Locus of Control in Chronic Fatigue Syndrome: Does it Matter?

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Abstract

The relationship between health locus of control and functioning in Chronic Fatigue Syndrome (CFS) was investigated. The hypothesis was that an internal health locus of control would be associated with less impairment in functioning than other dimensions of health locus of control. Prior research undertaken into CFS has been inconsistent in its finding's and it continues to be an area of controversial interpretations. A repeated measures design was used, 74 people participated at the initial stage of the study and 67 people participated in the second stage. The Functional Limitations Profile was used to assess levels of impairment. The Multidimensional Health Locus of Control was used to identify types of health locus of control orientation, and the Shapiro Control Inventory was used to establish a clearer picture of control issues. Correlations and *t*-tests were used to investigate the relationship between health locus of control and functioning. The results of these analyses indicated that an internal health locus of control was positively related to functioning. Multiple regression analysis was performed and showed that an internal health locus of control could successfully predict functioning measured at the second stage of the study. An unexpected discovery was that a doctor's health locus of control impacted negatively on functioning. The Shapiro Control Inventory revealed that the CFS sample fell within the normal range in the majority of control areas, but was outside the normal range in only six of the 23 control areas. These findings indicated that health locus of control does play an important role in CFS. It was therefore concluded that increasing a patient's sense of control and reflecting this in the treatment regime of CFS would aid recovery.

Chronic Fatigue Syndrome (CFS), otherwise known as Myalgic Encephalomyelitis (ME), Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) or Post Viral Fatigue Syndrome (PVFS), is a chronic illness, with fatigue as a central symptom. As these several names suggest, debate and contention surround the illness. The name CFS implies that fatigue is the central symptom and does not allude to anything further, except its chronic nature, while CFIDS implicates dysfunction in the immune system as well as highlighting fatigue and chronicity. On the other hand, PVFS indicates that the illness onset occurred after an unspecified virus, which resulted in fatigue. The name ME suggests that the illness is the inflammation of the brain, spinal cord and nerves, which results in muscle pain. Myalgia means muscle pain, Encephalitis refers to the brain, whilst Myelitis refers to the spinal cords and nerves and *itis* at the end of Encephalomyelitis means inflammation (Macintyre, 1998). Therefore, the name ME gives a very different picture of the illness. Even in the naming of the illness there exist large differences in opinion as to which name is a more accurate descriptor and which comes closest to implying the true cause of the illness. Throughout this paper the term CFS will be used as it is the most commonly-used name in New Zealand, where the research was conducted and from where the majority of the participants resided.

As illustrated and mentioned above, there is considerable disagreement regarding CFS and this disagreement spills over into every aspect. A brief history of CFS mapping the various conceptualisations over the last century, together with a consideration of the symptoms that are deemed to be part of CFS and its definitions, as officially defined in the United Kingdom and United States of America, are explored first. A picture of the personal characteristics, such as, gender and ethnicity of CFS sufferers is then drawn. A summary of the impact that CFS has on the lives of sufferers and their caregivers follows. The progression of CFS is then discussed, including the severity of symptoms and the outcomes of the illness anticipated by CFS sufferers. The role that personality plays is

then explored. Included here is a discussion of those studies that have attempted to implicate neuroticism in CFS. Possible psychological causes of CFS and the role that mental illnesses, such as, depression and anxiety are then investigated. Following is an examination of studies focussing on the psychological treatment of CFS, incorporating Cognitive Behavioural Therapy (CBT), social and financial support and relaxation therapy. The role of illness attributions in CFS is then explored, leading onto a consideration of the various ways of coping that CFS sufferers employ. Finally health locus of control and its implications for people with CFS is reviewed. From this platform stems the main focus of this research: the dimension of health locus of control adopted and its influence on functioning for people living with CFS.

1.1 What is CFS?

It is thought that CFS may have been present for at least a hundred years. DeLuca (2001) suggests that the illness we know as CFS may have been called neurasthenia in the late 19th century. It was first considered a neurological disease, but by the 20th century it was thought of as a psychiatric illness, whereby fatigue was caused by extreme nervous exhaustion and was conceptually included in the same categories as anxiety, depression and somatoform disorder (DeLuca, 2001). Today there is still a lack of agreement about the etiology, treatment and prognosis of CFS. This is perhaps because of the apparent complex nature of the illness, which may be best conceptualised within a biopsychosocial framework (Johnson, DeLuca & Natelson, 1999).

Today there exist greater consensus in the CFS literature as to the symptoms that are indicators of CFS. Those considered hallmark symptoms include the new onset of fatigue that lasts for at least six months, which is also exacerbated by exertion. Other symptoms resemble those associated with the flu, including sore throat, swollen glands

and lymph nodes, raised temperature, or hot and cold flushes, coughs, headaches, runny nose and eyes, and gastrointestinal complaints.

People with CFS often claim that they experience cognitive problems. These can include forgetfulness, trouble learning new information, a lack of concentration and difficulty with comprehension. Experiences in sensory disturbance are also reported. This may be a loss of vision, hearing, or dizziness, which can result in feelings similar to faintness. A large selection of these symptoms must be present before a diagnosis can be made.

1.2 The diagnosis of CFS

The United Kingdom medical profession use what is commonly known as the Oxford Criteria (Research diagnostic criteria, 2003) to diagnose CFS. Fatigue is considered to be the major symptom, which is required to impact on physical and mental functioning and must be considered severe and disabling. The fatigue also must have been experienced for at least six months and have been present for more than 50% of that time. The criteria state that other symptoms may be present and these can include myalgia (pain experienced in the muscle), and mood or sleep disorders. Conditions that need to be excluded before a diagnosis of CFS can be given include; a known organic brain disease; or any medical condition that is known to cause chronic fatigue; or psychological illnesses such as schizophrenia, manic-depressive disorder and substance abuse or eating disorders. However, depression, anxiety disorders and hyperventilation syndrome can be present within a diagnosis of CFS.

The Oxford criteria (research diagnostic criteria, 2003) differ somewhat from the CDC (Centers of Disease Control, 1994) definition that is used to diagnose CFS in the USA. The CDC (1994a) define CFS as a fatiguing illness, with a new and definite onset,

that cannot be explained, either by medical illness or exertion, and that impacts severely on lives across a wide range of areas, for example occupation, education and social activities. The CDC (1994a) definition differs in that it requires the presence of at least four of the following symptoms: short-term memory or concentration difficulties, flu-type symptoms, such as a sore throat, headache, swollen glands; un-refreshing sleep; and muscle or joint pain. Diagnosis also requires "post-exertional malaise lasting more than 24 hours" (CDC, 1994a, p1). As mentioned above, the Oxford criteria (Research diagnostic criteria, 2003) states that these symptoms may be present, but does not require them for the diagnosis of CFS. Post-exertional malaise is not included in the Oxford diagnostic criteria (Research diagnostic criteria, 2003). The CDC (1994a) criteria for CFS also excludes the presence of delusional disorders and severe obesity whereas the Oxford criteria (Research diagnostic criteria, 2003) does not make this exclusion.

1.3 The prevalence of CFS

CFS has been found most commonly to affect middle-aged, well-educated and high achieving women (Johnson et al. 1999). The CDC (1994b) estimated that between 0.004 – 0.0087 % of the population in the USA were currently diagnosed with CFS, based on a study conducted between 1989 – 1993. However, the CDC (1994b) has since revised it's figures and now estimates that between 0.075 – 0.265 % of the USA population is currently diagnosed with CFS. These figures provide an estimate of the current percentages of people in the USA thought to be diagnosed with CFS, but as yet figures are unavailable for lifetime prevalence rates of the illness. However debate exists about the number of people suffering from CFS, especially in studies that collect epidemiological information restricting the sample size to participants who are under

medical supervision. These studies have been criticised and the CDC (1994b) suggests that these studies do not accurately reflect the CFS population.

