor of childhood depression) does not rule out additional causative or complicating factors which could be leading to poor child self-reported adjustment.

Using both groups of children, no sex differences were found in the overall depression or pleasure scores (p>.79), and a correlation of results with the child's age produced a non-significant result (Pearson r=0.36).

## Teacher ratings of child problems and competencies

It was predicted that the children of the PVFS mothers would show significantly more problems in the school environment than the control children and would be reported to have fewer competencies. The importance of this assessment of child adjustment is that it represents behaviour which is observed outside of the home environment and judged according to age-related classroom norms by an independent rater. The stem and leaf plots of the problem and competency scores taken from the Teacher Child Rating Scale (Hightower et al. 1987) are presented in Figures 6 & 7. No sex differences were found in the teacher ratings of problems or classroom competencies (p values were all greater than .79) and correlations with age were not significant.

The teacher's ratings classified the PVFS children as having significantly more problems (the sum of acting-out behavioural problems, shy-anxious presentation and learning difficulties) than the matched control group (U=14, p<.01).

The teacher rated child competencies as presented in the classroom and play ground setting also displayed significant group differences with the controls reported as showing more competent behaviour than the children of the sick mothers. With a mean score of 71.2 (SD=11.7) in the PVFS group and of 85.1 (SD=10.5) in the control children, the PVFS children were rated as showing significantly fewer competencies (T=-2.65, df=16, p<.01).

Following these significant findings, futher analyses were carried out in order to identify those aspects of the school environment that the PVFS children were finding particularly difficult to cope with. Group differences on the extent of acting-out difficulties and the existence of learning difficulties on the problem scale were not significantly different (p values of greater than .1) However, a significant difference was found for a rating of shy and anxious behaviour which was greater in the PVFS children (U=111, p<.02).

On the competency scale the groups showed no differences in their

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# STEM AND LEAF PLOT OF TEACHER RATED CHILD PROBLEMS (TCRS)

PVFS children	98	11 8 8 8 Control	children
		<b>2</b>   0 0 1 1 1	
	32	<b> 2</b>   3	
	5	2	
		2	
	98	2	
	0	3	
		3	
	4	3	

Figure 7

### STEM AND LEAF PLOT OF TEACHER RATED CHILD COMPETENCIES (TCRS)

PVFS ch	ildren	98	5				Control	children
			6					
	9	66	6					
		4 1	7	0				
			7	5	6			
		3	81	0	3			
			8					
			9	3				
		5	9	6	6	7		

tolerance of frustration in the classroom setting, or in their degree of application to the tasks in hand (p values of greater than .1). The children in the PVFS group were found, however, to show less ability to assert themselves appropriately in comparison to the controls (U=57.5, p <.01), and were rated as showing more problems socialising with their peers (U=60.0, p <.02).

The teacher's rating of a child as being unduly shy or anxious includes items which identify that child as appearing unhappy or sad, withdrawn, timid, nervous or worried. The child may be seen as having difficulties expressing feelings to others. The children with sick mothers were seen by their teachers as being less assertive in the classroom setting. This item reflects difficulties defending views under group pressure, difficulty expressing ideas or participation in group discussions and identifies those children who are uncomfortable as leaders. Poor peer sociability is identified in terms of the ease with which a child makes friends and the extent to which other classmates like or wish to sit beside that child.

Research has pointed to the extraordinary predictive powers of peer nominations of classmates as popular, sociable, aggressive, etc. The early rejection of children by their peers has been shown to be a stronger predictor of later maladjustment than either parental or clinical ratings. In Bower's (1969) "classroom play" inventory, each child allocates his class mates to specified roles. Those children who are "rejected" by the other children are more likely to show behavioural problems and emotional maladjustment later in childhood (Cowen et al. 1973).

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The peer-sociability index suggests difficulties with the making and keeping of friends and in the extent to which they are liked by classmates. The teacher is in a good position to assess respective sociability to and from the target child, perhaps more so than a parental figure. It is apparent from this study that the PVFS children are not singled out for aggressive or acting-out behaviour but it is possible that friendship difficulties are confounded by the shy and anxious predispositions displayed by the children in school. It is of some interest that these children do not on the whole consider themselves as more depressed, with lower self-esteem or with less positive affective experiences than the control children. However, the teachers as independent raters of the children were picking out differences in these children in the way in which they presented themselves at school.

It is possible that some of the effects of the stresses of the home environment are being taken into the school setting of these children. The relationship between these two domains of home and school and the suggestions that the boundaries between them are somewhat permeable, provides some explanation for these findings and poses some important questions for ameliorative work in the counselling of the families of post-viral fatigue syndrome sufferers.

The implications of these findings are suggested in a correlational analysis within the sub-items of the teacher rating scale, using all 18 of the children in this study. The correlations provide tentative explanations as to the possible impact of the group differences which have been identified. They suggest relationships between the areas of competencies and difficulties which may point to their potential

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longer-term repercussions. The correlation among all of the children suggests a strong relationship of peer-sociability with both assertiveness (Pearson r=.69, p<.001), and with associated learning difficulties (r=.49, p<.05). Problems in self-assertion also show an association with problems of learning (r=.60, p<.005). As would be expected, given the validity of these items, poor assertion skills correlate significantly with a shy and anxious presentation (r=-.52, p<.01). Amongst all the children it seems to be those with shy and anxious predispositions who would present with peer sociability problems.

The relationship with learning difficulties acts as an important reminder that those children presenting with poor assertion skills and who are seen to be excessively shy or anxious may be at risk for academic problems should these become too severe. It is important to see that such presentations may be detrimental to learning in much the same way, although perhaps to a lesser extent, as the well documented relationship between acting-out behavioural problems and learning difficulties.

#### 6.6 A child's social network analysis

The assessment of children's social networks and friendship variables provides further understanding of the differential group effects of peer relationships and the impact of the permeable boundary which exists between a child's home environment and school / peer influences. We are reminded of Bronfenbrenner's (1979) writings of a child's "meso-system" and the importance and the effects of the linkages between social spheres.

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Firstly, the following group comparisons of friendship variables must be seen alongside the finding that teachers have already identified a group difference in peer sociability. The PVFS children are regarded as having more difficulties than the controls in attracting and in maintaining peer friendships. Secondly, the four areas of the social network interview which provide some qualitative understanding of the nature of peer friendships were examined for the child's reported best friend and for the mean of the five friends mentioned on the network list. Analysis failed to identify any significant differences between best-friend and mean-friend variables, and therefore only the mean-friendship scores will be reported here. Thirdly, it must be reported that three of the PVFS group expressed some difficulty in selecting 5 close friends whilst none of the control group did so. It was not feasible in this study to attempt an analysis of potential network size and therefore we have nothing to confirm the suggestion that perhaps the PVFS group had available to them a smaller network of friends. With the reported difficulties mentioned by the three children above and the teacher's assessment of poorer peer sociability, this remains however a possibility.

The results of the friendship interview suggest that the PVFS children have significantly less active relationships with their friends. With a median activities score of 10 in the PVFS group and 16 among the control children, the children of the sick mothers are reporting significantly less active relationships with the network members (U=60.5, p<.02). These less active relationships expressed by the children of mothers suffering from the PVFS were predicted given the findings of the Illinois group for the adolescents of depressed and

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arthritic mothers. It is clear from this study that such a finding extends to a group of younger children with a parental disorder which combines features of both a depressive illness and arthritis.

No significant group differences were found for the scores representing the extent to which the target children confided in their friends (U=79.5, p=.6). This study also failed to find a group difference of stress levels between the target child and his or her network friends (U=98.5, p=.3). The Illinois studies reported that levels of stress with best friends were elevated for the adolescents of depressed mothers in comparison to the arthritic or control mothers, whose children displayed very similar but low scores (Hirsch & Reischl, 1985). It is perhaps likely that the presence of ill health in the PVFS sufferers is not affecting the out of home relationships of their children in quite the same way. It had been suggested by the Illinois researchers that it was an element of embarrassment about parental illness, ambivalence towards that parent and anxieties about losing friendships from comparative exercises with friends' families along with the often "odd" and unpredictable parental behaviour which was adding strain to an adolescent's friendships with peers.

The fact that stress among friendships was less apparent in the physically ill arthritis group suggests that it is something about the unpredictability and "invisibility" of disorder in depressive illnesses as opposed to easily recognised physical conditions, which puts friendships at a perceived risk (ie. perceived to be so by the target child of the depressed mother). The interesting feature of the PVFS condition is that it is not always so physically apparent and not

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readily accepted as a "real" organic condition on a wide-spread basis. Its often vague presentation makes it difficult to label and as this study illustrates, it is frequently contaminated with depressive features. Most of the mothers in this study had undergone an extensive period of diagnostic uncertainty which was openly expressed by all to be the most stressful periods in the history of the illness. Such stresses could not have gone unnoticed by the children in these families.

In spite of this, it is clear in this study that friendships were not reported to be more stressful among the children of the PVFS sufferers. It is possible that these pre-adolescent children were less likely to regard friendships as being at risk because of perceived parental comparison. Alternatively, it is possible that the post-viral fatigue condition lacks some features of a clinically depressive condition, or perhaps differs from the depressed parents in the Illinois studies in terms of depressive severity.

Important group differences were found for boundary relationships between a child's parents and a child's peer group. The index of parent-child contact revealed significant group differences. The variable measures the extent to which a child's parent knows his or her friends, the extent to which the child knows his or her friends' parents and the degree of contact in terms of home visits and family outings between these three respective groups. With a mean-friendship contact score of 5.8 for the PVFS children and 9.8 for the control group children, the children with sick mothers reported less contact between peer groups and parents than those children whose mothers were well (U=60, p<.002). No sex differences were found for the reporting of activity, confidency, stress or parent contact scores in the children (p values range between .12 and .89).

### 6.7 Network densities and boundary densities

The two measures of friendship, network density and parent-friend boundary density, are calculated from network maps in which unweighted scores of 0 or 1 are reported for each potential relationship (the nodes in the network map). For the parent-friend boundary density the unweighted scores are reported. Weighting each potential parent child's friendship relationship with the contact scores (reported above) did not add anything to the analyses; unweighted scores were found to be equally predictive of child outcome measures.

For the child's best five friends, there was no significant group difference in the extent to which network members knew one another (T=0.55, df=16, p=.59). In both groups there were network densities ranging from .3 to 1.0, with 5 children in each group reporting densities of 1.0 (ie. all five of the friends on their network lists knew one another).

The target children were asked to report whether their friends were in the same school or neighbourhood as themselves. Among the control children, six reported that all 5 of their friends went to the same school as them, two had 4 of their friends from the same school and 1 from the same neighbourhood, and one control child reported 3 friends from school whilst 2 were family friends from the local neighbourhood. In the PVFS families, four of the target children named all 5 friends as coming from their school. A further four children reported 4 friends from their school plus an additional neighbourhood friend. Again, one child reported 3 friends from their school and 2 friends who lived away.

The density between network members is important given their potential confiding and supportive roles to the target member. The research findings of the utility of social network support have pointed to the importance of the isolation of certain network members in order that they can function in a supportive role. Where a network member is well integrated into the overall network of the target person, that member is unlikely to successfully serve the purposes of confidant. On the other hand in the social networks of children it is to be expected that the significant members are those with whom the target child spends some considerable amounts of time. Thus it is to be expected that the majority of friendships will be located in the school environment. Because of the difficulties and stresses for children in maintaining friendships over geographical distances it is of no surprise that most of these children are identifying a peer group within close proximity to one another.

An overall group difference for the parent-friend boundary density scores was found. With a median density between parental and peer groups of .5 among the children of the sick mothers and .8 among the control children, it is apparent that the boundary density is significantly less dense for the PVFS children, with fewer actual relationships between mother and father and the five network friends (T=-2.68, df=16, p<.025). Thus, there is less contact between a

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child's parents and his or her friends if the mother is ill. The direction of this relationship is not known but it is possible that sickness in a parent may mean that there is less frequent contact between a child's friends and parents with fewer friends visiting the family home and fewer outings with the families.

The following analysis is a direct replication of the findings of the Illinois group (Hirsch, 1985). The child's depression score (CDS) was used as the outcome variable in a regression analysis which aimed to identify a differential group effect of parent-friend boundary density upon child adjustment. For the purposes of this analysis, three siblings (falling into the 9-14 year old age group) from the families of the target children were added to each group as the outcome related to individual children. The increase in the sizes of each of the groups was expected to increase the power of the analysis. Thus 24 children are included in this analysis. The group identifier, the parent-friend boundary density and a product term representing the interaction between the two were entered as independent variables in that order.

The regression analysis displayed no significant group difference in the childhood depression scores. The test of the difference between the PVFS and the control groups was not significant [F(1, 22) = 1.54,p<.23]. Secondly, the parent-friend boundary density score was entered into the equation. This tested the significance of the slope of the regression of childhood depression on parent-friend boundary density. The increase in variance accounted for by this independent variable entered second was not significant [F(1, 21) = 1.11, p<.35]. A significant effect, however, was found for the interaction of group

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with boundary density, [F(1, 20) = 4.20, p<.01]. Where the analysis was repeated with only one child for each family, the result was still significant (P<.01). The results of the first regression analysis are entered into Table 2. Graphs of the two groups with separate regression lines are displayed in Figures 8 & 9.

Thus, among the children of the sick mothers, there is a positive relationship between childhood depression and parent-friend boundary density. A high boundary density between parents and friends is associated with more depression in the children, whereas a low density relationship appears to be more protective, in that is is associated with lower depression scores. The results for the control children run in a contrary direction. A higher boundary density is associated with lower depression scores. It is the high boundary density relationships among the control children and their parents, which appear to protect against poor child psychological adjustment.

The following exploratory finding was of some interest. Among the control families, a significant correlation was found to exist between the strength of the parent-child relationship (CAM) and the boundary density between the child's parents and his/her friends. It suggests that the child whose parents are more involved in his or her peer network, will report a better relationship with his/her mother, than if parents have little contact with peers. A correlation of -.80 (Pearson) between the CAM problem score and the boundary density is significant at a p value of .01, and is unlikely, therefore, to be a chance finding. No evidence was found for a similar or contrary relationship among the PVFS families (Peason r=.07). Thus, the child's relationship with his sick mother is not unduly affected by

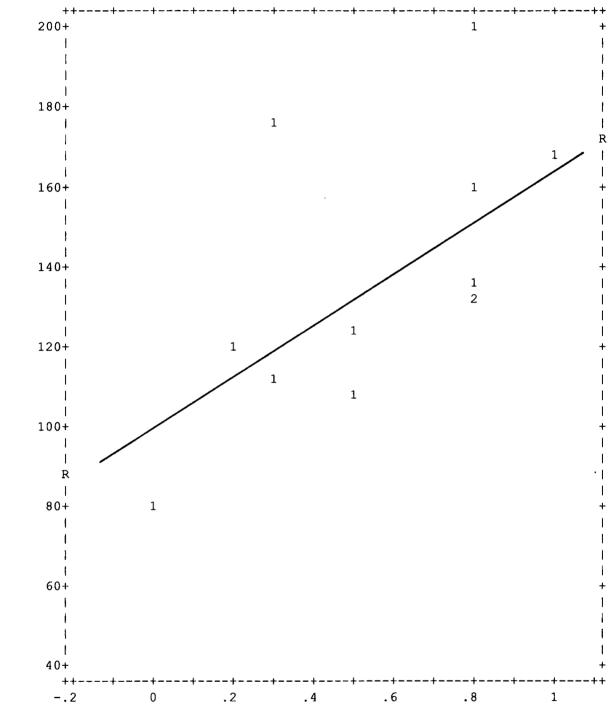
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# REGRESSION ANALYSIS OF CHILD DEPRESSION AND PARENT-FRIEND BOUNDARY DENSITY

\_\_\_\_\_

	Outcome variable:	CHILD	DEPRESSIC	N SCOF	₹Ē	(CDS)
Predictor	variables					
1. GROUP		F(change)	1.54	df=1,	22	p.2245
	'-FRIEND RY (PFB)	F (change)	0.69	df=1,	21	p.3451
3. GROUP	* PFB	F (change)	9.65	df=1,	20	p.0152

Figure 8



CHILD ADJUSTMENT AND PARENT-FRIEND BOUNDARY DENSITY IN POST-VIRAL FAMILIES

PARENT-FRIEND BOUNDARY DENSITY

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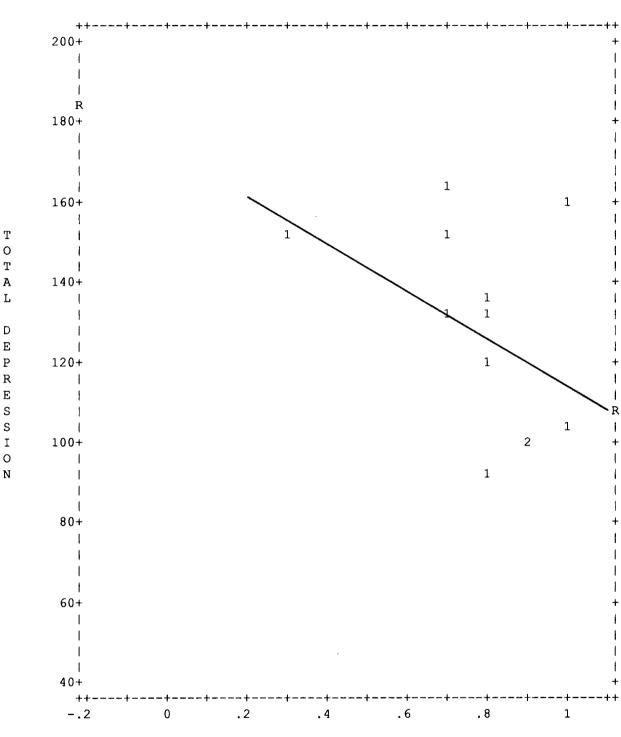
т Α  $\mathbf{L}$ D Е Ρ R Е S

S I

0

N

Figure 9



CHILD ADJUSTMENT AND PARENT-FRIEND BOUNDARY DENSITY IN CONTROL FAMILIES

PARENT-FRIEND BOUNDARY DENSITY

А L D Е Ρ R Е S S

the degree of involvement of the parents in the child's friendship group. Alternatively, as the previous analysis indicated, the density proportion appears to be more related to a self-reported measure of affective disturbance. Perhaps the children in these families are more likely to "internalise" family adversity, whereas the children of well parents are more inclined to focus on relationship difficulties as being located in the other person. However these results are to be interpreted, this finding once more highlights the importance of the boundaries separating the different spheres of influence in a child's life.

### 6.8 Family psychosocial climate

The family environment was expected to be of considerable importance in the assessment of the changes brought about when a member of a family becomes sick, and in the identification of family environment variables conducive to good child adjustment in the face of family adversity. In Hirsch's (1985) family study of the adolescents of depressed, arthritic and normal mothers, there were no overall group differences in family variables. His results found, however, that a more cohesive and expressive family which is low on conflict is more likely to predispose towards good adjustment (low symptom scores and high self-esteem) in the adolescents of depressed mothers. A family oriented to individual independence was also associated with healthy esteem in the children. In Hirsch's research, the same familv variables were important in families without parental illness, but the degree of expressiveness between family members was of paramount importance in the families with ongoing parental i11 health. Intellectual-cultural and active-recreational orientations were also

found to be important correlates of good self-esteem in the children of healthy parents.

The initial aim of this analysis is to look for any group differences in family climate which may be accounted for by the maternal illness. In addition to the family variables taken from the Family Environment Scale (Moos & Moos, 1986), Jensen's Family Routines Inventory (Jensen, 1983) is used. The organisation scale of the FES correlates positively with the FRI (r=.47, p=.05), and they are therefore combined for this analysis.

No group differences were found in reported family cohesion, expressiveness or the independence of individual members, achievement orientation, organisation or moral-religious emphasis (p values between .15 and .76). There were no significant differences in incongruence scores (that is, the rating of disagreement between parental reports) as rated by both parents (p=.5). There was a marginally lower intellectual-cultural orientation in the post-viral families (U=64, p<.1), and a marginally higher level of reported family conflict (U=103, p<.1), both of which showed trends which were only of borderline significance.

The only significant group difference was for active-recreational orientation. The families with sick mothers were significantly less active than the control families (T=-4.4, df=16, p<.001). The questions in this category ask if family members are active in sports, hobbies, recreational activities or courses outside of the home and school. Questions ask if friends often come around for meals and whether family members go out a lot. Families who spend a lot of their

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evenings and weekends at home and for whom watching the television or listening to the radio is the main form of entertainment will achieve low scores on this scale.

Secondly, a correlational analysis was conducted in order to investigate the relationship between family psycho-social climate and selected child adjustment variables. To reflect the analysis conducted by Hirsch, et al. (1985), family variables of cohesion, expressiveness, conflict, independence and intellectual-cultural orientation are entered. Child adjustment measures of depression (CDS), and teacher ratings of problems and competencies are used (T-CRS). In addition, the problem score of the Child's Attitude to Mother scale (CAM) is used.

The correlations are presented in Table 3. Among the children of mothers with the post-viral fatigue syndrome, only the family's active-recreational orientation shows any relationship with the child adjustment measures. Significant associations, however, are found for 5 of the family social climate variables and the parent-child relationship problem score. A more cohesive family with lower conflict levels and with a more cultural and active orientation is associated with a much better mother-child relationship. These family variables are not closely associated with the quality of the mother-child relationship among the control families. For both of the groups, it appears that families which foster more independence of family members will show more problematic mother-child relationships. The items relating to independence refer to family members who come and go as they wish, who think things out for themselves and who are encouraged to be independent in personal matters. It is possible that such an

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## CORRELATIONS OF FAMILY ENVIRONMENT AND CHILD OUTCOME VARIABLES

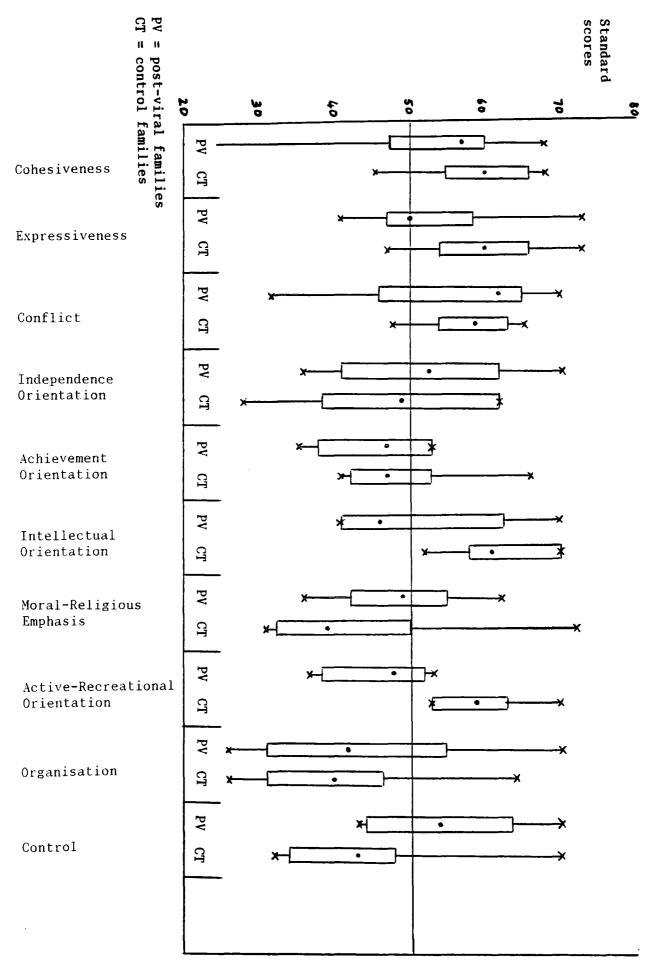
Family environment	PVFS	childr	en (N=	9)		Con	trol ch	ildren	(N=9)
	CDS	CAM	T.PROB	T.COMP	    	CDS	CAM	T.PROP	3 T.COME
Cohesion	.01	50*	37	.11	ł	17	.20	36	.06
Expressiveness	.21	03	14	11	Ì	.01	23	16	.51*
Conflict	.00	.48*	07	.17	ł	.73	***.39	.07	04
Independence	.03	.54*	.34	01	I	27	.66*	* .34	20
Intellectual-cultural	.16	44*	13	08	1	20	24	25	.35
Active-recreational	43*	66**	05	.14	1	08	37	.21	16
					_				
Pearson product moment	corr	elation	ıs *	p<.10					

\*\* p<.05 \*\*\* p<.01

CDS (Children's depression scale) CAM (Child's attitude to mother scale) T.PROB (Teacher-child rating scale problem score) T.COMP (Teacher-child rating scale competencies score). orientation is not adaptive for children of the age-group covered in this study. An emphasis on the children doing things separately from the family may not be conducive to good relationships with the mother.

In the control group there are also few correlations of family climate with child adjustment. There was a suggestion that a more expressive family fosters more school competencies in a child, as rated by his teacher. The family environment does not appear to be largely associated with child adjustment at school. A strong correlation was found, however, between the level of family conflict and the child's rating of depression. The fact that this was not suggested in the post-viral group implies that the level of expressed conflict poses no greater risks to child adjustment in the face of the existing family adversity. It has already been pointed out that there is a trend towards greater conflict in the post-viral group and that this is associated with more problems in the child's relationship with his or her mother. Perhaps it is because the child can identify the source of the family conflict to the mother and her illness that the child is not suffering from more severe depression.

Finally, the family social climate variables were expressed as subtest standardised scores (Figure 10) from census tract data (Moos & Moos, 1986). Overall, it can be seen that the families in this study are more cohesive than would have been expected, with levels ranging from below the 20th percentile to the 68th for the post-viral families, and the control family as more expressive than the average family. Conflict levels are higher than the comparative norms in both of the groups and organisation within the families is low given the normative data.



FAMILY ENVIRONMENT SCALE SUBTEST STANDARD SCORES

#### 6.9 Family observation

The home observation was conducted in order to provide independent measures of family life as observed to take place around the target child in each family. The aim was (i) to assess child adjustment within the family, in particular the activities in which the child is engaged; (ii) to evaluate the different patterns of interaction between family members and the target children, in terms of the amount of time spent together and the degree to which verbal interactions take place; and (iii) to assess the quality of verbal interactions.

Time spent by the children in the different behavioural categories, time spent in the same room as different family members and the time spent alone was recorded. Additionally, a frequency count was made of selected verbal interaction categories occurring between family members and the target children.

The children in the PVFS group were "out of contact" for a mean of 38 minutes (SD=41), ranging from no time "out of contact" for two children, up to 111 minutes in one case. The children in the control families were "out of contact" for a mean of 18 minutes (SD=30), with five children spending no time "out of contact". Overall, the children in the PVFS group spent marginally more time "out of contact" during the total time of the observation. Whilst this did not reach statistical significance (T=1.17, df=14.6, p=.26), there was considerable variation between the individual children. In order to permit a group comparison of time spent in child activities and time spent with different family members, the times were expressed as

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percentages of observed time (thus controlling for the time spent "out of contact").

#### Child activities

Child activities within the home environment are coded in 6 mutually exclusive categories: Personal, Domestic, Leisure-Active, Leisure-Passive (TV), Leisure-Passive (Other), and Educational-Intellectual. A 7th category represents the time during which the child was "out of contact". The mean total time spent in each of these categories is displayed in Table 4. The percentages of observed time (controlling for the time spent "out of contact") are reported.

The activity categories are broken down into two variables: GOAL-ORIENTED ACTIVITIES (including time spent in leisure-active, domestic, personal and educational pursuits), and NON-GOAL-ORIENTED ACTIVITIES (the summation of leisure-passive (TV) and leisure-passive (other)). The categories represent the amount of observed time (in minutes) the child spends in such behaviours.

The children in the PVFS families spent a mean 59.2 % (SD=13.2) of observed time engaged in non-goal oriented activities. The control children spent a mean of 45.7 % (SD=21.6) engaged in the same activities. The children of the sick mothers are therefore spending marginally more time in these passive pursuits than the control children (T=1.59, df=13.2, p=.13).

The children of the sick mothers spent a mean 39.9 % (SD=12.2) of

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## Table 4

	PVFS	child	dren	Control children				
Child behaviour categories	mean	(SD)	<pre>% of obs.time</pre>	mean	(SD)	% of obs.time		
Personal	27	(11)	11	28	(8)	12		
Domestic	9	(12)	4	6	(8)	3		
Leisure-active	27	(28)	11	49	(44)	20		
Leisure-passive-TV	48	(39)	20	62	(47)	26		
Leisure-passive-other	66	(35)	28	41	(14)	17		
Educational-Intellectual	23	(26)	10	35	(50)	15		
Out of contact	38	(41)		18	(30)			
- <u>, , , , , , , , , , , , , , , , , , ,</u>	[240]	*		[240]	*			

### TIME SPENT BY CHILDREN IN OBSERVED BEHAVIOURAL CATEGORIES

(\* = 4 hours allowing for rounding errors)

observed time engaged in goal oriented activities; the control children, a mean 54.3 (SD=21.6) engaged in the same activity. Thus, the children in the PVFS group are spending marginally less time taking part in active goal-oriented behaviours than the children of the control families (T=-1.74, df=12.6, p=.11).

From these results it would appear that there are no largely significant differences in how children spend their time on a week-day evening during the school term, although there were trends towards more passive / non-goal oriented and less active / goal oriented behaviours among the children of mothers with the PVFS. What is apparent in a study such as this is the large variation in family activities and interaction patterns. This cannot be surprising given the diversity of family life and given that this observation was conducted on only one occasion. No sex differences were found in the time spent by the children in the selected behaviour categories (p values were all greater than .28). Selected correlations with child adjustment measures were also unimpressive.

### Interaction between family members

During the observation, interaction was recorded according to whether the child was alone or in the presence of other family members. The children of the sick mothers spent an average of 30.1 % (SD=18.8) of the observed time alone. The children of the well mothers spent an average of 37.9 % (SD=22.3) of observed time alone. A comparison of group difference failed to reach statistical significance (T=-0.81, df=15.6, p=.43).

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Times during which mothers were not in the presence of the target child included time out of the house or more commonly, among the post-viral fatigue syndrome sufferers, time spent resting in bed, during which the mother was not to be disturbed. Times when the father was absent included time away from home (usually before returning from work), or time spent in the house away from the children. The whole family included all those members living at home who were available at the time of the observation. Time in which the whole family was together often involved the consumption of the evening meal and time spent watching television. The interaction variables used in these analyses include time solitary, time spent with mother, time spent with father, time spent with whole family.

Some significant differences emerged from these analyses. It became clear that the children of the post-viral mothers spent significantly more time with both of their parents, and the families spent significantly more time together as a whole family unit than the control families.

The sick mother was in the same room as her children for a mean of 44 (SD=23.9) of observed time. The mothers of the control children, for a mean 25.2 (SD=11.1) of observed time. The group difference was significant, with the sick mothers spending significantly more of the observation time with the target children (T=2.15, df=11.3, p<.05). The husband of the sick mother spend on average 26.4 (SD=23.4) of observed time with the target children; the fathers in the families with healthy parents, a mean proportion of only 12.3 (SD=11.8). The group difference reached borderline significance (T=1.62, df=11.8, p=.13). The complete families of mothers with PVFS were observed together for 19.8 % (SD=11.8) of observed time. Control families were observed together in a complete family unit for only 8.4 % (SD=5.0) of observed time. The group difference was statistically significant (T=2.69, df=10.8, p<.05).</pre>

No sex differences were found in these interaction categories (p values were all greater than .31).