The CDC (1994b) reported that figures showed a greater number of women than men were diagnosed with CFS (59%). The figure had been much higher in previous studies, with up to 85% of CFS samples being female. The CDC (1994b) also found that up to 83% of people diagnosed with CFS were Caucasian. While CFS is often thought to be a Caucasian illness, these figures indicate that CFS is not exclusively a Caucasian illness.

In an American epidemiological study, Torres-Harding, Jason and Taylor (2002) found that chronic fatigue was experienced by a number of different ethnic groups. While the largest percentage of participants with chronic fatigue were Caucasians at 40%, with Latinos contributing to 25% of participants with chronic fatigue. African-Americans represented 24%, 3% were Asian-American and a further 3% categorised themselves as 'other'. As the study was a random telephone interview design, participants were not diagnosed with CFS, but rates of fatigue were measured, in order to give a general picture. Significantly more females reported cases of chronic fatigue than males: 66.5% were female (Torres-Harding et al. 2002). They also found that socioeconomic-status and ethnicity were unable to predict levels of fatigue. However, further studies may be needed to clear up discrepancies within the research.

Benrud and Reddy (1998) disagree with the premise that more women than men suffer from CFS, suggesting that there is not necessarily more women suffering from CFS but rather that more women come forward seeking treatment as opposed to men. Benrud and Reddy (1998) further their theory by explaining that it is possible that women may think that there is something wrong with them, which then makes them more likely to seek treatment. However, men are more likely to attribute a CFS-like illness to their lifestyle, which means that they are more likely to make changes to their lifestyle or

battle on ignoring the problem and not attribute a CFS-like illness to a medical condition. This results in men being less likely to seek medical advice and therefore men could be underrepresented in medical-based prevalence studies.

1.4 The characteristics of people with CFS

In a study investigating possible differences between healthy people and those with CFS, Dobbins, Natelson, Brassloff, Drastal and Sisto (1995) found that while psychological problems were present in both groups, those with a diagnosed psychological illness were present only in the CFS sample. The CFS sample was also found to have more cases of eczema and pre-menstrual stress, and more likely to have engaged in sexual activity before the age of 18, and reported a significantly higher number of stressful events (Dobbins et al. 1995). Whilst the study provides some interesting differences between a healthy and CFS sample, results should be interpreted with caution, as the sample size was small, with only 40 participants, 20 in each group, healthy or CFS. The CFS sample was recruited through a university-based neurology practice, therefore these participants may also not accurately represent the CFS population.

1.5 The impact of CFS

CFS can have a debilitating effect on the lives of those people who suffer from the syndrome. Often the fatigue and associated symptoms are experienced persistently and cause severe limitations in previously productive people (Heijmans, 1998). CFS can impact on various aspects of a person's life, producing significant disruption and disability. Areas that are often affected include social interaction with friends and family,

and the ability to work and take part in recreational or sporting activities, all of which can place a strain on relationships between friends and family members (Abbey, 1995).

Goodwin (2000) found that CFS placed strain on the marital relationship when one partner was diagnosed with CFS. Husbands and wives reported feeling that they were unable to work effectively as a team, citing cognitive problems as the cause. Financial pressure was also reported as being increased, because the person with CFS was often unable to work. Intimacy levels were reported to have decreased as communication between couples became strained. Therefore, Goodwin's (2000) study shows that it is important to be aware that CFS does not just impact on the person who has been diagnosed with the syndrome, but it also impacts on the lives of others who are involved with the sufferer. It is also important to be aware that the impact of CFS is far-reaching and does not just manifest itself in physical problems; the ramifications of the illness can reach every aspect of a sufferers' life.

Chronic illnesses can also lead to uncertainty and anxiety (Garrett & Greene Weisman, 2001) which can cause high levels of distress (Looper and Kirmayer, 2002). Patients with chronic illnesses such as CFS often experience feelings of anger, confusion and loneliness and also may feel inadequate and frightened. Disruptions in ideals, goals, roles and ambitions may occur as a result of the changes in a person's life that a chronic illness produces (Garrett & Greene Weisman, 2001). This is true for people with CFS who are often put in a position where they must gain recognition of their illness, not only from friends and family, but also the medical profession, many of whom are unsure as to what constitutes CFS.

1.6 Illness progression in CFS

Another area of CFS that is unknown and subject to divergent findings is the expected illness progression. This encompasses the path the syndrome takes and the long-term outcome. Presently the area is surrounded in uncertainty and unpredictability.

> One important source of discouragement is the unpredictability of the illness: it is very difficult for the CFS individual to predict how much exertion can be tolerated without the risk of behavioral collapse. An activity that is well tolerated on one occasion may lead to a debilitating symptom flare-up at other times. If discouragement persists, a sense of hopelessness may be experienced, which further magnifies perceptions of incapacity (Friedberg, 1995, p. 149).

Friedberg (1995) explains how the unpredictable nature of CFS can cause interruption in daily life, with previously tolerated activities causing an increase in symptoms. This unpredictability can cause feelings of hopelessness and a lack of control over the syndrome and, therefore, the sufferer's life.

Ray, Weir, Cullen and Phillips (1992) investigated a number of factors relating to CFS, including the impact of the syndrome, frequency of symptoms and improvement levels. They found that 82% of participants felt that CFS impacted severely on their lives. Thirty-one percent felt they experienced symptoms all the time, 46% most of the time and 23% experiencing symptoms some of the time. Seventy-two percent of participants reported feeling better for a few days at a time, while only 28% reported feeling better for weeks at a time. Eighty-seven percent of participants reported that fatigue was exacerbated by physical activity and 83% reported an onset of fatigue after mental activity. Overall, 55% believed that over time they were improving, but 11% felt they were worsening over time. Therefore, Ray et al. (1992) have shown that CFS illness experiences vary, with differences covering a range of areas, from symptom frequency to illness outlook.

In a longitudinal study that investigated illness outcome in CFS, Johnson et al. (1999) found that over 18 months 3% of their sample reported a full recovery and 17% reported some improvement in symptoms. This finding suggests that there is little chance

of recovery or improvement from CFS, at least within an 18-month time frame. The CDC (1994b) reports that there is debate about what constitutes a recovery from CFS, acknowledging that there exists a group of people who were diagnosed with CFS that recover to a level enabling them to return to work and take part in other activities. The CDC (1994b) have found that most people with a diagnosis of CFS recover within five years. Russo et al. (1998) found that those participants who did not recover but continued to suffer from CFS, were older and less educated, had a longer illness duration and reported suffering from a larger number of symptoms.

Another factor that has received consideration is the type of onset, that is, whether the illness was of a sudden onset, typically over a few days or weeks, or of a gradual onset, which is when CFS is thought to develop over a number of weeks or months. Ray et al. (1998) found that a gradual onset of CFS was associated with a longer length in illness, whilst a sudden onset of CFS was associated with a shorter illness duration. However, Ray et al. (1998) believe that this finding should be considered carefully, as it may be that those who have a longer illness duration may not be able to clearly remember whether their illness onset was sudden or gradual.

Cope, Mann, Pelosi and David (1996) found that people with CFS made significantly more visits to their medical practitioner than a control sample without CFS, in the year preceding and following diagnosis. These findings may suggest that the experience of CFS is severe. However, it would be reasonable to expect that people with CFS would visit a medical practitioner more often particularly after diagnosis, if they were receiving some form of treatment. Another factor that could explain these findings is that the person may have been experiencing CFS during the year before a diagnosis was given, since it takes at least six months for a CFS diagnosis to be made (CDC, 1994a). Friedberg, Dechene, McKenzie and Fontanetta (2000) found that the severity of symptoms was higher in a long-term illness duration group, than in a short-term illness

duration group of participants with CFS. Those who had had CFS for more than 3 years reported more severe levels of fatigue, depression and stress than those who had had CFS for less than 3 years. Ray, Jefferies and Weir (1995) found that accommodation to CFS as a coping strategy was associated with a longer illness duration and more severe levels of fatigue.