### Verbal interactions

There was a significant group difference in the proportion of observed time in which family members talked to the target children. In the PVFS families, a mean of 61.9 % (SD=16.7) of observed time was spent in which conversational exchanges were taking place between the target child and family members. Significantly less of observed time was spent in this way in the control families. With a mean proportion of 45.5 % (SD=17.4) of observed time, in which talk took place between family members and the control children, the group difference was statistically significant (T=2.04, df=16, p<.05).

In order to look at selected functional categories of conversational interaction, the frequency counts of positive behaviour request, negative behaviour request, positive replies and negative replies were expressed as a proportion of the time in which family members spoke to the target child (see above), coded as rate per hour.

From the two group comparison, it appeared that groups did not differ significantly in the proportion of positive comments (postive behavioural requests and positive replies) per hour of observed time.

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A mean hourly rate of 12 positive behavioural request (SD=6.7), and 5 positive replies (SD=5.4) were issued between family members and target children in the PVFS families. In the control families, the rates were 9.1 (SD=7.2), and 5.1 (SD=3.4) respectively.

However, for the negative interactional items, significant differences were found. In the PVFS families, a mean hourly rate of 3.8 negative behavioural requests were made to the target children (SD=2.5). The corresponding frequency in the control families was smaller, with a mean hourly rate of 1.9 comments (SD=1.3). The difference was statistically significant, with more negative behavioural requests in the PVFS families (T=2.04, df=11.8, p=.05). Of those comments identified as negative replies, a mean hourly rate of 18.6 was located in the PVFS families (SD=7.6), and a mean hourly rate of 13.6 (SD=6.5) in the control families. There were more negative replies per hour of observed time in the PVFS families as opposed to the controls, a difference which reached borderline significance (T=1.9, df=15.6, p=0.13)

### 6.10 Discussion of findings

From these findings, it appears that the maternal sickness is serving to bring the families together in an interesting way. It was apparent that the sick mother was not less available to her children because of the debilitating illness, in spite of the fact that she may spend some considerable amount of time resting. Time spent in the home by the target child was more likely to be spent alongside other family members, whilst other indicators have shown that the time spent with the mother and general family orientation is less active, with less

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out-of-home family pursuits than the control families. Additionally, these children have reported less active relationships with network friends outside of the home environment. Fathers appear to be generally more involved in these families, spending more time in the company of the children. But there was also a trend for these relationships to be less active in comparison to the father-child relationships in the control families. The observational categories suggest that interactions between family members and the target children are somewhat more "negative" than they are in the control families. This may represent a subtle indicator of family strain resulting from the illness, or from the increased time the family are spending together. There is no evidence, however, that these signs of negative interaction are associated with family conflict, as rated by the parents on the Family Environment Scale.

The suggestion emerging from these findings is that the children of sick mothers show a greater family involvement than the children of Given the restrictions imposed by the post-viral well mothers. fatigue syndrome, and the relative isolation from their neighbourhoods (a point cogently made by many of these mothers), it is likely that such intense involvement with the family is felt to be restricting for The family-world of these children is relatively the children. "enclosed", with more solid boundaries existing between this sphere and the spheres of school and peer-group involvement. Children often expressed dissatisfaction in that it was not feasible for them to bring friends to the house, it being too much of a strain for their mothers. Similarly, mothers often expressed dismay that they knew so little about their children's lives out of the home, and that they were unable to become involved in school or community based activities

Following on from the work of the Illinois group, such separation of social systems, for example the low boundary density of the "meso-system" (Bronfenbrenner, 1979), may provide a parent-peer resource for the support of adaptive non-family involvements which may not be possible with a more permeable boundary between family and peers. Whether these children were able to establish confiding and supportive relationships with peers, in order to resolve issues of distress in other areas of their lives, is not clear. It is very likely that they were unable to, and thus, there are more child adjustment problems in the post-viral group. What is perhaps more evident is that increased contact with network-members and the families of the network-members evokes a degree of family comparison or awareness of difference, which may lead to distress. Some children spoke of the embarrassment they felt when friends saw their sick mothers and it became clear that many of the children avoided talking about their mother's illness to their peers. An awareness of what their friends' parents are capable of and the contrast of more active family life-styles to their own, may also lead to some degree of negative comparison with their own parents. More importantly, it is hypothesised that a depressed sick mother would induce more feelings of social embarrassment and ambivalence in a child. Eight out of 9 of the mothers with post-viral fatigue syndrome satisfied criteria for caseness on self-reported anxiety and depression.

It must be remembered that many of these mothers had been ill for a substantial amount of the children's lives. Self-reported illness durations ranged from 18 months to 14 years. Four of the group of 9

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report illnesses of over 3 years. Thus, it is very likely that the children's experiences of family life and the involvement of parents in their lives outwith the family per se, would have been very different to that of children from families with well parents. The poorer integration between family and friendship life may explain the target children's greater predisposition towards shy and anxious behaviour out of the home, the less assertive behaviour in the classroom and the poorer peer relationships. It is well established that depression in a parent can lead to interpersonal problems in the children (Orvaschel et al. 1980). Children of depressed parents have also been identified by their teachers as being more shy and withdrawn than the children of non-depressed parents (Weintraub et al. 1975).

In spite of these findings, many families are able to maintain a supportive family climate with resources for protecting against the effects of stress and for maintaining adjustment in the children. In view of the crisis theories of chronic illness (Moos & Moos, 1984), it may be that family distress is at its most pronounced at the onset of illness. What was apparent in many of these families was the ways in which they had adjusted their lives around the illness, and thus, other family members may have learnt adaptive strategies to minimise its disruptive effects. And yet, as the mothers' reports on the coping scale indicated, the quintessence of the post-viral fatigue syndrome is its unpredictability, the limitations it makes upon planning for the future, and the degree of "preoccupation" it demands because of the excess reactivity of the symptoms to physical or emotional environmental change.

Levels of organisation and routinisation, whilst not statistically

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different to that in the families with well parents are, however, low given the normative data of the Family Environment Scale. The types of family interaction also appear to be more negative and conflictual, and parent reported family conflict is considerably higher than the normative levels in a substantial number of the families. It is negativity and instability in the family environment along with an unpredictable and variable parental disorder, which are perceived to be the most damaging facets for the child of a depressed and sick parent (Billings & Moos, 1983). In their study, the children of parents with chronic and unchanging affective disorders were better adjusted than the children of parents with affective disorders with a changeable, non-chronic course.

In this study, measures of child adjustment and of family interaction were taken independently of the mothers. Consequently, the increased problems in the children of the sick mothers, and the group differences in observed behaviour at home cannot be explained in terms of the mother's predisposition to negatively distorted views of themselves or their families, as would be predicted by cognitive models of depression. However, in spite of this precaution, there is little evidence to suppose that maternal ratings had a distinctly negative bias. On ratings of family environment, the level of agreement between spouses in the post-viral fatigue syndrome families did not differ from that among the well parents.

One very obvious methodological failing of this study is the absence of any reliability data for the family observation. It proved not feasible to collect reliability data because I was working single-handed. It was also felt that the presence of another rater in

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a family home would have been too intrusive, altering family routines and contributing to a more crowded and chaotic atmosphere, to an extent which was considered to be unacceptable. There were no opportunities to video record family activity and interaction, which could have provided samples for inter-rater assessments. For many of the families and for the observer, the four hour evening observation was likely to be felt as arduous enough without the presence of another unfamiliar researcher, a video camera, or the possibilities of repeating observations with selected families.

Thus, it must be accepted that firstly, behavioural and interactional categories have not been validated as such, although they were devised for the purposes of this study from an extensive review of validated observational studies. Secondly, their reliability from one visit to the next, or across raters has not been assessed. However, this was designed as an initial study to formulate hypotheses about families, which can be confirmed in future research.

## Discussion

## 7.1 Introduction

The Post-viral fatigue syndrome is a poorly understood disorder evoking much controversy among researchers and medical professionals. There are a growing number of persons who adhere to a primary psychiatric explanation for the aetiology, maintenance and prognosis of the condition (Wessely & Powell, 1989; Stokes et al. 1988; Wessely, 1989; 1990). The syndrome has recently been described as a modern-day neurasthenia (Wessely, 1990), a "twentieth-century overload disease" (Steincamp, 1989), a disorder of "environmental hypersensitivity" (Stewart, 1987). It has been linked to a number of ill-understood conditions with transient, non-specific symptoms, such as candidiasis, allergy syndromes, fibromyalgia, irritable bowel conditions and various unexplained fatigue and somatic conditions. The label of post-viral fatigue, or myalgic encephalomyelitis has been described as a welcome legitimation of disorder for the suggestible patient with a proclivity to somatise distress.

Those who are sceptical of the organic origins of this disorder, regard the virological explanations as indicative of a contemporary trend in illness belief:

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"Viruses are among the commonest explanations given for non-specific transient illnesses that abound in the community [..]. The agent is external, and is beyond the subject's control. There is no "maleficium", nor guilt or self-blame. External attributions of illness to entirely organic causes distinguish M.E. (myalgic encephalomyelitis) patients from matched psychiatric controls" (Wessely, 1990).

A belief that a virus is neither a necessary nor a sufficient agent in the development of a condition characteristic of the "post-viral" fatigue syndrome, is founded upon two types of evidence.

Firstly, in patients selected on account of presenting chronic fatigue, no symptomatic differences have been found between those with and those without serological evidence for a past or persistent viral illness (Wessely & Powell, 1989). Specific organisms, when located, also show little uniformity. Enteroviruses, Epstein-Barr, influenza, hepatitis A, herpes-zoster, cytomegalovirus and toxoplasmosis have all been implicated. In Wessely and Powell's study, of those patients referred to a neurological centre for unexplained chronic fatigue, 72 % expressed beliefs in a precipitating viral illness, whilst only 33 % showed serological evidence for this. Such lack of uniformity is also characteristic of Taerk's study of patients with suspected post-viral fatigue syndrome (Taerk et al. 1987). Half of his group displayed no evidence of viral infection.

Secondly, many express a suspicion of the viral-aetiology hypothesis because of the ubiquity of symptoms of fatigue. Fatigue is a commonly reported symptom in general population samples, general-practice attenders and psychiatric patients. A recent survey identified that it is present in the community with a skewed distribution, but with no point of rarity (Wessely & Powell, 1989), identifying it as a continuous and not a categorical variable. Evidence for muscular abnormalities (Jamal & Hansen 1985; Behan et al. 1985; Arnold et al. 1984), whilst still controversial do not entirely explain the persistence and severity of the fatigue (Lloyd et al. 1988). What is more, raised anti-body titres to specific viruses have been located in community samples evincing no clinical signs of illness (Dawson, 1987; Bell et al. 1983).

The result of such changes of direction from belief in the virus as an explanatory agent, to the psychological and psycho-immunological status of the host, has resulted in considerable methodological confusion and a lack of uniformity of case-definition in recent studies, which can only have obfuscated our understanding of the syndrome. In many investigations into the disorder, the "post-viral" label has been dropped. The syndrome is now often described as a chronic fatigue syndrome (Holmes et al. 1988).

The 47 subjects selected by Wessely (1989), were a hospital sample of referrals to a neurologist with unexplained chronic fatigue. Ά complaint of fatigue was regarded as unexplained, where no diagnosis has been reached on preliminary investigation. The exclusion criteria included neurological complications, muscle enzyme or nerve-conduction problems, EMG or muscle biopsy abnormalities, all of which may be affected by a post-viral condition, in spite of their controversial standing in the research literature (Behan & Behan, 1988). Virological evidence was not regarded as criteria for exclusion, although it was also not seen as a necessary requirement for a diagnosis.

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Stokes et al. (1988) describe a condition they refer to as an "effort syndrome". It appears from their discussion that this is believed to be analogous to the post-viral fatigue syndrome or myalgic encephalomyelitis. Their 30 patients are selected on the basis of excessive general and muscular fatigue with no evidence of neuromuscular disease on clinical, biochemical, histological and histochemical investigations. Serological status was not reported although some of the patients were said to have a history of viral illness.

The study by Manu and Mathews (1988) includes 135 consecutive patients attending a university fatigue clinic. The authors use newly developed operational criteria for the diagnosis of the chronic fatigue syndrome (Holmes et al. 1988). The criteria, developed for the Centres for Disease Control (CDC), are based upon the specific exclusion of patients with evidence of current or past psychiatric disorder or psychotropic medication use. The syndrome is regarded as an amalgamation of potentially related symptoms for which viral infection may be but one aetiological factor. The limited utility of such criteria are highlighted in Manu and Mathew's findings. They assert that 95 % of their sample fail to satisfy the requirements for a diagnosis of chronic fatigue syndrome. Sixty-seven percent of the subjects had been excluded on the basis of a past or current psychiatric diagnosis alone.

Given our current understanding of the prominence of psychiatric accompaniments to the post-viral fatigue syndrome, and of a suggested psychiatric vulnerability, such criteria clearly do not serve any useful purpose. They do not permit a diagnosis of the fatigue

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syndrome if reactive or endogenous psychiatric disorder accompany the disorder, or if pre-morbid psychiatric episodes have occurred. They also preclude the possibility of investigating the psychiatric profiles of patients and establishing whether the syndrome can be regarded as a variant form of depression.

The operational criteria established for Hickie's study (Hickie et al. 1990) do not exclude patients on the basis of psychiatric status. They reflect a movement away from an external aetiological agent, to the immunological status of the host. Alongside signs of a chronic, persistent or relapsing fatigue, the demonstration of impaired cell-mediated immunity is a necessary requirement. Fatigue must have persisted for more than 6 months, with two major or one major and three minor indicators (symptoms, signs or laboratory findings):

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    Symptoms: (i) major: concentration / memory impairment;
(ii)minor: myalgia, arthralgia, depression, tinnitus,
paraesthesia, headaches;
    Signs: (i) major: lymphadenopathy;
(ii)minor: pharyngitis, muscle tenderness;
    Immunological assessment:
(i) major: cutaneous anergy, T4 or T8 lymphopenia;
(ii)minor: hypoergy.
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The criteria established by Hickie permit greater homogeneity of case-definition. They rest upon the primacy of immunological deficiencies in the host, irrespective of current persistent infection. Sixty-percent of their sample reported an acute infectious onset, only 17 % of which had been serologically documented. It is not clear that current serological status was examined.

There is enough evidence to convincingly support the role of a compromised immune system in the aetiology of the fatigue syndrome.

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Decreased numbers of suppressor / cytoxic (T8) cells have been found in patients with illnesses of up to 6 months duration, and decreased helper / inducer (T4) cells were characteristic of those chronic sufferers who had been ill from 1-20 years (Behan et al. 1985). Circulating immune complexes were located in a significant proportion of these patients. Such abnormalities were found along with serological evidence of infection with Coxsackie B and Epstein-Barr viruses (Behan et al. 1985; Straus, 1985; Jones & Miller, 1987). It is believed that these viruses can persist in an ongoing or latent form and that viral DNA or protein products may alter the host tissue, thereby inducing changes in immune functioning (Jones & Miller, 1987). An inflammatory process has been linked to the action of these viral agents, causing the alteration of muscle metabolism and perhaps also promoting psychiatric complications which are familiar accompaniments to the disorder (McDonald et al. 1987).

The present thesis took as its starting point the central role of a viral illness and altered host immuno-competence in the identification of the syndrome. All subjects had shown raised specific anti-body titres to the enterovirus, Coxsackie B. The virus is known to play an aetiological role in disorders such as encephalomyelitis, paralytic poliomyelitis, aseptic meningitis, Bornholm's disease (an epidemic myalgia), myositis (a disorder of the skeletal muscle), and myocarditis (Behan & Behan, 1988). The epidemiology and symptomatology of these virus infections are consistent with the known features of the PVFS. Behan and colleagues are foremost in supporting the role of these viruses as primary causative agents in a large proportion of PVFS sufferers. They hypothesise a process by which the virus may interfere with cell metabolism, without however causing the

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destruction of the cell, thereby ensuring the persistence of the virus. The Coxsackie viruses are understood to be responsible for damage to muscle fibres and to exert a detectable alteration in the host's immunoregulation.

The neutralising antibody test which forms the basis of the serological diagnosis in this study, is open to some criticism. The probability of recent infection is likely to be greater, the higher the anti-body count, but often results are difficult to interpret. Significant counts of various Coxsackie B specific antibodies have been identified among healthy population controls (Bell et al. 1983). More accurate specificity has been achieved with recent advances, permitting a routine test for IgM specific antibodies (ELISA. McCartney et al. 1986). This was not, however, available at the time of this study. Raised specific antibody titres to Coxsackie B viruses, alongside a clinical profile characteristic of the fatigue syndrome, were treated as sufficient to satisfy criteria for a diagnosis of PVFS. Additionally, 16 of the 29 subjects had received a positive entero-viral antigen test (viral protein 1), providing evidence for a current or persistent viral infection (Yousef et al. 1988).

The subjects selected for the purposes of this research represent a fairly homogenous group, all showing positive evidence of viral infection. This stands in direct contrast to the rag-bag of subjects investigated in a number of other studies, where those with evidence of viral infection and/or immune system dysfunctions, and those without, are treated as a single group. Until the independent and interacting effects of the virus, the immune system and psychological factors are fully understood, it is important that subject groups are

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carefully selected.

Perhaps another cause for methodological concern is the subject source for this study. All 20 of the subjects from the first study, and all 9 of the mother sufferers in the second, were selected from the membership lists of the self-help organisation -The M.E. Association. It is possible that this may represent a highly select sample, with a bias towards particular patterns of symptom attribution and psychological awareness. A frequent undercurrent to the M.E. Association literature is a mistrust of the psychiatric 1 psychological professions and an emphasis on the "real" organic nature of the disorder, with a rejection of psychological interpretations of aetiology or maintenance. This understanding was also evident in the investigation of illness behaviour in Hickie et al.'s study (1990), and is therefore not exclusive to a self-help group of sufferers.

The Association provided the most practical means of access to sufferers and their families. Group leaders were able to make personal introductions to maximise consent. Many of the subjects commented that they were not heavily involved with the group. It provided them with supportive telephone contacts and information on managing their conditions, but many reported that they were too unwell to attend meetings, or that they were not comfortable being part of a group of sufferers. For the majority of the subjects, it was the family which provided the most support.

The need for careful case selection is of paramount importance when subjects are selected from an open-membership organisation. In a recent questionnaire survey directed to 107 members, only 17 could

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provide a specific laboratory diagnosis, whereas 90 could not (Zala, 1989). Of this latter group, 6.6 % had had no laboratory investigations, results were not available for 16.6 %, and 9.6 % had been diagnosed with other medical conditions, allergy and immune deficiencies. Almost 61 % of respondents had received negative test results and a suspected virus was reported in 13 percent. There were significant differences in the origin of the diagnosis of PVFS between those with and those without serological evidence. In the clear diagnosis group, 76.4 % had received a diagnosis from their family doctor or hospital consultant. Only 23.6 % had made a self-diagnosis from lay or media information. On the other hand, 62.2 % were self-diagnosed among those without a clear laboratory diagnosis. A11 of the subjects in the present study had both serological evidence and a G.P. / consultant diagnosis.

### 7.2 Aims of studies

The primary aim of the first study was to provide qualitative and quantitative evidence on the range of psychiatric symptomatology in a well-defined and homogeneous sample of patients with the syndrome. Systematic investigation into such features have been few, whilst their presence has been consistently reported as complicating sequelae of the disorder. All too often such features have been disregarded as representing an understandable measure of distress and "utter despair", on account of the struggle for medical recognition (Ramsay, 1986). Alternatively, depressive features have been subsumed under an "organic" understanding of the disorder, explained exclusively as the effects of viral infection of the central nervous system, and often erroneously labelled as "encephalitic" symptoms (Yousef et al. 1988).

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Others have identified the "true" syndrome by means of a "good pre-morbid personality" (Holmes et al. 1988; Behan et al. 1985).

The first study was devised with three objectives in mind. The first was to assess systematically psychological symptoms in the PVFS and to investigate the similarities of presentation with the affective disorders. The second objective was to come to some understanding of psychological features as potential vulnerability factors and their role in the aetiology, maintenance of and adjustment to the illness. Thirdly, an attempt was made to determine whether discriminating characteristics could be identified to aid diagnosis.

The second study investigated the PVFS from a family perspective. In particular, it looked at the children in families where the mother was suffering from the syndrome. It aimed to assess the impact of the illness upon the mental status and coping strategies of the sufferer. Secondly, to ascertain the effects of illness upon family social climate and the interaction patterns between family members. Thirdly, various measures of child adjustment were considered, including relationship with mother, observed behaviour in the home environment, classroom problems and competencies rated by a teacher, and social network and peer relationship indices. The children in these families were expected to be at greater risk for emotional and behavioural problems than a group of children with healthy parents.

It may seem that these two studies are unrelated, in that the second study does not clearly follow on from the findings of the first. However, in spite of a growing research interest into the post-viral fatigue syndrome, it is still, as yet, a poorly understood disorder

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for which a number of contradictory hypotheses persist. Psychological investigations into the condition have been few, and when these have occurred, have largely concentrated upon diagnostic and descriptive features of the syndrome. The starting point of future psychological research must be an awareness of the often severe repercussions of the disorder upon sufferers and their families. Whatever the final outcome of the debate on the importance of viral, immunological or psychological aetiological factors, the very real nature of the disorder for those who encounter it must be acknowledged. To view such a disorder outside of the context of the family and social contexts in which it presents, can only serve to limit our future understandings of the syndrome.

### 7.3 Discussion of study findings

Both studies attest to a significant prevalence of affective symptomatology in the sufferers of the PVFS. Using a measure of depression and anxiety which takes account of somatic symptoms which may be part of the condition or of a psychiatric illness, significant psychiatric morbidity was identified. As expected, the subgroup of 9 mothers with school-aged children were somewhat more at risk for a depressive illness presentation. Eight of the subjects (89 %) satisfied the criteria for a depressive or mixed depression and anxiety disorder. Using a more representative group of sufferers with a 3 to 2, female to male ratio, an age range of 23 to 65 years, with a mean age of 46, eleven of the 20 subjects (66 %) showed evidence of a clinically significant depression or mixed psychiatric disorder.

Sixty percent (N=12) of these patients received current CATEGO

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diagnoses according to the ICD criteria (Wing et al. 1974). Diagnostic categories were not unlike those received by the sample of psychiatric patients being treated for depression. The PVFS group exhibited significantly more psychiatric morbidity than a sample of arthritis sufferers, whose conditions were of a similar debilitating nature. This raises the question as to whether the psychiatric manifestations of the PVFS are more than that which could be described as a response to disability and ill health. It is believed that the psychological symptoms may be an integral part of the disease process. The mechanisms involved are as yet unknown, but suggestions have been made concerning the role of endogenous interferons (McDonald et al. 1987), and viral damage to the dorsal raphe nucleus (Maurizi, 1985).

An alternative explanation is that the arthritis sufferers are better adjusted to their conditions. They had been ill for significantly longer than the PVFS subjects. Additionally, pre-diagnostic uncertainty had prevailed for a significantly longer period for the PVFS subjects, the majority of arthritis sufferers receiving a more or less immediate diagnosis. This diagnostic uncertainty was reported by many to be the most stressful period of their illness.

The results from this study suggest that affective changes in the PVFS are at least partially a reaction to a chronic state of ill health. Responses on the Pleasure Scale (Clark et al. 1983) were indicative of a hedonic presentation, suggesting that these subjects retain a degree of reactivity to situational events. Anhedonia is hypothesised to be the most effective way of discriminating between depressive disorder and the emotional adaptive responses to a physical illness (Snaith, 1987). A longitudinal investigation into the changing course of the PVFS and corresponding ratings of depression may uncover the degree to which psychiatric morbidity is a reaction to fatigue and functional limitations.

The estimated prevalence of previous life-time psychiatric disorder (separate from current episode), which was of sufficient severity to warrant treatment, was 60 % in this sample of PVFS sufferers. This corresponded with the findings of Taerk et al. (1987), who reported a total life-time prevalence rate of 67 % (DSM-III criteria). Owing to methodological difficulties in the dating of illness onset (the long duration of diagnostic uncertainty and the self-reporting of onset permitted the attribution of all previous episodes of ill-health or psychiatric morbidity in terms of the syndrome), it was not possible to accurately separate psychiatric episodes occurring pre-morbidly from those which occurred during the course of the current illness. As a result, the findings from this study can only go so far in the investigation of a psychological-vulnerability theory. The same criticism can be levelled at Taerk's study. When only pre-morbid psychiatric episodes are considered, there is only a trend towards more disorder in the PVFS group in comparison to healthy controls, a difference which fails to reach statistical significance.

In this study, a past episode of psychiatric disorder (occurring outside of or in the early stages of illness) has less influence on current psychiatric presentation than it does in either depressed or arthritis patients. Whilst the PVFS subjects do report more previous life-time episodes than the arthritis subjects, and almost as many as the depressed group, it is not clear how many of these occurred pre-morbidly. Many of the episodes did appear to have taken place

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during the period of diagnostic uncertainty. A psychiatric diagnosis received during this period could be interpreted in a number of ways. It could represent genuine disorder, reflecting the ongoing struggle for recognition of an unidentified illness. It could be a reflection of the confusions of the medical profession, as the patient moves from specialist to specialist, perhaps finally arriving back with their G.P. or in a psychiatric clinic. Psychiatric diagnoses have frequently been given prior to the discovery of many chronic physical conditions. Finally, a psychiatric illness may actually have occurred, preceding the fatigue syndrome. However, the patient may have retrospectively attributed this period of disorder to the onset of the PVFS. A clear deliniation is not easy given that symptom presentations are so similar.

In only 4 of the 20 PVFS patients was it possible to clearly define a pre-morbid disorder which was not within 12 months of suspected illness onset. There was nothing to suggest that these four subjects had more severe current psychiatric symptoms. All in all, there is little to support a hypothesis of psychiatric vulnerability to the PVFS. The role of psychological factors will be uncovered in future longitudinal research.

Kruesi et al. (1989) investigated 28 patients with a diagnosis of chronic fatigue syndrome. The life-time prevalence rate of psychiatric disorder was close to that of the present study. Fifty-four percent were said to have had a previous life-time episode (DSM-III). Thirteen of the 15 cases were for a major depressive disorder. The authors report the onset of the depressive disorders to closely relate in time to the start of the fatigue syndrome. However,

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they conclude that psychiatric disorders preceding the fatigue syndrome were more common than those following its onset. Such a conclusion may not be justified, as it appears that pre-morbid diagnoses are largely accounted for by phobic and panic disorders. It is argued by Hickie et al. (1990), that the significant prevalence rate for simple phobia in their study in likely to be a result of the interview method and is unlikely to be of psychopathological significance in this sample of patients.

In their recent study (Hickie et al. 1990), the most extensive investigation into the psychological-vulnerability hypothesis to date, 48 patients with a diagnosis of chronic fatigue are compared with 48 patients with a non-endogenous depression (DSM-III-R major or minor depressive disorder). Corroboration of self-reported symptoms was achieved following an independent interview with a relative. This is important given that there may be a tendency for the chronic fatigue subjects to underreport psychiatric morbidity. Pre-morbid psychiatric episodes, episodes occurring during the course of the fatigue syndrome and current psychiatric status are reported. The criteria for dating the onset of the fatigue syndrome are not reported, although prolonged periods of pre-diagnostic investigation are mentioned.

Fifty percent of the chronic fatigue patients reported a psychiatric episode during the course of their illness. The majority of these diagnoses were for major depressive disorders. Panic attacks were also frequently reported, although these met the criteria for panic disorder in only two of the patients. There were no reports of generalised anxiety disorder. A subset of the chronic fatigue patients were investigated for current disorder prior to entry into a

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treatment trial of immunogloblin infusions. Conservative ratings on the GHQ and the Zung depression scale suggest psychiatric problems of a clinical severity in between 24-45 % of the chronic fatigue patients, significantly less prevalent and less severe than ratings of disorder in the depressed controls. Pre-morbid life-time episodes occurred in 24 % of the chronic fatigue subjects. Half of these episodes were accounted for by episodes of depression. The pre-morbid prevalence rate is comparable to that reported in a three site epidemiological survey (Robins et al. 1984), and is significantly lower than the 90 % prevalence of previous disorder reported in the currently depressed psychiatric group. Relative corroboration of psychiatric episodes attest to the validity of this data.

Hickie reports that the psychiatric profiles of the chronic fatigue patients differ substantially from those of the depressed patients seen in psychiatric settings. The chronic fatigue patients presented as less neurotic; suicidal intent, weight loss, tearfulness and restlessness were infrequently reported.

The present study attempted to distinguish post-viral fatigue cases from a major depressive psychiatric group on the basis of presenting psychiatric symptoms. Symptoms entered into a logistic regression analysis were those which were seen to discriminate between the two groups on their frequency of presentation.

The additional discriminating power of three symptoms provided adequate separation of the two groups with only a marginal degree of overlap. Eighty percent of the PVFS group were correctly diagnosed with a confidence level of 67 %. Pathological guilt and anxious

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foreboding were poor predictors of the post-viral fatigue syndrome, whilst characteristic of 17 of the 20 depressed subjects, either alone or in combination. The greatest certainty of a diagnosis of PVFS as opposed to a depressive disorder was where the patient was observed to display slowness in movement and gait, without anxious foreboding or pathological guilt. The poor discriminating power of a number of other symptoms is indicative of the difficulties of diagnosing on clinical presentation.

It is important to stress that in this study there were no possibilities that the interviewer could conduct the investigations "blind". Such a procedure could not be easily achieved anyway, given the differences in histories and presenting style. It is hoped that the standardised psychiatric interview used in this study will have minimised any potential biasing effects. As in all studies of this kind, this initial exploratory regression analysis is likely to overestimate the success of the discrimination, which needs replicating on further groups.

The results from this study point to important differences in current symptom profiles and the contribution of past psychiatric episodes, which suggest that the PVFS is not a somatic manifestation of a depressive illness. There are, however, many similarities in presentation which attest to the prevalence and severity of psychiatric symptoms in the PVFS. These symptoms, alongside a more general debility and impairment of functioning have serious implications for the adjustment of the patient and family members.

In the investigations of the burdens of caring for disabled or

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mentally disordered persons in families, the coping style and attitudes of the sick member towards the disorder have considerable implications for the adjustment of family members (Orford, 1987). The review of children of depressed mothers indicated how children are receptive to maternal cognitive style and depressive attributional A parent displaying poor coping and adjustment can foster bias. feelings of low esteem and self-efficacy in the children, shaping future problem-solving skills and rendering them more vulnerable to depressive disorder in the future (Gizynski, 1985; Jaenicke et al. 1988). The more positive a response the sick person makes to the illness, the less burden and emotional strain is placed upon the family.