1.7 Causes of CFS

There are many theories as to what causes CFS, with studies often contradicting each other. Possible causes range from medical explanations such as an immune dysfunction, a virus, dietary problems, hypotension or brain abnormalities. Psychological theories as to the causes of CFS are just as varied. Research studies have proposed personality factors, self esteem, depression, anxiety, stress and a form of chronic pain as possible explanations for CFS. Some researchers have focussed on a single factor, whilst others have suggested numerous factors are implicated. The same controversies exist within the area of treatment of CFS. Trials have studied the effectiveness of CBT, relaxation therapy and graded exercise regimes, amongst others.

1.8 Causes of CFS: The role of personality

Research comparing participants with CFS to participants with either depression or those who attended orthopaedic clinics found that the only significant difference between the groups on a personality measure was on the neuroticism scale of the Eysenck

Personality Questionnaire (Eysenck & Eysenck, 1975, cited in Chubb et al. 1999). The participants who were diagnosed with CFS and depression were found to have significantly higher scores on the neuroticism scale than the group comprised of orthopaedic clinic attendees. However Chubb et al. (1999) noted that a raised score on the neuroticism scale is common whilst suffering from depression and levels typically return to normal after recovery. There were no other significant differences found between any of the sample groups on the psychoticism, extraversion or social desirability scales of the personality measure. Chubb et al. (1999) found no differences in personality between the CFS sample and the depressed and chronic pain control samples, which suggests that CFS may not be a result of personality factors, such as, neuroticism.

Christodoulou et al. (1999) found that participants with CFS had similar personality characteristics to participants with Multiple Sclerosis. Christodoulou et al. (1999) argues that because of these similarities it is likely that personality factors do not cause CFS, but rather when a person sufferers from CFS they undergo changes in their view of the world. This changes their personality characteristics so as to be similar to that of people with Multiple Sclerosis, which is also debilitating chronic illness. However, Van Houdenhove, Onghena, Neerinckx and Hellin (1995) suggest that hyperactivity or workaholism might contribute to people developing CFS. They suggest that this type of person might be prone to CFS because they neglect themselves in favour of others, not wanting to let anybody down.

On the other hand White and Schweitzer (2000) found that participants with CFS had significantly higher levels of perfectionism and significantly lower levels of self-esteem than a healthy control group. These factors were measured after participants began to suffer from CFS. Therefore, it is unclear whether higher levels of perfectionism and lower levels of self-esteem caused CFS to develop, or whether these factors changed due to the development of CFS and a subsequent loss of a normal life, free from a chronic

illness. Conversely Powell, Dolan and Wessely (1990) found no evidence of participants with CFS having lowered self-esteem levels.

Natelson and Lange (2002) discounted the theory that CFS is a result of negative personality features as not all CFS sufferers present with negative personalities. Lewis (1996) points out that while studies have examined personality factors of CFS sufferers in the past, these studies fail to take into account the literature that supports the position that the CFS experience changes a person's personality. Therefore, researchers cannot be sure if any 'personality factors' cause CFS, or arise as a results of CFS. "People cope in different ways with different aspects of their illness and different strategies may be adaptive at different times." (Lewis, 1996, p 246).

1.9 Causes of CFS: The role of psychological illness and distress

An area surrounded by more controversy than any other in the study of CFS concerns the possible role of mental illness as the cause of the syndrome. Theories propose that CFS is as yet an unrecognised form of mental illness. This is argued because a number of people who have CFS also meet the criteria for psychiatric illnesses. CFS is often perceived as being closely related to depression or anxiety. Wessely (1995) opposes the view that CFS is an unrecognised mental illness. Rather he claims that CFS is not just a physical illness, but has a strong psychological component that needs to be addressed. Nevertheless, research has shown that people with CFS often score highly on scales measuring depression fuelling such a position. Powell et al. (1990) found that participants with CFS scored within the depressed range on the mood change, weight, appetite and sleep disturbance, somatic symptoms, anhedonia, pessimism about the future and feelings of helplessness scales. These results may be inflated as weight, appetite and sleep

disturbances along with somatic symptoms are often considered and experienced as symptoms of CFS (Macintyre, 1998). Powell et al. (1990) found that participants with CFS did not score in the depressed range for the more severe markers of depression, including suicidal ideation, lowered self-esteem and guilt. Powell et al. (1990) found that the CFS group was significantly different from the depressive group in several ways. The depressive group had lower levels of self-esteem and reported experiencing more guilt than the CFS group, and those CFS participants who scored within a depressive range still differed significantly from the depressive group, scoring less on the depression measure. In support of Powell et al.'s (1990) findings, Short, McCabe and Tooley (2002) found that participants with CFS experienced mild to moderate depression when compared to a control group of healthy participants.

Natelson and Lange (2002) found that 36% of participants with a diagnosis of CFS also met the criteria for major depression. Fifty-seven percent of participants with a diagnosis of CFS and Fibromyalgia (FM, a similar illness to CFS that is distinguished by fatigue and pain), also met the criteria for major depression. They also found that 73% of participants suffering from CFS, FM and Irritable Bowel Syndrome also met the criteria for major depression. These findings support Natelson and Lange's (2002) recommendation that research into the aetiology of CFS be confined to studies that use a homogenous sample of participants who do not meet the criteria for any psychiatric illness. Samples that are comprised of participants that do met criteria for psychiatric illnesses may limit the generality of the findings, thus supporting a psychiatric basis of CFS and overshadowing any possible biological basis for the syndrome (Natelson & Lange, 2002).

Natelson and Lange (2002) disagree with the argument that because some participants with CFS have benefited from CBT this proves that CFS is a psychological illness. Natelson and Lange (2002) argued that because CBT is a useful treatment in both

psychological and medical illnesses, the argument that CFS is a psychological illness does not follow.

Related to the preposition that CFS is a form of depression is the theory that CFS is the result of anxiety. Roy-Byrne et al. (2002) conducted research using monozygotic and dizygotic female twins in which one twin had been diagnosed with CFS. The use of twins as part of the methodological design was an attempt to control for biological and or environmental differences during childhood that may impact on results in non-twin studies. The study investigated differences in fatigue levels and psychological distress in each twin. Roy-Byrne et al. (2002) reported that "Up to three-quarters of patients with fatigue syndromes have comorbid mood or anxiety disorder...." (p 29). In addition Roy-Byrne et al. (2002) found that those twins with CFS suffered more psychological distress than the twins without CFS, thus supporting the premise that psychological distress is more prevalent amongst those with CFS. However, they questioned the nature of this relationship. Their study showed that those twins with CFS reported more symptoms of psychological distress than the twin without CFS, but the direction of the relationship between psychological distress and CFS is not known. It is possible that psychological distress causes CFS, but conversely CFS could cause psychological distress, or both CFS and psychological distress could be caused by a third factor (Roy-Byrne et al. 2002). Short et al. (2002) found no significant difference in levels of anxiety between participants with CFS and healthy participants; however, they do suggest that anxiety could be linked to illness duration and severity or personality attributes and psychosocial desirability.

It has been proposed that victimisation plays a role in CFS. In research conducted by Schmaling and DiClementi (1995), between 67% and 78% of participants were found to have histories of sexual or physical abuse. Schmaling and DiClementi (1995) reported that these findings are twice as high as the level usually found in healthy or random

samples. This led Schmaling and DiClementi (1995) to conclude that prior victimisation, in the form of sexual or physical abuse, can cause CFS. However, the number of participants in the groups studied were 15 and 61, so any conclusions should be considered tentative at this stage, due to the low number of participants. Further studies with larger samples should be conducted to corroborate these findings.