The coping style of the PVFS mothers in this study is characterised by a "fighting spirit". The majority of the mothers reported positive attitudes and states of mind, retaining a sense of humour and firmly believing that they would get better. Only a minority expressed fatalistic ideations of helplessness and wanting to give up. What became clear through discussions with family members was the extent to which the illness had taken over their lives, defining family roles and objectives and substantially altering day to day functioning. In many ways, it was apparent that the illness had become a joint family responsibility.

The sick mothers displayed an "anxious preoccupation" about their conditions. This measure was marginally related to child problems in the classroom. The nature of the disorder and the available advice on management demands vigilent monitoring of symptoms and evaluation of their potential dietary, environmental and emotional antecedents.

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Most of the mothers believed that there was something they could do to improve their conditions from day to day, and many would blame themselves for relapses, saying that they must have "overdone things". In such a condition perceived to be so reactive to external events, and for which sole responsibility for management rests with the family, the potential for feelings of guilt and self-blame among family members is perhaps enhanced. It is the perceived ability to control the illness, which may in itself be unpredictable and changeable, irrespective of what is done to manage it, which encourages personal attributions of responsibility and blame.

The affective symptoms of a maternal depressive illness are tangible Their understanding of the illness and their for the children. meaning and causality are very important attributions of in determining child adjustment (Beardslee & Podorefsky, 1988). In the same way, the presenting symptoms of the PVFS are understandable to the children. The expressed fatigue, irritability, emotional lability and depressive / physical withdrawal, along with the often limited involvement in their own lives, could easily be interpreted as something for which they were responsible. The children in these families appeared to be sensitised to the effects of the illness, and were well informed about theories of aetiology - most attributing the condition to external viral agents. Two girls in the study commented that they had initially believed that their mothers were unhappy and depressed. An exploration of the growth of self-understanding and the search for meaning among sufferers and family members would be welcomed.

Significantly more of the children of sick mothers, in comparison to

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the matched children with healthy parents, reported that their mothers put too many limits upon them, that their mothers did not understand them and that they could not depend upon their mothers. There was no indication, however, that the PVFS children found their mothers more irritating or more embarrassing than the control children. Mother-child relationships (as measured on the CAM), on the whole, appeared close, although three children were suspected of having relationship problems with their sick mothers (only one of the controls satisfied criteria for a relationship problem).

Characterising all family relationships in the PVFS sample was a low activity orientation. Children reported less active relationships with both parents and with their friends. Family members were significantly less involved in out-of-home recreational pursuits, including sporting activities, hobbies and social contacts. Children were marginally less involved in clubs and activities with peers than the children of healthy parents. There was also significantly less contact between the family and the social lives of the children.

Parents in the PVFS families were significantly less likely to know their children's friends; the friends were less likely to come to the homes of the sick parent and were less likely to go on outings with them. Whilst a low activity orientation in a PVFS family was associated with more severe depression in the children and a more problematic relationship with the sick mother, the separation of family and peer group spheres, through low parent-friend contact appears to have a protective effect for child psychological adjustment. It was those children with sick mothers whose friends were in most contact with the family who displayed the highest

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depression scores. At school, the PVFS children were rated by their teachers as showing more relationship difficulties with their class peers, with poorer assertiveness and significantly more shy and anxious behaviour than controls. The less active peer relationships may also be placing these children at risk. The studies by Hirsch et al. (1985; 1987) demonstrated the importance of active peer relationships for the maintenance of self-esteem and psychological adjustment in the face of parental ill health.

The low active orientation of the sick parents and their families is worthy of comment. As the observational study illustrated, the illness has served to bring family members together in a way which was not apparent among the well families. Families spent considerably more time together at home and children spent less time away from their parents. The observations suggested that this increased contact was around non-active pursuits, such as watching television or talking together. A family orientation towards increased independence of family members, assessed by parental self-report (FES), was associated with more child adjustment problems.

Mothers often described that they were somewhat isolated from their neighbourhoods and social networks. The literature on families coping with chronic illness or depression show how a whole family can become isolated with its sick member, gradually being withdrawn from the social sphere. Such isolation is associated with increasing family conflict. Characterising the interactions between family members in this study was an excess of negative comments, negative behavioural requests and minimal responses. This is perhaps a result of the increased time family members spent together, as there was little to suggest, on parental report (FES), that general orientation was more conflictual than the control families. Generally, family relationships in the PVFS group, were reported to be cohesive, expressive and supportive.

For the children, their experiences of family life appear to be somewhat "enclosed". What is more, the family experience seemed almost exclusively to occur within the home. There was little involvement of family members in activities occurring outside of the house. The boundaries between these different spheres were seen to be of importance in protecting the child from family adversity, whilst permitting the maintenance of independent social identities and relationships. The isolation of social network members from sources of stress, enhances their potential for the provision of support and coping resources, whilst placing relationships at less risk (Hirsch, 1981). For the children in this study, it appeared that they largely avoided talking to their friends about their mother's illness, thereby making it more difficult for them to have their friends come to their houses. It is hypothesised that friendships were less useful for the provision of support, than for the building of alternative social identities and providing a source of emancipation from the family.

Peer contact may provide these children with the potential for positively rewarding interactions and a range of intrinsically stimulating activities which may not be available at home, given the restricting nature of the parental illness. It is suggested that considerable encouragement may be needed for some of these children to develop such friendships, given their often shy and unassertive natures, and given the intensity of family involvement for many of

# 7.4 Implications for management of the PVFS and providing support for their families

In the remaining discussion, I will consider the proposals which have been recommended for the management of the PVFS. In the light of the findings from this study, I will also suggest potential avenues through which support and guidance may be offered, in which a family-oriented treatment approach will be recommended. The following cautionary note must be added. None of the management proposals recommended in the literature or suggested here have been evaluated on patients suffering from the syndrome. As yet, very little has been on offer to PVFS sufferers and their families in the way of psychological interventions or consistent advice on management. Recommendations from physicians and the self-help literature are largely contradictory and difficult to follow.

However, psychologists have become increasingly involved in working with the physically ill. Supportive counselling is a means of focussing upon the stresses of coping with a physical condition and its treatment regimes. It allows for the ventilation of distress and anxieties by sufferers and their families, and works towards a reevaluation of life-goals in the light of the functional limitations imposed by the condition. Stress management techniques have been used where life-style and methods of coping with stress may exacerbate a disorder or delay remission. Interventions of this kind have been successful in the modification of Type "A" behaviour, a personality trait which has been associated with a high risk for ischemic heart

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disease (Friedman et al. 1986), hypertension (Patel & Marmot, 1988), and conditions such as asthma and diabetes. Finally, behavioural and cognitive modification programmes have been applied to minimise the debilitating avoidance behaviours associated with chronic and relapsing conditions, such as coronary heart disease (Wallace, 1982), chronic pain (Pearce, 1983), and in aiding adjustment to disorders such as multiple sclerosis (Larcombe & Wilson, 1984).

In a study of depressed women receiving surgical treatment for breast cancer, Maguire et al. (1974) comment on the small number of patients with physical illnesses who are referred for psychological help. The same point was made by Hong et al. (1987), in their study of patients with end-stage renal disease. Assumptions are made concerning the ineffectiveness of psychotropic physical and psychological intervention treatments for the physically ill (Popkin, 1984; Moffic & Paykel, 1975). It is probably for similar reasons that PVFS patients are infrequently offered psychological care. Those referrals which are made, are frequently persons with chronic fatigue for which no organic or serological evidence can be found. Little has been offered to aid management and adjustment to those who have received corroborated laboratory diagnoses. Resistance by the sufferers, who are reluctant to attest to the aggravating role of psychosocial stressors, and the tendency to regard the physical condition as the sole reason for their distress (Hickie et al. 1990), may well also have played a contributing part. The acrimonious debate over "organicity" versus perjorative "psychiatric" explanations for disorder must also take some of the blame.

More recently, suggestions have been put forward for the contribution

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of psychologists in the management of PVFS (Gadd, 1989; Wessely et al. 1989). I would endorse the caution expressed by Gadd, however, in the undertaking of treatment regimes which may over-fatigue a relapse-prone patient. The liaison with medical specialists is of considerable importance.

A new controversy appearing among physicians is of the relative values of rest-treatment as opposed to a programme based upon the gradual build up of exercise. On the one hand, is the belief that exertion of a physical or mental nature is likely to induce relapse and postpone recovery (Yousef, 1989). However, rest treatments have not been evaluated systematically, and Schooley (1988) asserts that there is no evidence to indicate that physical activity will worsen a condition, or that forced rest will improve it. Many neurologists and physiologists have addressed issues concerning the cardiovascular unfitness, respiratory dysfunctions and muscular wastage resulting from a prolonged cessation of activity (Greenleaf & Kozlowski, 1982).

Wessely et al. (1989) explain the chronic fatigue of the condition in terms of a vicious circle of chronic avoidance behaviour, prolonged inactivity with fatigue occurring at increasingly lower thresholds of stimulation. They understand that symptoms of fatigue, muscle pain, dizziness and breathlessness will be attributed by the patient to the initial infectious episode, with cognitions encouraging further withdrawal from everyday activities. They stress the need to "call a halt without loss of face", in returning responsibility to the patient in order to "pick up the pieces". The cognitive-behavioural approach which they recommend involves increasing tolerance to activity and eliminating avoidance behaviours.

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The rehabilitative strategies which they propose are based upon a belief that the fatigue in the chronic stage of illness can be explained almost exclusively in terms of unfitness and deterioration of muscles from disuse. They make one proviso, that the rest-treatment may be appropriate for some chronic fatigue sufferers, although, they say, it is not possible that such cases can be identified. The problem is that neither have we had any systematic evaluation of these treatments, nor is there any consensus among researchers and physicians as to what is to count as a chronic (post-viral) fatigue condition. Careful selection of cases, for which viral contagion and immunological dysfunctions have been located must become a starting point.

It is feasible that a cognitive-behavioural approach based upon Wessely et al.'s recommendations could prove beneficial to sufferers of the PVFS. Activity monitoring and the encouragement of social interaction were found to be beneficial for a sample of depressed patients suffering from multiple-sclerosis (Larcombe & Wilson, 1984). The treatment programme aimed to increase the sense of self-efficacy, to increase involvement in intrinsically rewarding activities and to encourage behaviours which are positively rewarding to others. Following a six week treatment trial, there was a clinically significant improvement in depression, which was maintained at a one month follow-up.

In the PVFS, there are possibilities that avoidance behaviours may intervene in the natural remission of the disorder, fostering chronicity of fatigue and abnormal illness behaviours. The

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encouragement of activity up to the point of current functional capacity must be recommendable. Such a process will involve a careful balance between the often unrealistic expectations of family and friends, and the anxieties of the patient in resuming activity and maintaining as much independence as the illness will tolerate. A cautious approach to such programmes is essential.

A family approach to treatment is recommended. It is increasingly recognised that the family plays an important part in response to illness and subsequent outcome, and is a key resource in the care and rehabilitation of a sick member. It is also acknowledged widely in the research literature that illness may lead to disadvantages and restrictions, not only for the patients but also for those living with them. This thesis has shown how the PVFS may exert changes within the family which have repercussions for a child's functioning at school, amongst peers and in the social sphere. However, there were many other ways in which these families showed very adaptive functioning and coping styles. Family relationships were cohesive, expressive and members tended to hold fairly consensual understandings of the In spite of the restricting and isolating nature of the illness. condition, it seemed to have brought the family together in a way which would not have been expected in a healthy family.

The involvement of professionals in a family oriented treatment approach would be to assist this process of adjustment and to address issues of meeting the needs of all family members. Inteventions should focus upon the following three areas:

# 1. Family expectations and interpretations

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Engagement in family treatment provides an opportunity for family members to explore the ways in which they construe and interpret the illness. Where medical opinions are divided, it is of no surprise that family members may deny the presence of illness or remain sceptical about the validity of the diagnosis. The consequence may be unrealistic expectations and demands upon the PVFS sufferer, making it difficult for them to accept the sick role and abdicate role responsibilities.

The ventilation of feelings around these issues is of considerable importance. Misinterpretations of emotional and physical symptoms as volitional behaviour, or as outcomes for which the other family members could be made to feel responsible, could adversely affect family relations and stand in the way of mastering the "tasks" of coping with illness in a family (Moos & Tsu, 1977). Where behavioural changes are attributed to illness, less family stress will be generated through the misapplication of criticism and blame, and more likely to be adaptive. coping strategies are Specific intervention in the retraining of communication and problem-solving skills may be necessary where interaction patterns have become dysfunctional.

# 2. Family coping strategies and meeting the needs of family members

A family may require assistance in generating those responses to sickness which are adaptive for the PVFS sufferer and simultaneously meet the needs of all family members. Therapeutic intervention provides the opportunity for family members to openly explore

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alternative solutions to family dilemmas and conflicts resulting from the illness. Orford's collection of papers on families coping with chronic physical and mental disorder (1987), identifies the adaptive potential of a variety of coping strategies. Those involving coercion, collusion, control and avoidance are believed to be the most unhelpful. Emotional disengagement, the setting of clear goals and expectations, stressing positive gains, reordering life-priorities and the ability to be assertive about one's own needs, are more likely to be helpful in the generation of a rehabilitative environment which minimises the strain on all family members, whilst providing the encouragement necessary for the maintenance of a maximum level of functioning, autonomy and quality of life.

The family of the PVFS sufferer must learn ways of coping with the sick person's reaction to disorder, the depressive and physical withdrawal, the angry resistance or anxious preoccupation and somatic self-focus. They must learn to accept the new limitations to the sick person's functioning, whilst preserving a positive image of, and positive relationship with them. They must also learn to adapt to the resulting restrictions to their own lives, and the added responsibilities which they will be required to take.

Open discussion with the family can lead to an increased awareness of the needs of all members, especially the children, and how these can best be met. The children may require encouragement in taking active roles outside of the family, in developing multi-dimensional friendships with peers, and in developing interests in sporting activities, clubs and societies. Such involvements are important for the development of alternative social skills, for the building of

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confidence and self-esteem and for providing the opportunities which the family is presently unable to offer on account of the parental illness. The development of an active pursuit with a healthy family member, which takes them outside of the home environment, may also be of benefit.

# Addressing the problem of family isolation and the importance of the linkages between social spheres

Social restriction and isolation is common to families coping with many disorders (Orford, 1987); it was also apparent among the families of PVFS sufferers investigated here. It has been shown that family isolation produces deprivation from informal support networks, the use of which is closely related to general family wellbeing (Finlayson, 1976). The extent to which social networks are used for the provision of support for family adversity is dependent upon the extent to which relationships are separated from sources of conflict (Hirsch, 1981). Thus, in this study, a child showed more problems of adjustment where parents (including a sick parent) were more involved in their social lives, and where the child's friends had more contact with their families.

Other research has addressed the adaptive potential of family-school-peer group linkages, in dealing with problems in children which occur in either of these spheres (Dowling & Osborne, 1985). Their conceptual input emphasises a joint systemic approach and an understanding of the permeability of the boundaries across which stresses, maladjustments and competencies can be exchanged. The reasons why such linkages appeared to be adaptive for the children of

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healthy parents in this study, but not so for the children of mothers suffering from PVFS, is not clear and demands further research.

A family intervention can address issues of parental involvement and over-involvement and generate awareness of problems which may arise in the school environment or among peers, creating the openness necessary for the generation of problem-solving strategies, and the careful balance between providing family support, whilst permitting a degree of independence from family stress. The potential damaging effects of the isolation of the family, and the "enclosed" experiences of family life available for sufferers and their families, set important goals for ameliorative endeavors. Firstly, family members may need to be taught the skills which render them an effective support-network and problem-solving unit in their own right. Secondly, members may need help in developing network-building skills, and in mobilising emotional and problem-focussed support. Thirdly, the possibilities of joint family involvement in pursuits which take them out of the home environment, and away from an often overriding illness-focus must be encouraged.