Van Houdenhove et al. (1995) found that a CFS group scored significantly higher on an action-proneness scale than control groups consisting of participants with an organic disease, such as Multiple Sclerosis or Paraplegia, participants diagnosed with a mood disorder and participants suffering from chronic pain. The CFS group scored very similarly to the chronic pain group. This led Van Houdenhove et al. (1995) to conclude that CFS could be the result of people somatatising their illness in an attempt to rid themselves of uncomfortableness or stress. Van Houdenhove et al. (1995) also suggested that people with CFS try to present themselves as action-prone prior to illness onset to lessen the chance, and avoid the stigma, of a psychiatric diagnosis.

Blakely et al. (1991) found that there were no significant differences in levels of depression, anxiety and dysfunction between those female participants with CFS and those who suffered from chronic pain. Both groups differed significantly from the healthy control group. Discriminant function analysis revealed that there was considerable overlap between the chronic pain and CFS samples on measures of symptoms, depression, personality factors, anxiety and dysfunction (Blakely et al. 1991). These findings support Blakely et al's. (1991) position that CFS is a sub-group of chronic pain, rather than a separate syndrome.

The above studies do not provide clarity as to the causal relationship between personality features, self-esteem or emotional states and physical functioning. It is possible that the emotional states of a CFS sufferer causes the exacerbation of physical symptoms. It is also likely that an increase in severity of physical symptoms may cause a

decline in emotional state. At best, studies have shown that relationships between these factors exist. In order to examine the relationship further, within-subject longitudinal designs would be necessary.

1.10 Causes of CFS: A biopsychosocial approach

Finally, a further theory suggests that CFS may be caused by a multitude of factors, each interacting with each other. Heijmans (1998) suggests that people may have a predisposition to developing CFS, which is initiated by a virus and is exacerbated by a person's attempt to carry on when they get ill, resulting in the development of CFS. Lewis (1996) shares a somewhat similar view, suggesting that emotional disturbance could be a predisposing factor, or a reaction to illness, or a type of depression, but that it is likely that CFS is "a set of conditions and that etiologies and prognoses are also likely to be heterogeneous." (Lewis, 1996, p 234). That is, that at present CFS encompasses a range of conditions, aetiologies and prognoses, all of which differ from each other. However, perhaps the best framework to conceptualise CFS within is the stress model, which takes into account psychological, physical and social factors, and immunological and viral symptoms (Lewis, 1996). She suggests that CFS sufferers may overlook the possibility of stress as a cause of their illness because they focus on viral causes, but susceptibility to a viral illness may have been lowered by stress in the first instance.

1.11 Treatment and models of CFS

While it is important to understand the causes of CFS, particularly in order to tailor treatment programs effectively, it is also necessary to consider the person with CFS. Sharpe (1998) suggested that medical diagnosis of CFS is better for the individual in

terms of preserving a more socially acceptable role, placing less responsibility on them, and affording them more financial and social support. Psychiatric diagnosis may imply weaknesses to patients, family and friends, employers and government aid departments etc. This could lead to less support being forthcoming and also promote attitudes from others to 'get over it' (Sharpe, 1998). However, Sharpe (1998) does not suggest that this means that psychological treatment should not be available to those that suffer from depression and anxiety as part of CFS. It may mean though, that they are more likely to get treated for these disorders.

Friedberg (1995) suggested that there may exist an interaction between negative affect, fatigue and perceived illness severity. Thus, if a person is experiencing emotional difficulties in coping with CFS, they may have an increase in fatigue, which could lead to a perception that their illness is getting worse This could then lead the person to experience more negative emotions such as frustration, anger and feelings of hopelessness. Thus, a continuous cycle of negative affect, fatigue and illness severity is created. Friedberg (1995) found that stress plays an important role in the exacerbation and disability of CFS, and emotional distress was found to predict relapses. These findings have important implications for the treatment and recovery for CFS sufferers. Clinicians treating CFS should be aware of the role that emotions play. Therefore it may be necessary, as part of the treatment, that the patient learns to recognise the impact of negative emotions on their illness and perhaps have a course of relaxation therapy, or be encouraged to talk through their feelings.

Chandler, Lee and Pengilly (1997) found that people with low self-esteem want to succeed at tasks, but don't believe that they will. Results from their study also indicated that those participants with high self-esteem were more likely to attribute their success at tasks to internal causes than those participants with low self-esteem. Chandler et al. (1997) also found that those participants with low self-esteem were more likely to

attribute their failure to complete or perform tasks well to internal causes. Their research also indicated that expectations of success and actual performance were positively related; thus, as a participant's expectations of success increased, then so did their subsequent performance of the task. While Chandler et al. (1997) did not investigate self-esteem in people with CFS, these findings could be applied to that group. Medical professionals treating CFS sufferers need to be aware of the impact that low self-esteem may have on treatment outcomes, particularly if a patient's own behaviour is involved in the treatment process, like CBT, relaxation therapy or a graded exercise approach therefore, self-esteem may need to addressed within the treatment.

In a study designed to ascertain the effectiveness of treatment in CFS, Deale, Chalder and Wessely (1998) compared 13 sessions of CBT to relaxation therapy in participants with CFS. CBT involved participants designing and implementing a program of rest and graded activity. Causal attributions were not challenged as part of the treatment, but they were measured for both experimental groups pre-and post-treatment. Participants were contacted after 6 months and improvements were gauged. Deale et al. (1998) reported that 70% of participants in the CBT group reported improvement, which was significantly more than participants in the relaxation group where only 19% reported an improvement. Further analysis showed that the CBT group improved on measures of fatigue and fatigue symptoms, but not mood.

Deale, Husain, Chalder and Wessely (2001) re-contacted the participants from the 1998 study for a 5 year follow-up. Sixty-eight percent of participants in the CBT group reported improvements, while only 36% of participants in the relaxation group reported improvement. Significantly more participants in the CBT group were assessed as no longer meeting the criteria for CFS, or not experiencing relapses, or their symptoms had improved. Deale et al. (2001) reported that while similar numbers of participants in each group were in employment, the participants in the CBT group were working significantly

more hours. Eighty percent of participants in the CBT group and 50 % in the relaxation group thought that their treatment was useful, and 88% of participants in the CBT group and 61% in the relaxation group reported continuing with the use of the techniques they had been taught in treatment (Deale et al. 1998).

Prins et al. (2001) compared CBT treatment of CFS to the use of a support group directed by a social worker and to a group receiving no intervention. Participants in the support group and those receiving no intervention were not prohibited from seeking further medical treatment, while those in the CBT group were prohibited from such treatment. Results of the study showed that CBT was more successful at treating CFS than use of either support group or no intervention (Prins et al. 2001).

Sadlier, Evans, Phillips and Broad (2000) investigated the effectiveness of Multi-Convergent Therapy (MCT) with CFS. They reported that MCT involves aspects of CBT, connective tissue massage (Ebner, 1985, cited by Sadlier et al. 2000), meditation and fitness training. MCT incorporates patients in the treatment process, and in decision-making and goal setting aspects, which increases an individual's internal sense of control (Sadlier et al. 2000).

Participants were divided into four groups with different goals. The first group's goal was to improve quality of life from pre-to post-treatment. Scores on a quality of life scale significantly improved for all participants in this group. The second group's goal was to effect a decrease in symptoms and 61% of participants in this group achieved the goal. Participants in the third group set a goal of returning to work, which all participants achieved. The fourth group set a goal to return to work or school and to take part in regular exercise. One participant dropped out of the study before completion, but the other participant achieved the goal. Sadlier et al. (2000) reported that all the participants in the study made significant improvements with regards to the goals that they had set for themselves to achieve.

Jason, Fricano, Taylor and Halpert (2000) proposed that there are distinct phases within CFS and understanding and working within these phases may result in better outcomes for people suffering from CFS. They asserted that the existence of these phases could explain the contradictory responses from CFS sufferers and consequently researchers' inability to adequately identify patterns and processes within CFS.

Jason et al. (2000) identified four phases within CFS. The first phase was the Crisis phase where sufferers experienced greater levels of illness severity, higher levels of fatigue and psychological distress. Sufferers in this phase also reported greater levels of impairment and engaged in accommodation coping styles more often than sufferers in the other phases. Following this stage is the Resolution phase. This phase is characterised by the possibility of relapse but with sufferers are more prepared to handle such an event. Moderate levels of impairment in functioning, both physical and psychological are reported in this phase, along with moderate levels in illness severity. Jason et al. (2000) distinguish this phase as a move towards psychological transcendence, or acceptance, with an attempt to integrate pre-and post-CFS lifestyles. The next phase, Stabilisation, was defined as a plateau in the perception and experience of symptoms and a greater adaptiveness to the illness. Sufferers experienced lower levels of impairment in physical and psychological functioning, fatigue and severity. Jason et al. (2000) also reported that this phase is marked by a move from denial of the illness towards a self-care-oriented style of coping. The final phase of CFS as defined by Jason et al. (2000) is the Integration phase, in which people with CFS are able to successfully integrate their pre-and post-CFS lifestyles and cope with CFS in a planned fashion. Jason et al. (2000) believed that this model of CFS allows for a new understanding of the processes within CFS and thus, medical services could be tailored to each phase.

1.12 Illness attributions and CFS

The causes to which people attribute their illnesses can affect every stage of that illness, from choosing which type of treatment to seek to whether to adhere to treatment regimes and advice given by the chosen medical professional (Sensky, 1997). Within the context of CFS this may mean that a person with CFS may choose to go their general practitioner (GP), a specialist such as a neurologist, a psychiatrist or an immunologist, a naturopath or an acupuncturist. Each of these professionals will offer different treatment regimes and possibly different success rates. Clements, Sharpe, Simkin, Borrill and Hawton (1997) noted that differences in attributions held by the patient and treating professional could result in disharmony and maladaptive treatment, especially if there is little trust or communication. Sensky (1997) also noted that people look to make external factors, such as, an infection causes for their illness, rather than looking to internal causes, such as psychological status. Causes are usually those that come to mind easily and therefore may be influenced by media exposure, or support groups' views (Sensky 1997).

Clements et al. (1997) investigated the development of illness beliefs in CFS. They found that 70% of the participants attributed their illness beliefs to personal reflection. Forty-two percent of participants reported that self-help literature and or the media developed their beliefs about CFS. Thirty percent of participants believed that their beliefs about CFS were developed by health professionals that they were in contact with, while 27% identified other people as contributing to the development of their illness beliefs.

In an early study into the role that attributions play in CFS, Anderson and Arnoult (1985) found that if attributions concerning the illness are reinforced then participants were likely to feel more positive. For example, if a person with CFS feels that alcohol

makes them feel worse, then by avoiding the consumption of alcohol and experiencing a lessening in symptoms, their attributions are reinforced. This may lead to regaining a sense of control over their illness and life. Anderson and Arnoult (1985) suggest then that treatment should encourage those with CFS to make realistic attributions and develop realistic expectancies about their illness.

Howlett and Lindegger (1996) compared a sample of participants with CFS to a sample of participants with a chronic physical disease, such as rheumatoid arthritis, chronic emphysema, multiple sclerosis, myasthenia gravis and insulin-dependent diabetes, and a third sample of participants who had been diagnosed with depression. Howlett and Lindegger (1996) found that the CFS sample held attributions similar to the chronic physical disease group, rather than the depression group. The depression group held negative attributional styles, while both the chronic physical and CFS groups held positive attributional styles. The CFS sample scored between the other two groups on a measure of illness behaviour. The depression group scored highest in illness behaviour, except in the illness conviction category, where the CFS participants held the strongest illness convictions. However, on the measure of depression the chronic physical disease group scored the lowest, which was significantly different from the CFS and depression group, both of which did not differ significantly from each other.

These results from Howlett and Lindegger (1996) show that the CFS sample is most like the chronic physical disease group regarding attributional style. The CFS group was also found to have strong illness convictions, but was not similar to either the depression sample or the chronic physical disease group in illness behaviour. However, the CFS group was found to be very similar to the depression group with regards to depression, suggesting that CFS is in some way similar to depression.

Chubb et al. (1999) examined attributions in participants with CFS, participants from an orthopaedic clinic who were otherwise healthy and participants with depression.

Their findings were similar to Howlett and Lindegger's (1996) results, in that they found that CFS sufferers were similar in attributions to a sample of chronic physical disease sufferers. In Chubb et al's. (1999) study, participants with CFS scored significantly higher on attributional dimensions than the depressed participants and were similar to the participants from the orthopaedic clinic. Chubb et al. (1999) reported that these results indicated that participants with CFS attribute good events as internal (within their control), stable and global. While bad events are seen as external (out of their control), global and stable, which was found to be significantly different from the participants from the orthopaedic clinic. Chubb et al. (1999, p 357), suggest that

> This may explain why some CFS patients have rather rigid and immutable views about the physical nature of their illness. If developing CFS can be considered a 'bad event' individuals will consider it is due to external factors which are out of a personal control (external) but which also tend to remain the same (stable) and also tend to recur in varying situations (global). When treating individuals with CFS, it may prove helpful to discuss this hypothesis with them with a view to them gaining some insight into their condition. The cause to which patients attribute their illness could be incorporated and explored as part of cognitive therapy.

In a study investigating illness attributions in CFS, Ray et al. (1992) found that a high percentage of participants thought their illness was due to wholly or mainly to physical causes, 53%. Forty-three percent attributed CFS to both physical and psychological factors and 3% believed their illness was due to psychological factors alone. Sixty percent of the sample were optimistic about their future and these participants were more likely to have a shorter illness duration as well as feeling that they were improving. Participants were asked whether they considered that their illness was of a sudden or gradual onset. Fifty-eight percent of the sample identified a gradual onset, while the remaining 42% identified a sudden onset.

Petrie, Moss-Morris and Weinman (1995) investigated catastrophic thinking, which was defined as expectations that were highly exaggerated negative responses, or responses that indicated that the worst possible outcome was expected, in CFS. They

found that 31% of answers given by participants with CFS were catastrophic. In contrast, there were no significant differences between participants who gave catastrophic answers and those who did not in the following categories: age, length of illness, psychological adjustment, number of physical symptoms they associated with CFS and the number of health visits made in the past two months. However there were significant differences between the two groups in fatigue and disability levels. Those participants who gave catastrophic answers reported significantly more fatigue and disability in work, household management, social interaction, recreation and pastimes, and rest and sleep. A possible interpretation of these results is that more disability and fatigue in the above areas could influence a person with CFS to give catastrophic answers. On the other hand catastrophic thoughts could be responsible for more impairment and fatigue on the above scales.

Heijmans (1998) investigated causes that participants with CFS attributed to their illness. Over half (57%) of the participants in the study felt that their illness was due to physical causes, such as an infection. Just under a quarter of the participants thought that their illness was due to psychological causes, such as stress or lifestyle. A further 11% believed that their illness was due to environmental causes, such as pollution or chemical exposure. Four percent of participants felt that their illness was due to heredity causes or fate and the last 4% did not know what caused their illness. A further, investigation of the causes that participants attribute to CFS found that 70% of participants believed that CFS was due to a virus or germ, while 27% believed that CFS was because of their own behaviour (Edwards, Suresh, Lynch, Clarkson & Stanley, 2001). The final 23% attributed CFS to their "...state of mind..." (Edwards et al. 2001, p67). They also investigated the role that illness perceptions played in emotional adjustment. Edwards et al. (2001) found that those participants suffering from anxiety, depression and higher levels of impairment or fatigue were more likely to have negative illness perceptions about CFS. These

negative illness perceptions included the outcome of the illness, that is, whether recovery would occur, the length of time that a person expected to suffer from CFS and whether symptoms would ease during the course of the illness.