A family oriented intervention package is likely to be of considerable help for the PVFS sufferer. It can help to reduce family stress and alleviate the damaging effects on other family members. It can also generate the relevant skills and problem-solving strategies with which to deal with it. By enhancing a sense of self-efficacy and personal esteem, it can aid the passage through an often prolonged period of illness, perhaps also with the effect of alleviating symptoms and strengthening the immune system, resulting in an early recovery. It may also generate positive attitudes and outlooks which may be important in preventing the development of chronic avoidance behaviours and severe depressive reactions. The beneficial effects of such interventions are for future research to uncover in systematic treatment trials.

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# Ethical procedures and permissions

The subjects with post-viral fatigue syndrome were selected from the Myalgic Encephalomyelitis Association, Northumberland, Durham and Cleveland support groups. Initial contacts were made by the group leaders, who confirmed that the subjects satisfied the study criteria (by means of age and for the second study, having school-aged children). Permission was sought by the group leaders for addresses and telephone numbers to be passed on to the research psychologist. An introductory letter was sent to the subjects followed with telephone contact for the arrangement of a first meeting, during which diagnostic status was confirmed and any queries regarding involvement in the study were dealt with.

For the first study, a signature of consent was sought from the proband sick subject. For the family study, individual consent was sought from both parents and from the target child who was to be involved in the study. The nature of the study was explained to the child along with their rights to make a decision about involvement or withdrawal from the study if they so wished. The family were allowed a few days to reach a consensual decision. An identical procedure was followed for the families of the control children.

Parental and child permission was sought for contacting the schools and primary teacher involved in the education of the target children. The project was initially cleared by the Directors of Education of Durham County Council and Newcastle-upon-Tyne City Council, the districts covered by the children in this study. The permission of the Head Teacher was sought prior to contacting the primary teacher. They were not informed of the parental status of the target children, instead the project was framed as an exploration of the school and family life of children from a variety of families.

The subjects with arthritis were selected from the Arthritis and Rheumatism Council. Initial contacts were made with group leaders, who wrote to subjects explaining the nature of the study. An introductory explanation of the study written by the research psychologist was included. Subjects wishing to take part contacted the psychologist themselves.

Approval for the selection of psychiatric in-patients and out-patients receiving treatment at Winterton Hospital, was awarded by the Chairman of the Ethical Committee of South West Durham Health Authority and the District Medical Officer.



APPENDIX 2

Interviews, questionnaires and assessment devices

ANY PREVIOUS	EPISODES OF	NERVOUS PROBI	LEMS / BREAKDOWN:	5 REQUIRING	TREAT
FROM G.P. OR	RESULTING IN	N CONSULTATION	TO OTHER PRAC	TITIONER?	

## MYALGIC ENCEPHALOMYELITIS STUDY

SURNAME	SUBJECT ID	I <u>_I</u> _I
FIRST NAME	GROUP: 1=M.E. 2=ARTHRITIS 3=DEPRESSION	11
	SEX: <b>1-Male</b> 2=female	I_1
TELEPHONE	MARITAL STATUS: 1=Single 2-Married 3=Divorced/Sepai	RATED II
TODAY'S DATE (as 01 JAN 89)	III	<u> </u>
DATE OF BIRTH	II_I_I_	<u></u> _
STATUS OF ILLNESS: 1-LIVING AT HOM 2-LIVING AT HOM 3-DAY-PATIENT 4-INPATIENT		11
WHEN DID CURRENT ILINESS START?	NO. MONTHS DURATION (approx.)	I <u></u> II
(Date as accurately as possible. I ceased or when subject became unab at home and at work.)		
WHEN WAS IT DIAGNOSED?	NO. MONTHS BEFORE DIAGNOSIS (approx.)	
DETAILS OF DIAGNOSIS GIVEN/ TESTS	CONDUCTED	
MEDICATION TAKEN? 1-YES 2=NO		II
IF YES: FOR HELP WITH PAIN FOR HELP WITH DIZZINESS FOR HELP WITH OTHER SYMPTOMS TO HELP WITH NERVES/COPING ANY OTHER MEDICATION FROM GP	1=YES 2=NO	

	1=YES 2=No		
	ZENO		1
WHEN DID 7	HIS OCCUR? (Attempt )	to date as accurately as possibl	e) '
DID YOU GO		L DURING THIS EPISODE?	
	1=YES 2=NO		<u>ا</u>
	Z=NO		'
	OUR HEALTH RETURN TO ely as possible)	NORMAL AGAIN? (Attempt to date	
HAVE YOU I	AD ANY OTHER EPISODES	S OF NERVOUS PROBLEMS?	
DESCRIBE			
-			
		IC ILL HEALTH IN YOUR FAMILY? ents, siblings, uncles, aunts et	· ~ `
(Include .	l=YES	enca, albiings, unclea, aunca eu	,
	2=NO		
DESCRIBE			
		IC NERVOUS PROBLEMS IN YOUR FAMI	
		blems requiring treatment.)	
	1=YES		
	2=NO		<u>-</u>
DESCRIBE			
		me questions about how you've be	en fe
T would ne			
	which response sums up	p how you are or have been feel:	ing in
lately. ( past few (	which response sums up	p how you are or have been feel:	ing in
lately. ( past few (	Which response sums up days? I tense or 'wound up'	p how you are or have been feel:	ing in
lately. ( past few (	Which response sums up days? I tense or 'wound up'	p how you are or have been feel; : Most of the time A lot of the time	
lately. ( past few (	Which response sums up days? I tense or 'wound up'	p how you are or have been feel: : Most of the time A lot of the time From time to time, occasionally	
lately. ( past few (	Which response sums up days? I tense or 'wound up'	p how you are or have been feel; : Most of the time A lot of the time	
lately. ( past few (	Which response sums up days? I tense or 'wound up'	p how you are or have been feel: : Most of the time A lot of the time From time to time, occasionally No, not at all	
lately. ( past few (	which response sums up days? I tense or 'wound up' I enjoy the things I	p how you are or have been feel: : Most of the time A lot of the time From time to time, occasionally No, not at all	
lately. ( past few (	Which response sums up days? I tense or 'wound up' Il enjoy the things I	p how you are or have been feel; : Most of the time A lot of the time From time to time, occasionally No, not at all used to enjoy:	
lately. ( past few (	Which response sums up days? I tense or 'wound up' Il enjoy the things I	p how you are or have been feel; : Most of the time A lot of the time From time to time, occasionally No, not at all used to enjoy: Definitely as much	

<ol> <li>I get a sort of frightene to happen:</li> </ol>	d feeling as if something awful is	about
	Very definitely and quite badly	1_14
	Yes, but not too badly	I I 3
	A little but it doesn't worry me	1_12
	Not at all	II 1
4. I can laugh and see the f	unny side of things:	
	As much as I always could	J I 1
	Not quite so much now	1_12
	From time to time but not too ofte	nl_  3
	Only occasionally	11 4
5. Worrying thoughts go thro	ugh my mind:	
	A great deal of the time	1 4
	A lot of the time	1 1 3
	From time to time but not too ofte	n   [   2
	Only occasionally	_  1
6. I feel cheerful:		_
	Not at all	11 4
	Not often	1_1 3
	Sometimes	<u> _</u>   2
	Most of the time	II 1
7. I can sit at ease and fee	l relaxed:	
	Definitely	1 1
	Usually	1 2
	Not often	1 3
	Not at all	I <u>i</u> i 4
9. I feel as if I am slowed	down:	
	Nearly all the time	1 4
	Very often	1 3
	Sometimes	1 2
	Not at all	1 1
9. I get a sort of frightene	d feeling like 'butterflies' in the	stomach:
	Not at all	
,	Occasionally	1 2
	Quite often	1 3
	Very often	1_14
10. I have lost interest in m	y appearance:	
	Definitely	I <u> </u>
	I don't take as much care as I	
	should	1_13
	I may not take guite as much care	
	I take just as much care as ever	_ 1

.

## 11. I feel restless as if I have to be on the move:

Very much indeed	1_14
Quite a lot	_  3
Not very much	1 2
Not at all	_ I <u>_</u>   1

12. I look forward with enjoyment to things:

.

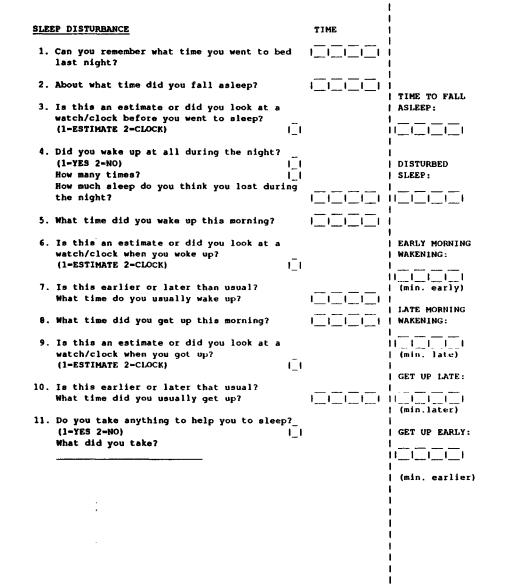
As much as I ever did	1 1
Rather less than I used to	1 2
Definitely less than I used to	i_i 3
Hardly at all	1_14

### 13. I get sudden feelings of panic:

Very often indeed	1_14
Quite often	1 3
Not very often	1 2
Not at all	I_I 1

14. I can still enjoy a good book or radio or T.V. programme:

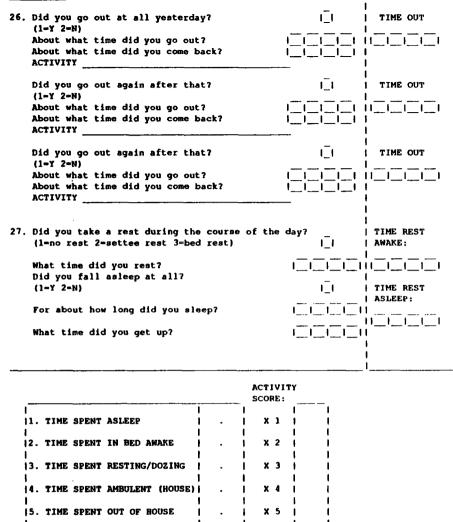
Often	1 1	ι
Sometimes	1 1 2	2
Not often	I ₹	3
Very seldom	1 1 4	



MOOD DISTURBANCE	
12. Think about how you felt first thing this morning, either before you got up or just after getting up. Look at the following scale. If you imagine 5 to represent how you feel when you are your <u>normal self</u> , how would you rate the way you felt this morning?	
 SADDEST 1 2 3 4 5 6 7 8 9 10 HAPPIEST	
MOST         MOST TENSE 1 2 3 4 5 6 7 8 9 10 RELAXED	
MOST          MOST Tired 1 2 3 4 5 6 7 8 9 10 Energetic	
Read the following statements. Do they apply to the way you felt this morning. Rate according to these criteria: l=not at all 2=yes, but only a little 3=yes, definitely	
13. I felt miserable and sad.	Ū.
14. I felt I had nothing good to look forward to.	۱ <u>–</u> ۱
	I_I
	1_1
17. 1 felt guilty as if 1 had done something wrong.	+_1
18. I felt disappointed / disgusted with myself.	I <u></u> I
19. I felt in some way to blame for the way I am	1 <u>-</u> 1
20. I felt that life wasn't worth living.	1 <u>¯</u> 1
21. I was more irritable than usual.	i_i
22. I felt as if I was being punished for something.	_    DEPRESSIVE   THOUGHTS:   (2=1 3-2)
24. Do you feel at your most miserable in the mornings?	MORNINGS WORST: mentally []
(1-Y 2-N) I_I 25. Do you feel at your most tired in the mornings? I_1	physically _      
	l

### ACTIVITIES

TOTAL TIME



TOTAL

SCORE

.

al
•
1
ng İ
I.

		1	-1	-1	-1	-1	-1	-1	-1	-1	-1	
	SADDEST											HAPPIEST
	MOST	1	-1	-1	-1	-1	-1	-1	-1		-1	MOST
	TENSE	1	2	3	4	5	6	7	8	9	10	RELAXED
	MOST	1	-1	-	-1	-1	-1	-1	-1		-1	Most Energetic
	TIRED	1	2	3	4	5	6	7	8	9	10	ENERGETIC
29.	When did (1=most 2=most 3=most	tir tir	ed i ed a	n th fter	e mo act	rnin ivit	д У	ster	day7	,		ı_ı

#### FATIGUE

(RETARDATION ITEMS ASSESSED BY INTERVIEWER AT INTERVIEW OR JUDGED ON THE LAST FEW DAYS. ASK APPROPRIATE QUESTIONS).

30. Retardation (motor)

0 Normal motor activity, adequate facial expression. 1 Doubtfully decreased motor activity (eq. facial

- expression slightly or doubtfully retarded).
- 2 More clear motor retardation (eg. reduced gestures; slow pace).
- 3 All movements very slow.

4 Motor retardation approaching or including stupor.

31. Retardation (verbal):

This item includes changes in the flow of speech and the capacity to verbalise thoughts and emotions.

- 0 Normal verbal activity
- 1 Doubtfully reduced verbal expression or inertia in conversation.
- 2 More pronounced inertia in conversation (eg. a trend to longer intermissions).
- 3 When the interview is clearly prolonged due to long pauses and brief responses.
- 4 When the interview can only be completed with marked difficulty.

1 1\_1

32. Retardation (intellectual):

This item covers difficulties is concentration, making decisions about everyday matters and memory, ie. intellectual impairment.

- 0 The subject has neither more nor less difficulties in concentration and/or memory.
- 1 It is doubtful whether the subject has difficulties in concentration and/or memory.
- 2 Even with a major effort it is difficult for the subject | to concentrate on his work, but still without influence | on the subject's daily life.
- 3 More pronounced difficulties with concentration, memory | or decision making (eg. has difficulties to read an | article in a newspaper or watch a TV programme right | through. Score 3 as long as the loss of concentration | or poor memory has not clearly influenced the interview).
- 4 When the subject during the interview has shown | difficulty in concentration and/or memory, and/or when | decisions are reached with considerable delay. | | |

#### 33. Tiredness and pains:

This item includes weakness, faintness, tiredness, fullness and soreness merging into real pains more or less diffusely located to muscles or inner organs. Muscular fatigue is normally located in the extremities. The subject may give this as the reason for difficulties in this work as he has a feeling of tiredness or heaviness in arms and legs.

- 0 The subject is neither more nor less tired or troubled by bodily discomfort than usual.
- 1 Doubtful or very vague feelings of muscular fatigue or other somatic discomfort.
- 2 Feelings of muscular fatigue or somatic discomfort are more pronounced. Painful sensations sometimes occur (eg. muscular headache, but still without influence on the subject's daily life).
- 3 Muscular fatigue or diffuse pain in clearly present, which interferes occasionally with the subject's daily life.
- 4 Muscular fatigue and diffuse pains are constantly causing the subject severe distress, so that it markedly | interferes with the subject's daily life. | |\_|

NAME



. . . . . .

TODAY'S DATE (as 01 JAN 89)

A. PLEASURE SCALE

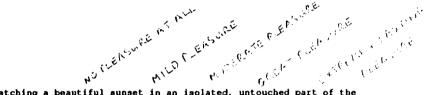
(READ THE FOLLOWING OUT TO THE SUBJECT:)

What follows is a list of situations that might influence how a person feels. Please read each one carefully and decide how much the situation would give you pleasure <u>right now</u>, in your present mood. Then circle the number that best describes your response.

Rate a situation as pleasurable if:

- you would enjoy the situation;
- the situation would lift your spirits; or
- the situation would be fun for you.