Ray, Jefferies and Weir (1997) found that there was no relationship between causal attributions and fatigue or impairment. This suggests that a person's belief as to the causes of their illness, physical or psychological, has no bearing on the amount of impairment or severity of symptoms that is experienced. Deale et al. (1998) investigated whether causal attributions would be influenced by CBT. They found that there were no significant changes in attributions from pre-to-post treatment. This supports Ray et al's. (1997) conclusion that causal attributions do not play a role in the recovery of a person with CFS. However, Deale et al. (1998) did find that beliefs about exercising when feeling tired changed significantly after CBT treatment. After CBT, participants felt that it was good to exercise when they were feeling tired, which differs from views held pre-treatment.

Moss-Morris et al. (1996) undertook a comphrensive study into attributions about CFS. A strong illness identity was positively correlated with a belief in the serious consequences of CFS and a more chronic time course of the illness. This indicates that the stronger the illness identity of a person with CFS, then the more likely it is that they will have had CFS for a long time and hold more serious beliefs about the nature of the illness. The time-line of CFS was found to positively correlate with the consequences of CFS, but correlate negatively with a belief in controllability. This indicates that the longer a person has been ill, the more likely they are to associate more consequences with CFS and the less likely they are to feel in control of their illness. Emotional attributions about CFS and a belief that CFS is the result of an immune system disease were found to positively correlate with serious consequences. This means that the more emotional attributions a person holds with regards to CFS along with a belief that CFS is caused by

an immune system disease, the more likely they to are report more serious consequences of CFS. No significant correlations were found concerning physical attributions.

Illness identity and emotional causes were found to be significant negative predictors of psychological adjustment (Moss-Morris et al. 1996). That is the more strongly a participant identified with CFS and the more emotional causes that they identified the less psychologically adjusted they were. Moss-Morris et al's. (1996) study found that illness identity was a significant negative predictor of vitality, while emotional causes and internal sense of control were positive predictors of vitality. Therefore, the more a person identifies with CFS the less likely it is that they will exhibit vitality. In contrast, the more emotional causes and internal sense of control a person holds with regards to CFS, the more likely they are to exhibit vitality. Illness identity and serious consequences were also positive predictors of dysfunction. This means that the more strongly a person identifies with CFS and the more strongly a belief in serious consequences of the illness, the more dysfunction they are likely to experience.

Whilst research into the causal attributions of CFS may yield interesting results, outcome attributions can be better predictors of coping and distress (Amirkhan 1998), i.e., the perceived outcome of an event is a better predictor of stress and coping than the attributions about the event itself. In terms of CFS this means that what caused CFS is a poorer predictor of coping and stress than attributions about the illness progression. Amirkhan (1998) noted that attributions take into account three variables, locus of control, stability or permanence and the controllability of attribution.

1.13 Coping with CFS

Moss-Morris et al. (1996) found that coping also interacted with attributions about CFS. Illness identity was positively correlated with the coping styles of planning, venting

emotions and behavioural and mental disengagement. This suggests that as illness identity increased so did the use of planning, venting emotions and behavioural and mental disengagement coping styles. A belief that CFS had serious consequences was positively correlated with planning, suppression of competing activities, seeking emotional support, venting emotions and mental disengagement. That implies that as a belief in the seriousness of CFS increased, so did the use of these coping styles. Internal control or cure was positively correlated with active coping, planning, positive reinterpretation and growth and was negatively correlated with behavioural disengagement. This suggests that as a sense of internal control increased so did the use of active coping, planning, positive reinterpretation and growth coping strategies, and the use of behavioural disengagement decreased. A strong belief in the illness lasting a long time was positively associated with coping by suppressing competing activities and behavioural disengagement. Holding emotional attributions about the cause of the illness was also positively related to behavioural disengagement.

Moss-Morris et al. (1996) found that dysfunction was significantly negatively Related to emotional support and positively related to behavioural and mental disengagement. Psychological adjustment was significantly negatively related to venting emotions and behavioural disengagement. Psychological adjustment was positively related to positive reinterpretation and emotional support. Vitality was significantly negatively related to behavioural and mental disengagement. Moss-Morris et al. (1996) concluded that "...beliefs about CFS impact on coping strategies or that coping responses influence how patients view their condition. Thus, patients who believed they have some control over CFS reported significantly more positive coping responses, ...and significantly less behavioural engagement." (p 21)

In a New Zealand-based study, Blakely et al. (1991) examined coping differences between participants with CFS, a chronic pain group and a healthy control group. The

CFS sample showed significantly more use of an escape or avoidance type of coping than either of the control groups. Males with CFS had significantly higher levels of accepting responsibility than males in the chronic pain group and significantly higher levels of distancing than both the male chronic pain and healthy control participants. Blakely et al. (1991) conducted a discriminant function analysis between the CFS and chronic pain samples. Neither group could be successfully distinguished from each other, which led to Blakely et al. (1991) to conclude that CFS could be a form of chronic pain.

In a study comparing coping styles between twins, where one twin was diagnosed with CFS, Afari et al. (2000) found no significant differences between twins with and twins without CFS. There were non-significant differences reported, twins with CFS used more avoidant coping, but both groups of twins used predominantly problem-solving skills. However, these results did not reach statistical significance, possibly due to a small sample size. Another interpretation of these results is that there are no statistically significant differences between twins with regards to coping styles and CFS. This would indicate that coping styles do not play a role in the development or maintenance of CFS.

Ax (1999) investigated coping differences in CFS participants with and without caregivers and found no significant differences between either group in coping styles. A further study (Ax, Gregg & Jones 2001) found that accommodation to illness was significantly correlated with impairment, which indicates that the more a person accommodates to CFS the more impairment they would experience. Ax et al. (2001) also found that there were no gender differences in coping amongst CFS sufferers.

Heijmans (1998) found that a cognitive avoidant coping style was negatively correlated with social functioning, mental health and vitality. Problem focussed and seeking social support behaviour was positively correlated with mental health. However no coping strategy was found to correlate with physical functioning. Heijmans (1998) also found that participant characteristics and illness representations were not good

predictors of adaptive outcome. A strong illness identity and a belief in the chronicity of the illness and a psychological basis for the illness were found to explain most of the variability of mental health problems in CFS. Heijmans (1998) reported that a cognitive avoidant coping strategy strongly correlated with a belief in the chronicity of CFS and a belief that CFS is largely uncontrollable. These findings led to the suggestion that interventions with CFS should be aimed at fostering a sense of control over the illness and challenging negative expectations and beliefs about the course of CFS.

Ray et al. (1997) found that accommodating to CFS, focussing on symptoms, information seeking and disengagement coping strategies were significantly related to increased fatigue and impairment levels. However, when multiple regression was performed, illness accommodation was not found to be significantly related to fatigue and impairment at the follow-up stage when functioning at the initial stage was taken into account. Maintaining activity as a coping strategy was found to be associated with lower levels of impairment. Focussing on symptoms and disengagement coping strategies were associated with less change in symptoms during the year-long course of the study. These findings indicate that focussing on symptoms, information seeking and disengagement coping strategies have a negative impact on the health of a person with CFS and perhaps treatment should discourage these types of coping. On the other hand maintaining activity as a coping strategy is associated with lower levels of impairment and therefore, may be beneficial to the health of a person with CFS and should be encouraged. Ray et al. (1997) concluded that there may be other factors that influence illness accommodation as a coping strategy and could explain the differing results with illness accommodation:

> With an internal locus of control...accommodation is more likely to have a strategic and goal-directed function: here, it is suggested, activity is moderated to take up the task of recovery, and this could lead to a more balanced and consistent approach. If the effects of accommodation on the course of CFS are conditional upon perceived control, this has relevance for the debate about relative benefits of

accommodating to illness versus increasing activity levels. (Ray et al. 1997, p 414)

1.14 Health locus of control

Health locus of control is a dimension of control that describes a person's control orientation, or place of control, towards their health. Health locus of control is made up of four dimensions, internal, which is defined as a belief that outcomes are contingent on one's own actions or efforts (Wallston, 1992). The other dimension of health locus of control is external, which consists of chance, doctors and others, and is contingent on environmental factors (Shapiro, Blinder, Hagman & Pituck, 1993). A person who holds a chance health locus of control believes that the outcome of their health is due to chance or fate. A person who holds either a doctor or others health locus of control believes that either doctors of other people determine the outcomes of their health. Locus of control is conceptualised as a generalised expectancy that is used from one situation to the next and is trait-like rather than state-like. However Wallston (1992) defines a health locus of control as a disposition to behave in a certain way in a situation and can therefore, change with experiences and situations.

Shapiro et al. (1993) and Wallston (1992) assert that locus of control is only one aspect of control. Wallston (1992) goes on to say that "Only if the person truly values health would the person's IHLC beliefs predict whether or not the person would engage in those actions which supposedly promote, enhance, or maintain health." (p187). Wallston, Wallston, Smith and Dobbins (1987) noted that is it important to be aware that there is a difference between control, which is the ability to do something, and responsibility, which is the belief that something should be done.

Research into the health locus of control construct has revealed that those people with an internal health locus of control use more information seeking behaviour, have higher levels of adherence to treatment and make and keep more appointments with health professionals (Wallston & Wallston, 1978). Stein, Smith and Wallston (1984) found that "...individuals who value being healthy *and* who believe that it is their own behavior that controls their health (*i.e.*, HLC internals), have the greatest potential for behaving in a health-enhancing manner." (p112). This supports Wallston and Wallston's (1978) assertion that internal beliefs should be trained so that people recognise the need to use health professionals as a resource, as well as believing that their own actions can obtain and maintain their health. Shapiro, Schwartz and Astin (1996) found that those people who believe that they can do something about their illness or consequential stresses have more positive psychological adaptation to their illness.

1.15 Health locus of control and CFS

Knussen and Lee (1998) found that those participants with CFS who felt their illness was more stressful and that they lacked control over its course were more likely to experience severe symptoms than those participants that felt more in control of their illness and its stresses. They also found that those participants who reported experiencing more emotional distress over their illness were less optimistic and less likely to accommodate to CFS by reducing activity than those participants that reported less emotional distress.

There have been a few studies that have investigated the area of locus of control and CFS, however it is an area that warrants further investigation given the outcomes of these studies. Ray et al. (1995) conducted one of the first studies in this area,

investigating whether any relationships existed between locus of control, illness attributions and coping styles. The results indicated that locus of control was not significantly related to illness attributions in participants with CFS. A weak, but not significant correlation was detected between internal locus of control and accommodating to illness, suggesting that as internal control increased, so did accommodating to CFS. The results of this study suggest that locus of control does not play a central role in the precipitation and maintenance of CFS. A study by Cope et al. (1996) supported the conclusion that locus of control is not implicated in CFS as no significant differences in locus of control were found between participants with CFS and a healthy sample.

However, research in the last few years has disagreed about the role that control plays within CFS, concluding that control may in fact be central to recovery from CFS. Clements et al. (1997) found that in a study on control and CFS most participants felt that they could control their symptoms in the short-term, thereby stopping themselves from feeling as sick. However, participants felt that there was little they could do to control their symptoms in the over time. The most frequently employed strategy was a reduction in activity, followed by a resting or pacing of activities with the avoidance of certain activities. It should be noted that all these strategies all have an internal focus, as they are strategies that an individual can put in place.

Heijmans and De Ridder (1998) found that an internal locus of control was positively related to feelings of control over CFS, whereas external locus of control and confidence in doctors was associated with reduced feelings of control over CFS. However, they did not ascertain whether locus of control had any impact on functioning. Prins et al. (2001) found that a low sense of control in participants with CFS led to an increase in fatigue and functional impairment. While this study did relate control to functioning, thus potentially determining whether one aspect of control is more helpful than another in promoting improvement, the locus of control was not differentiated.

Prins and Bleijenberg (1999) suggested that the treatment of CFS should not focus on causal attributions, but rather on how a person with CFS can recover. They proposed that such an approach to treatment could lead to an increase in a patient's internal locus of control, which may mean that a patient could feel more in control of their recovery. This could also include learning to effectively cope with CFS.

Ray et al. (1997) completed the most conclusive study to date. The research was a follow-up design spanning one year. Minimal intervention was offered to participants as part of the investigation in the form of recommending moderate exercise, rest and relaxation, and those participants who were depressed were prescribed a low-dose of antidepressants. A significant reduction in fatigue was reported at the follow–up stage by participants, as was a reduction in impairment (Ray et al. 1997). Education level and internal locus of control were both found to negatively correlate with fatigue levels (Ray et al. 1997). This means that the higher the education level or the higher the internal locus of control score for a participant at time one then the lower the fatigue score is likely to be at time two. Thus, a high internal locus of control, or a high level of education is likely to predict improvement in fatigue levels. Multiple regression analysis was performed and showed that an internal locus of control was a significant factor in predicting an improvement in impairment at time two in participants with CFS (Ray et al. 1997).

Further study in this area is required to validate the findings that implicate locus of control in improvements of functioning and fatigue. Previous studies have used an older form of the MHLC. The revised format of the MHLC differentiates between the doctors and other people that may impact on a person's control of an illness. It is possible that the splitting of these two scales makes the MHLC more sensitive, particularly to issues that arise in CFS samples. The revised format also includes a chance scale, instead of external control, which has now been split into chance, doctors and others scales.

The present study investigates the role of control in CFS. My hypothesis is that a person's beliefs about their illness can impact on the course or outcome of CFS. That is, a person's locus of control about CFS will be related to their illness progression. If a person has a high sense of internal control concerning CFS, then they are more likely to improve over time, as opposed to those that have a low sense of internal control over their illness. Those participants who have a low sense of internal control over their illness are predicted to make less improvements in functioning in the same time period. Those who attribute more locus of control to doctors, chance or others are also less likely to improvement over time, than those who have high internal locus of control. Individuals' sense of control concerning CFS will be measured using two questionnaires, the Multidimensional Health Locus of Control (Wallston, 1993a,b) and the Shapiro Control Inventory (Shapiro, 1994). These identify and determine individuals' control surrounding CFS. The Functional Limitations Profile (Patrick & Peach, 1995) will be used to determine levels of functioning and fatigue. Participants will be tested at two different times, six months apart, in order to gauge any changes in functioning and fatigue that may have occurred over time.

2 Method

2.1 Participants

Each participant included in this study identified him or herself as experiencing the effects of CFS. Seventy-four people (62 females and 12 males) participated in the first stage of the study and 67 participants (57 females and 10 males) went on to complete the second stage. The remaining seven people from the first stage did not respond when the questionnaires were sent out at the second stage of the study.

The average age of the participants was forty-seven years, (range 21-72 years). Twenty-three participants were employed at the first stage of the study and 25 participants were employed at the second stage. Fifty-one participants were unemployed at the first stage of the study, while 42 participants were unemployed at the second stage.

The modal education level represented by participants was tertiary. One participant failed to complete secondary school to a recognised formal qualification level, 25 participants completed their education to a secondary school certification level, 23 participants completed some form of undergraduate tertiary education, and 18 completed a postgraduate qualification. No information was collected about individuals' socio-economic status.

Participants received a reward for their involvement in the study. Those participants who were New Zealanders were given a $5 Instant Kiwi scratch ticket. Participants from other countries were given a University of Canterbury pen.

2.2 Materials

2.2.1 Personal Circumstances Questionnaire (refer to appendix one). This questionnaire developed for the study was sent to participants at stage one. The answers gathered

provided essential information about each participant and their suitability for inclusion in the study. These included questions concerning the onset of CFS, when a CFS diagnosis was made, and who provided or supported such a diagnosis when participants were self-diagnosed. A screening question asked whether or not a participant had been diagnosed with Glandular Fever in order to exclude participants thus diagnosed. However no one was currently under a diagnosis of Glandular Fever. Participants were also asked to provide contact details for use in the follow-up stage of the study.