Circle only one number for each situation and do not skip any items. If a situation does not apply to you, try and imagine that it does anyway.



5

1 You sit watching a beautiful sunset in an isolated, untouched part of the world.

1 2 3 4

2 When you leave the house wearing new and attractive clothes, several people give you compliments on how great you look.

1 2 3 4 5

3 You accidentally overhear your child boasting to friends about what a terrific parent you are.

1 2 3 4 5

4 You are listening to beautiful music in peaceful surroundings.

1 2 3 4 5

5 While fishing, you feel a tug on your line and watch a 6-pound fish jump out of the water with your bait in its mouth.

1 2 3 4 5

6 You reach sexual climax with someone you love very much.

1 2 3 4 5

7 You come to the end of a job that you find meaningful because of its immediate results.

could have a better companion or lover".

- 8 Several years after your youngest child has moved out of the house, you
- realise that all your children have made happy and successful lives for themselves.
- 9 Your spouse surprises you with a tender hug and tells you that "no one

1 2 3 4 5

10 After much concentration and hard work you finally master a new skill on your own.

1 2 3 4 5

11 After some vigorous physical exercise, you pause to catch your breath and relax your muscles.

1 2 3 4 5

12 You discover in the newspaper that your lottery ticket is worth  $\not \leq 5000$ .

1 2 3 4 5

13 Your supervisor gives you an unexpected merit pay increase in recognition for outstanding work.

1 2 3 4 5

14 You are skiing down a mountain very fast while still in good control of yourself.

1 2 3 4 5

15 While raking leaves on a beautiful autumn day, you pause to watch your children playing in the leaf-piles.

1 2 3 4 5

16 A group of your neighbours selects you to receive an award for your work in the community.

1 2 3 4 5

17 You lie soaking in a warm bath.

1 2 3 4 5



18 You are skillfully flying an aeroplane by yourself on a clear day

19 You lie basking in the sun on a relaxed week-end.

20 During a quiet early-morning walk along the seashore, you feel very much at peace and at one with the universe.

21 You sit savoring a good meal of well-prepared food.

22 Someone whose career you have taken an interest in and encouraged begins to become very successful. 

- 23 You come to the end of a difficult and complicated task without having made a single mistake.

24 You win a very large bet you have made on a football game.

25 Your work on a physical fitness programme results in many compliments on how healthy and trim you are looking.

> A

26 Someone gentle begins to scratch your back.

27 Your neighbours rave about the way you keep up your house and garden.

28 You take off on a trip to China, scheduled to visit all the places you've read and heard about.

29 You find yourself at a lively party with many facinating people.

né " préasure préasure préasuré au propérate préasuré préasure propération propération de la préasure de la pré 30 Someone who makes you feel loved wraps you in his/her arms and hold you 115 5.1 close.

31 You sit with good friends, huddled close to a warm bonfire and roasting marshmallows on a chilly night.

32 You spend a slow and gentle period of time in sexual foreplay with someone you love very much.

33 Someone calls on you for help during an emergency, and your help sees him/ her through a difficult situation.

34 You come to the end of a difficult work project that has taken much of your energy and many weeks of time.

35 You find that one of your close friends is someone you can talk to about almost anything.

36 A member of the opposite sex takes a special interest in you.

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**B. HOPELESSNESS SCALE** 

Read the following statements and think about how they apply to the way you feel. Rate each statement by circling either the TRUE or the FALSE response.

1 I look forward to the future with hope and enthusiasm.

TRUE / FALSE

2 I might as well give up because I can't make things better for myself. TRUE / FALSE

3 When things are going badly, I am helped by knowing they can't stay that way forever. TRUE / FALSE
4 I can't imagine what my life would be like in 10 years. TRUE / FALSE
<b>5 I have time enough to accomplish the things I most want to do.</b> TRUE / FALSE
6 In the future, I expect to succeed in what concerns me most. TRUE / FALSE
7 My future seems dark to me. TRUE / FALSE
8 I expect to get more of the good things in life than the average person. TRUE / FALSE
<b>9 I just don't get the breaks, and there's no reason to believe I will in the future.</b> TRUE / FALSE
10 My past experiences have prepared me well for my future. TRUE / FALSE
11 All I can see ahead of me is unpleasantness rather than pleasantness. TRUE / FALSE
12 I don't expect to get what I really want. TRUE / FALSE
13 When I look ahead to the future, I expect I will be happier than I am now. TRUE / FALSE
14 Things just won't work out the way I want them to. TRUE / FALSE
15 I have great faith in the future. TRUE / FALSE
16 I never get what I want so it's foolish to want anything. TRUE / FALSE
17 It is very unlikely that I will get any real satisfaction in the future. TRUE / FALSE
18 The future seems vague and uncertain to me. TRUE / FALSE
19 I can look forward to more good times than bad times. TRUE / FALSE
20 There's no use in really trying to get something I want because I probably won't get it. TRUE / FALSE
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		(iii) Third child	
FAMILY INTERVIE	<u>i</u>		
		name of H.T. name of F.T.	
MOTHER'S SURNAME	_ ID		
FIRST NAME		(iv) Forth child	
	-	name of H.T.	
ADDRESS	-	name of F.T.	
		6 HOW MANY OF YOU ARE THERE LIVING	
	-	TOGETHER IN YOUR HOME?	MOTHER
	-		FATHER
	-		TARGET CHIID
TELEPHONE NUMBER	-		MALE SIBLINGS
1 TODAY'S DATE (as 7JUL87)			FEMALE SIBLINGS
2 MOTHER'S DATE OF BIRTH (as 01 JAN 64)			GRANDPARENTS
			OTHERS
3 NUMBER OF CHILDREN LIVING AT HOME			
		7 SO, THERE ARE OF YOU ALTOGETHER?	
	SEX DATE OF	8 DO YOU HAVE A PAID JOB AT THE MOMENT?	
	(M=1 F=2) BIRTH	If YES:	
4 NAME OF FIRST CHILD		a) WHAT DO YOU DO? (.Name of job	
NAME OF SECOND CHILD		.Description .Skill/training	
		.Supervision/, management	
NAME OF THIRD CHILD		responsibilities .Industry/business/	
NAME OF FORTH CHILD		profession of employer	
		Number of people employed	
5 WHICH SCHOOLS DO THEY GO TO?		at workplace )	
5 which schools be their go for		b) IS THAT FULL-TIME OF PART-TIME?	
(Name and type of school:			FULL-TIME =1
Private=1 L.E.A. =2			PART-TIME =2 Other =3
D.E.A. =2 Other =3)		IF NO:	offier -5
	SCHOOL ID TYPE	c) WHAT WAS YOUR LAST FULL-TIME JOB?	
		(.Name of job	
(i) First child		.Description .Skill/training	
name of H.T.		.Supervision/management	
name of F.T.		responsibilities	
(ii) Record shild		.Industry/business/ profession of employer	
(ii) Second child		.Number of people employed	
name of H.T.		at work place)	
name of F.T.			

d) WAS THAT PART-TIME OF FULL-TIME			l (b	WAS THAT PART-TIME OR FULL	TIME?	
	FULL-TIME =1		-, -		FULL-TIME =1	
	PART-TIME =2				PART-TIME =2	
	OTHER =3				OTHER = 3	
9 DO YOU WORK EVENINGS OR WEEKENDS WHEN THE Children are at home from school? (Yes=1, No=2)			12 DOE:	S HE WORK EVENINGS OR WEEKI	ENDS? (YES-1, NO-2)	
					questions about how you've been feeling	
					ow you are or have been feeling in the p	bast few
And now, what about your schooldays.			day	3?		
10 COULD YOU TELL ME WHAT QUALIFICATIONS YOU OBTAINED AT SCHOOL OR ELSEWHERE?			13	I feel tense or 'wound up		
	HIGHER EDUCATI	ION = 1			Most of the time	
	'A' LEVELS	<b>≕</b> 2			A lot of the time From time to time, occasionally	
	A DOVDOO				No, not at all	
	'O' LEVELS	= 3				
	C.S.E.	= 4	14	I still enjoy the things	I used to enjoy:	
	C.S.B.	= 4			Definitely as much	
	NONE	<b>≕</b> 5			Not quite so much	
					Only a little	
	OTHER (specif	[y)			Hardly at all	
		<b>—</b> 6	15	I get a sort of frighten to happen:	ed feeling as if something awful is abou	it
				<b>-</b>	Very definitely and quite badly	
11 DOES X'S FATHER HAVE A PAID JOB AT THE MOMENT?					Yes, but not too badly	
If YES:					A little but it doesn't worry me Not at all	
a) WHAT DOES HE DO?						
(.Name of job			16	I can laugh and see the	funny side of things:	
.Description						
.Skill/training .Supervision/management					As much as I always could Not quite so much now	
responsibilities					Definitely not so much now	
.Industry/business					Not at all	
profession of employer						
.Number of people employed at workplace )			17	Worrying thoughts go thr	ough my mind:	
at workprace )					A great deal of the time	
b) IS THAT FULL-TIME OR PART-TIME?					A lot of the time	
	FULL-TIME =1				From time to time but not too often	
	PART-TIME == 2 OTHER == 3				Only occasionally	
	JINER -J		18	I feel cheerful:		
If NO:					Not at all	
c) WHAT WAS HIS LAST FULL-TIME JOB?					Not often	
(.Name of job .Description					Sometimes Most of the time	
.Description ,Skill/training					LUGE OF THE CAME	
.Supervision/management			19	I can sit at ease and fe	el relaxed:	
responsibilities						
.Industry/business/ profession of employer					Definitely Usually	
profession of employer .Number of people employed					Not often	
at work place )					Not at all	
-						

20 I feel as if I am slowed down:

Nearly all the time Very often Sometimes Not at all

21 I get a sort of frightened feeling like 'butterflies' in the stomach:

Not at all Occasionally Quite often Very often

22 I have lost interest in my appearance:

Definitely I don't take so much care as I should I may not take quite as much care I take just as much care as ever

23 I feel restless as if I have to be on the move:

Very much indeed Quite a lot Not very much Not at all

24 I look forward with enjoyment to things:

As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all

25 I get sudden feelings of panic:

Very often indeed Quite often Not very often Not at all

- 26 I can enjoy a good book or radio or TV programme:
  - Often Sometimes Not often Very seldom
- 27 Have you seen your Family Doctor lately? (YES=1, NO=2) If YES: a) Was that for physical problems? (Y=1, N=2) Please describe \_\_\_\_\_\_

b) Was that for emotional problems? (Y=1, N=2) Please describe

Have you seen any other doctors about your physical problems? 28 (YES=1, NO=2) If YES: a) Have you seen any neurologists? (How many?) b) Have you seen any virologists? (How many?) c) Have you seen any other specialists? (How many?) d) Have you seen any other G.P.? (How many?) Have you seen any other doctors about psychological/emotional problems? 29 (YES=1, NO=2) If YES: a) Have you seen any psychiatrists? (How many?) b) Have you seen any psychologists? (How many?) c) Have you seen any psychotherapists? (How many?) d) Have you seen any counsellors? (How many?) Have you seen anybody else? (YES=1, NO=2) 30 If YES: a) Have you seen a specialist in acupuncture? (How many?) b) Have you seen a homeopathic doctor? (How many?) c) Have you seen any other healers? (How many?) Have you ever been into hospital because of your nerves? 31 (YES=1. NO=2) 32 Are you taking any medication at the moment? (YES=1, NO=2) If YES: a) Anything to help with pain? (Y=1, N=2) b) Anything to help with dizziness? c) Anything to help with other symptoms? d) Anything to help you to sleep? e) Anything to help with your nerves/ coping? f) Any other medication from your doctor? q) Any other medication from your chemist? 33 Is there any history of chronic ill health in your family? (YES=1, NO=2) If YES, please describe 34 Is there any history of nervous problems in your family? (YES=1, NO=2) If YES, please describe

COPING WITH I	POST-VIRAL FA	TIGUE SYNDRO	OME		Definitely does <u>not</u> apply to me	Poes <u>not</u> apply to me	Applio to me
NAME	DAT	E					
					16 I feel that there is nothing I		
The statements given below are on the statements given below are on the statement of the st					can do to help myself 1	2	
circle the appropriate number al	longside each	statement,	indicatine	j how	17 I try to carry on my life as I've		
far it applies to you at present					always done 1	2	
	Definitely	Does not		Definitely	10 I would like to make contact with	_	
	does <u>not</u> apply to me	apply to me	to me	applies to me	others in the same boat 1	2	
					19 I am determined to put it all		
l I avoid doing things that I					behind me 1	2	
believe will make my symptoms	9						
worse eg. eating certain food	is 1	2	3	4	20 I have difficulty in believing	-	
2 I feel that I can't do anythi					that this happened to me 1	2	
to cheer myself up	-	2	3	4	21 I suffer great anxiety about my		
		-	_	-	condition 1	2	
3 I feel that problems with my							
health prevent me from planns	-	_			22 I am not very hopeful about the		
ahead	1	2	3	4	future 1	2	
4 I believe that my positive					23 At the moment I take one day at		
attitude will benefit my heal	lth 1	2	3	4	a time 1	2	
5 I don't dwell on my illness.	1	2	3	4	24 I feel like giving up 1	2	
6 I firmly believe that I will	get				25 I try to keep a sense of humour		
better	-	2	3	4	about it 1	2	
7 I feel that nothing I can do make any difference		2	3	4	26 Other people worry about me more	2	
maxe any difference	1	2	3	4	than I do 1	2	
8 I've left it all to my doctor	rs 1	2	3	4	27 I think of other people who are		
			_		worse off 1	2	
9 I feel that life is hopeless	1	2	3	4			
10 I have been doing things that	τ T				28 I am trying to get as much information about my condition as		
believe will improve my healt					I can 1	2	
e.g. resting		2	3	4			
					29 I feel that I can't control my		
11 I've put myself in the hands		-	2		symptoms 1	2	
God	1	2	3	4	30 I try to have a very positive		
12 I have plans for the future,	e.a.				attitude 1	2	
holidays, jobs, housing	-	2	3	4		-	
					31 I avoid finding out more about it 1	2	
13 I worry about my condition		-			•• - · · · · · · · · ·	_	
getting worse	1	2	3	4	32 I see my illness as a challenge 1	2	
14 I've had a good life, what's	left				33 I feel fatalistic about it 1	2	
is a bonus		2	3	4		-	
					34 I feel completely at a loss about		
15 I think my state of mind can		-	-		what to do 1	2	
a lot of difference to my he	alth. 1	2	3	4			

Definitely applies to me

	Definitely does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
35 I feel very angry about what happened to me		2	3	4
36 I count my blessings	1	2	3	4
37 I try to fight the illness.	1	2	3	4

FAMILY ROUTINES INVENTORY		<ol><li>Non-working parent and children do somet almost every day (e.g. shopping, walking</li></ol>	etc.).
		A. IS THIS A ROUTINE? (Y=2; N=1)	_
DATE		B. ALWAYS-EVERY DAY	
		3-5 TIMES	3
NAME ID		1-2 TIMES	2
		ALMOST NEVER	1
I would like to get some idea of the usual fa	mily routines which take	8. Family has a 'quiet time' each evening w	hen everyone talks or plays quietly
place in your family. Consider the following	routines and see if they	A. IS THIS A ROUTINE? (Y=2; N=1)	_
apply to your family. Think about the	way your family has been	B. ALWAYS-EVERY DAY	4
operating in the last month or so.		3-5 TIMES	3
		1-2 TIMES	2
1. Parent(s) have sometime each day for just	talking with the children.	ALMOST NEVER	1
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;	N=1)		
B. ALWAYS-EVERY DAY	<u> </u>	9. Family goes to some special place togeth	er each week.
3-5 TIMES A WEEK	3	A. IS THIS A ROUTINE? (Y=2; N=1)	
1-2 TIMES A WEEK	2	B. ALWAYS-EVERY DAY	<u> </u>
	2	3-5 TIMES	3
ALMOST NEVER	Ι	1-2 TIMES	2
			2
2. Parent(s) have certain things they do ever	y morning while getting ready	ALMOST NEVER	Ι
to start the day.			
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;	N=1)	10. Family has a certain 'family time' each	week when they do things
B. ALWAYS-EVERY DAY	24	together at home.	
3-5 TIMES A WEEK	3	A. IS THIS A ROUTINE? (Y=2; N=1)	
1-2 TIMES A WEEK	2	B. ALWAYS-EVERY DAY	4
ALMOST NEVER	1	3-5 TIMES	3
		1-2 TIMES	2
3. Working parent has a regular time for havi	ng fun with the children	ALMOST NEVER	1
after coming home from work.	ing that with the children		
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;	N-1)	11. Parent(s) read or tell stories to the ch	ildren almost every day.
B. ALWAYS-EVERY DAY	n – – – – – – – – – – – – – – – – – – –	A. IS THIS A ROUTINE (Y=2; N=1)	
3-5 TIMES A WEEK	3	B. ALWAYS-EVERY DAY	<u> </u>
1-2 TIMES A WEEK	2	3-5 TIMES	3
	2	1-2 TIMES	2
ALMOST NEVER	I	ALMOST NEVER	-
h		RENUST NEVER	·
4. Working parent takes care of the children	sometime almost every day.	10. Each abild has seen time each don for he	dare elene
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;	N=1)	12. Each child has some time each day for be	
B. ALWAYS-EVERY DAY	4	A. IS THIS A ROUTINE (Y=2; N=1)	<del></del>
3-5 TIMES A WEEK	3	B. ALWAYS-EVERY DAY	4
1-2 TIMES A WEEK	2	3-5 TIMES	3
ALMOST NEVER	1	1-2 TIMES	2
		ALMOST NEVER	1
5. Children do the same things each morning a	s soon as they wake up.		
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;		<ol><li>Children take part in regular activities</li></ol>	after school.
B. ALWAYS-EVERY DAY	<u> </u>	A. IS THIS A ROUTINE? (Y=2; N=1)	
3-5 TIMES A WEEK	3	B. ALWAYS-EVERY DAY	- 4
1-2 TIMES A WEEK	2	3-5 TIMES	3
ALMOST NEVER	2	1-2 TIMES	2
ALMOSI NEVER	Ι	ALMOST NEVER	1
		ADTOSI NEVEN	1
6. Parent(s) and children talk/ play together	sometime each day.	the Veyne shildness as to slow school the same	a dava aaab waak
A. IS THIS A ROUTINE IN YOUR FAMILY? (Y=2;	N=1)	14. Young children go to play-school the sam	e days each week.
B. ALWAYS-EVERY DAY	4	A. IS THIS A ROUTINE? $(Y=2; N=1)$	<del>_</del> .
3-5 TIMES A WEEK	3	B. ALWAYS-EVERY DAY	<u> </u>
1-2 TIMES A WEEK	2	3-5 TIMES	3
		1-2 TIMES	2
ALMOST NEVER	1	1-2 1111125	2

.

15.	Children do their homework at the same time each A. IS THIS A ROUTINE? (Y=2; N=1)	day durin	g the week.	
	B. ALWAYS-EVERY DAY	_	4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
16.	Parents have a certain hobby or sport they do tog A. IS THIS A ROUTINE? $(Y=2; N=1)$	gether reg	ularly.	
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
17.	Children have special things they do or ask for ( (eg. a story, kiss, drink). A. IS THIS A ROUTINE? (Y=2; N=1)	each night	at bedtime	
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
			•	
18.	Children go to bed at the same time almost every A. IS THIS A ROUTINE? $(Y=2; N=1)$	night.		
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
19.	Family eats at the same time each night. A. IS THIS A ROUTINE? (Y=2; N=1)			
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
20.	At least some of the family eats breakfast toget? A. IS THIS A ROUTINE? (Y=2; N=1)	ner almost	every morning.	
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	
	1-2 TIMES		2	
	ALMOST NEVER		1	
21.	Whole family eats dinner together almost every no	ight.		
	A. IS THIS A ROUTINE? (Y=2; N=1)		4	
	B. ALWAYS-EVERY DAY			
	3-5 TIMES		3 2	
	1-2 TIMES		2	
	ALMOST NEVER		t	
22.	At least one parent talks regularly to his or her A. IS THIS A ROUTINE? $(Y=2; N=1)$	r parents	regularly.	1
	B. ALWAYS-EVERY DAY		4	
	3-5 TIMES		3	1
	1-2 TIMES		2	
	ALMOST NEVER		1	

23.	Family regular visits with the relatives.		
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1
24.	Family checks in or out with each other when som	eone lea	ves or comes home.
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1
25.	Working parent(s) comes home from work at the sa	me time (	each day.
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1
26.	Family has certain things they almost always do	to greet	the working
	parent(s) at the end of the day.		
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1
27.	Parent(s) have certain things they almost always	do each	time the children
	get out of line.		
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1
28.	Children do regular household chores.		
	A. IS THIS A ROUTINE? (Y=2; N=1)		
	B. ALWAYS-EVERY DAY		4
	3-5 TIMES		3
	1-2 TIMES		2
	ALMOST NEVER		1

### TEACHER-CHILD RATING SCALE

NAME OF SCHOOL	ID	
TEACHER	DATE	

A. Please rate this child on the following items by circling the number which corresponds to this scale:

	Not a Problem	Mild	Moderate	Serious	Very Serious Problem
1. Disruptive in class	1	2	3	4	5
2. Withdrawn	1	2	3	4	5
<ol> <li>Underachieving (not working to ability)</li> </ol>	1	2	3	4	5
4. Fidgety, difficulty sitting still	1	2	Э	4	5
5. Shy, timid	1	2	3	4	5
6. Poor work habita	1	2	3	4	5
<ol> <li>Disturbs others while they are working</li> </ol>	1	2	3	4	5
8. Anxious, worried	1	2	3	4	5
9. Poor concentration, limited attention span	1	2	3	4	5
10. Constantly seeks attention	1	2	3	4	5
11. Nervous, frightened, tense	1	2	3	4	5
12. Difficulty following directions	1	2	3	4	5
13. Overly aggressive to peers (fight	s) 1	2	з	4	5
14. Does not express feelings	1	2	3	4	5
15. Poorly motivated to achieve	1	2	3	4	5
16. Defiant, obstinate, stubborn	1	2	3	4	5
17. Unhappy, sad	1	2	3	4	5
18. Learning academic subjects	1	2	3	4	5

	ROBLEM SCALE	ACT-OUT	SHY-ANX	LEARN.
1				¦
R/	AW SCORE	1	l l	i i II

### B. Please rate the following items according to how well they DESCRIBE the child:

1	the child:					
		Not at All	A Mo Little	derately Well	Y Well	Very Well
		<b>M11</b>	DICCIG	Well	WEII	WC11
1.	Accepts things not going his/her way	1	2	3	4	5
2.	Defends own views under group pressure	1	2	3	4	5
Э.	Completes work	1	2	3	4	5
4.	Has many friends	1	2	3	4	5
5.	Ignores teasing	1	2	3	4	5
6.	Comfortable as a leader	1	2	3	4	5
7.	Well organized	1	2	3	4	5
8.	Is friendly towards peers	1	2	3	4	5
9.	Accepts imposed limits	1	2	3	4	5
10.	Participates in class discussions	1	2	3	4	5
11.	Functions well even with distractions	1	2	3	4	5
12.	Makes friends easily	1	2	3	4	5
13.	Copes well with failure	1	2	3	4	5
14.	Expresses ideas willingly	1	2	3	4	5
15.	Works well without adult support	1	2	3	4	5
16.	Classmates wish to sit near him/h	er l	2	3	4	5
17.	Tolerates frustration	1	2	3	4	5
18.	Questions rules that seem unfair/ unclear	1	2	3	4	5
19.	A self-starter	1	2	3	4	5
20.	Well liked by classmates	1	2	3	4	5

۱ ۱	COMPETENCE SCORE	   FRUST.	I ASSERT.	I TASK O.	PEER SOC.
!-		!	! <u></u>	!	
i	RAW SCORE	1	1	r f	/ I
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How well do you know this child?

Very Well Moderately Well Not Very Well

1 2 3

Are you aware of any situation in this child's life ( home, friends, special problems etc.) that might be affecting his/her behaviour or performance in school? If YES, please describe:

### Thankyou for your help

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### SOCIAL NETWORK INTERVIEW: FRIENDS AND FAMILY

Date of Interview

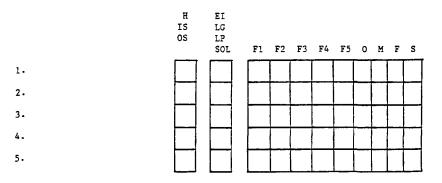
Name of Target Child

D.O.B.

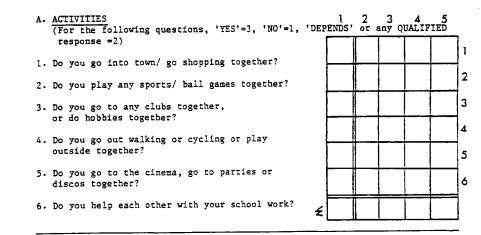
(ASK FOR NAME OF BEST FRIEND AND FOUR OTHER IMPORTANT FRIENDS)

1.			
2.			
3.			
4.			
5.			

(TALK TO CHILD ABOUT HOBBIES, SPECIAL INTERESTS, ACTIVITIES. TRY TO COMPILE A COMPREHENSIVE LIST. ASK WHAT CHILD DOES IN FREE TIME AT SCHOOL, ASK ABOUT EACH EVENING AFTER SCHOOL AND WEEKENDS. SPECIFY IF IN SCHOOL; OUTSIDE SCHOOL; HOME, AND WITH WHOM CHILD PARTAKES IN ACTIVITY. CODE INTEREST ON EDUCATIONAL/INTELLECTUAL; LEISURE-GROUP; LEISURE-PAIR; SOLITARY ORIENTATION)



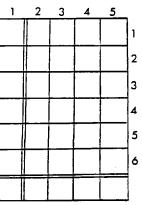
(IS= in school; OS= outside school; H= home; O= other; M= mother; F=father; S= sibling; EI= educational/intellectual; LG= leisure-group; LP= leisurepair; SOL= solitary activity). FRIENDS AND GROWN-UPS



B. CONFIDENCY

(For the following questions, 'YES'=3; 'NO'=1; 'DEPENDS' or any qualified response=2)

- 1. Would you tell N. secrets?
- 2. Do you tell N. about your family and your home?
- 3. Would you tell N. if you were worrying about something?
- 4. When you are happy, is N. the sort of person you can share it with, who will be happy just because you are?
- 5. Do you talk to N. about his/her family and home?
- Would you talk to N. about a special girl or boy you may like?



- C. STRESS
  - (For the following questions, 'YES'=3, 'NO'=1, 'DEPENDS' or any QUALIFIED response =2. The scoring in questions 2, 4, 5, 9, 12 is reversed).
- Do you sometimes quarrel, argue or fight about things?
- 2. Do you really care about one another?
- Does N. sometimes annoy you or say things that upset you?
- 4. Can you trust N. to keep secrets, and know that he will not split on you?
- 5. Do you like being with N.?
- 6. Does N. nag you a bit, or bully you if you don't want to do what he/she wants to do?
- 7. Does N. sometimes interfere with your activities?
- Bo you sometimes find you would like to see more of N. but can't?
- 9. Is N. very patient with you?
- 10. Does N sometimes do things which embarrass you?
- 11. Is there anyone or anything that tries to stop you being friends?
- 12. Is it easy getting in touch with N. if you want to see/play with him/her?

			1
			2
			3
			4
			5
			 6
			7
			8
			9
			10
			11
			12
£			

1 2 3 4 5

D. FRIENDSHIP SATISFACTION

(For the following questions, 'YES'=3; 'NO'=1; 'DEPENDS' or any 'QUALIFIED' response =2. The scoring in questions 4. and 5. is reversed.)

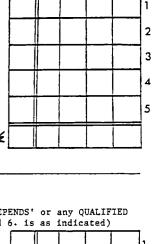
- Would you like to sit next to N in school? (If they do, ask if this is what they have chosen to do (=3) or if they would prefer not to (=1; Q=2)).
- Does N really listen to what you have to say and show interest in it?
- 3. Do you and N do exciting things and have fun together?
- 4. When you are with N, do you sometimes feel that you would rather be doing something with someone else?
- 5. Do you sometimes wish that N played with you a bit more than his/her other friends, or feel that you can't always be with N when you want to?

E. PARENT-FRIEND BOUNDARY

(The scoring in questions 1. to 4. is 'YES'=3; 'DEPENDS' or any QUALIFIED response =2; 'NO'=1. Scoring in questions 5. and 6. is as indicated)

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- Does N come back to your house after school or at weekends sometimes?
- 2. Do you go to his/her house?
- 3. Do you go on outings with his/her family?
- 4. Does he/she come on outings with your family?
- 5. How well do your parents know N.? (VERY WELL =3; QUITE WELL=2; DO NOT KNOW=1)
- 6. How well do you know N.'s parents? (VERY WELL =3; QUITE WELL=2; DO NOT KNOW=1)



2

13

4

5

6

2 3 4

### F. PERCEIVED DIFFERENTNESS

(For the following questions, 'YES'=3; 'DEPENDS' or qualified response=2; 'NO'=1) 1 2 3 4 5

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- Do you think your family is different to N.'s family?
- 2. Are there things about your family you would prefer N. not to see?
- Do you worry what N. may think about your family?
- 4. Do you ever wish your family was more like N.'s family?
- 5. Would you like to be like N?

FRIENDSHIP MAPS

### FAMILY AND RELATIVES

## A. ACTIVITIES

2

3

5

(For the following questions, 'YES'=3, 'NO'=1, 'DEPENDS' or any qualified response =2) M F

2

3

4

5

- 1. Do you go into town/ go shopping together?
- Does M/F take you out at weekends, to visit places or people?
- 3. Do you go to any clubs together, or do hobbies together?
- 4. Do you go out walking or cycling or play outside games together?
- 5. Do you go out to the cinema, watch films on TV, or read a book together sometimes?
- 6. Does M/F help you with your school work?

# THE CHILD'S ATTITUDE TO MOTHER SCALE - SCORING SHEET

NAME OF CHILD \_\_\_\_\_ CHILD ID

DATE OF INTERVIEW

DATE OF BIRTH

Rarely or none of the time =1 A little of the time =2 Some of the time =3 Good part of the time =4 Most or all of the time =5

RECODE

	My mother gets on my nerves.		
	I get along well with my mother.		
	I feel that I can really trust my mother.		
	I dislike my mother.		
	My mother's behaviour embarrasses me.		
f.	My mother is too demanding.		
g.	I wish I had a different mother.		
h.	I really enjoy my mother.		
i.	My mother puts too manylimits on me.		
	My mother interferes with my activities.		
-	I resent my mother.		
	I think my mother is terrific.		
	-		
	I hate my mother.		
	My mother is very patient with me.		
ο.	I really like my mother.		
p.	I like being with my mother.		
q.	I feel like I do not love my mother.		
r.	My mother is very irritating.		
s.	I feel very angry towards my mother.		
	I feel violent towards my mother.		
	I feel proud of my mother.		
	I wish my mother was more like others I know.	<u> </u>	
	My mother does not understand me.		
x.	I can really depend on my mother.		
У٠	I feel ashamed of my mother.		

TOTAL SCORE

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