2.2.2 Demographic Questionnaire (refer to appendix two). The Demographic Questionnaire was sent to participants at the second stage of the study, and gathered information about each participant's gender, age and educational history. In addition participants were questioned about their CFS illness experience. Participants were asked to identify which causes they attributed to their CFS. A list of seven options was provided for participants to choose from. Participants were not restricted in the number of causes they could select from the list. The options ranged from physical causes, such as viral illnesses, to chemical sensitivities and allergies; medical causes, such as complications after surgery; trauma, such as car accidents or the sudden loss of a loved one; high stress levels; and psychological factors, such as personality and mental health predispositions. The seventh option was "other". This allowed participants to indicate that they did not fit into the any of the previous six categories. Participants were asked to elaborate further on each cause they chose, for example, giving the name of the viral illness that they credited with the cause of their CFS.

Participants were then asked to identify whether they believed their illness to be of a sudden onset, defined as one month or less; or of a gradual onset, which was defined as more than one month. The next set of questions covered the type and number of symptoms a participant had experienced in the previous nine months. Participants were provided with a list of twenty symptoms to choose from. A wide range of symptom

options was listed as follows. Flu-like symptoms covered such complaints as, sore throat, tender neck/lymph nodes, swollen glands, coughing, runny nose and streaming or weeping eyes, unusual headaches and muscle or joint pain. Cognitive problems included symptoms such as concentration difficulties and impaired memory. Psychological symptoms listed included depressed mood, negative thought patterns, lack of motivation and difficulty focussing on tasks, mood swings or heightened emotionality, obsessional thoughts and anhedonia, (the inability to experience pleasure from previously pleasurable activities). Symptoms often thought to distinguish CFS from other illnesses, such as depression, were also included, e.g., unrefreshing sleep, post-exertional malaise and persistent unexplained fatigue that had resulted in a reduction of activity. Other symptoms listed were an increased or a lack of appetite and a newly developed intolerance to certain foods.

2.2.3 Functional Limitations Profile (FLP) (Patrick & Peach, 1995). (Refer to appendix three for the altered version). The Functional Limitations Profile (FLP) was designed to assess the level of impairment a person suffers due to a particular illness. Participants were asked to think back to the previous month when answering each question and only agree with the statement if it was related to their CFS illness.

The original scale consisted of 136 items divided between twelve subscales. However, in this study the FLP was shortened, in part because some of the questions did not appear to be relevant to the majority of CFS sufferers. Also, the author believed that the participants would be unable to cope with the number of questions contained in the original FLP. Therefore, a revised version of the FLP was used, with eleven subscales rather than twelve, and 98 questions rather than 136.

Questions that were deemed irrelevant to CFS were deleted from each category as necessary.[i] The eating subscale was deleted entirely. The original FLP contained many

questions that assessed a person's ability to perform tasks. These tasks would most likely be compromised if the person was suffering from a disease like Arthritis, (for example 'I move my hands or fingers with some difficulty or limitation'). As people with CFS do not usually have problems similar to people suffering with Arthritis these questions were removed. The eating subscale of the FLP was not included in this study as regulating food intake is more frequently used as a treatment in CFS, rather than being a symptom of the illness.

Nine of the eleven subscales were grouped together into two distinct categories: One, physical dimension, which included the ambulation, body care and movement, mobility and household management subscales; Two, psychosocial dimension, which included the recreation and pastimes, social interaction, emotion, alertness and sleep and rest subscales. Scales that were not incorporated into these two categories were the communication and work subscales, which remained independent.

Each question was assigned a certain weight. The higher the weighting value, the more severe the disability indicated by the statement. With each statement assigned a weighting it was possible to derive a percentage of disability or impairment suffered by each participant for each subscale. The subscales were then added together into the two dimensions, physical and psychosocial functioning, to allow a percentage of impairment for the two dimensions to be attributed to each participant. Then all eleven scales were added together to provide an overall FLP score, which indicated a total level of impairment for each participant. Once again, this figure was expressed in a percentage form.

The physical dimension included four subscales. The first subscale, ambulation questioned participants' ability to remain self-mobile, that is, their ability to walk and move around in their environment. Body care and movement, the second subscale,

focussed on participants' ability to keep their balance, dress themselves, their ability to stand, (with or without someone's help) and whether they were clumsy.

The third subscale, mobility, assessed whether a person was able to move about within their house and community, for example whether or not they were able to leave the house, or whether they were confined to their bed. The fourth subscale, household management, ascertained whether or not a participant was able to perform their usual daily chores, for example paying the bills, doing the housework, or maintaining the house and garden.

The psychosocial dimension included five subscales. The recreation and pastime subscale asked participants to identify how frequently they engaged in their recreational hobbies. This scale also questioned whether participants had increased or decreased their levels of inactive versus active pastimes over the last month. The social interaction subscale required participants to identify their level of social interaction, and whether CFS had impaired their level and quality of social interaction, e.g., participants were asked whether they continued to visit friends or have visitors. Participants were also asked whether they became irritable and disagreeable with other people more easily, showed less affection to their family, took less of an interest in those around them and did not attend to the needs of their family as well as they had prior to the onset of CFS.

The emotion subscale determined whether CFS was affecting participants' mood and emotions. For example, questions asked participants if they had attempted suicide because of their illness, whether they talked about being a burden to those around them, whether they laughed or cried suddenly or whether they were more impatient or irritable. The Fourth subscale, alertness, identified the impact that CFS had on participants' cognitive abilities. The statements determined whether or not participants' concentration levels, ability to learn new information and memory had been affected and whether they were easily disorientated, confused or had more minor accidents. The last subscale, sleep

and rest, focussed on the sleep and rest patterns of participants, in particular whether sleep and rest periods had increased as a results of CFS.

Communication, the first scale that was treated independently from the physical and psychosocial dimensions, assessed how CFS impacted on participants' ability to communicate clearly with others. This included written communication, whether typed or hand written, and spoken communication. Participants were asked to identify whether they had trouble speaking clearly, or remembering the correct words, or whether they had trouble following a conversation.

Participants' ability to work was assessed in the work Section, the second of the independent subscales. If a participant was unemployed they were asked to indicate whether they were retired, or not working because of their illness. Those participants that were employed were asked to indicate whether they worked full-time or part-time, required help with certain tasks, or could not perform in specific areas of their work any longer because of CFS.

The internal consistency of the FLP has been shown in previous research, where high scores have been obtained when the FLP has been used with ill samples. Correlations have been reported between 0.60 for the communication scale and 0.83 for the body care and movement scale (Charlton, Patrick and Peach, 1983, cited in Johnson, Wright and Weinman, 1995). Test-retest reliability has been demonstrated with the FLP, and an average change of 5.3% within forty-eight hours on the overall score was recorded. In the same study, a 1.5% change was recorded on the physical dimension and a 15.3% change was recorded on the psychosocial dimension (Johnson et al. 1995). They report that the FLP has validity. Whilst these studies have found that individual scales are unable to predict disabilities, the ambulation and household management scales can identify correctly 89% and 84% of those measured with physical disabilities.

2.2.4 Multidimensional Health Locus of Control (MHLC) Wallston, K. (1993a,b). The Multidimensional Health Locus of Control (MHLC) scale is an eighteen statement, six point Likert scale that examines control aspects towards a nominated illness, in this case, CFS. The eighteen statements were divided into four scales, internal health locus of control, (six items), which measures the amount of control over CFS that a sufferer attributes to their own actions; chance health locus of control, (six items), which measures the amount of control over CFS that a sufferer attributes to fate; doctors health locus of control, (three items), which measures that amount of control over CFS a sufferer attributes to doctors and others health locus of control, (three items), which measures the amount of control that a sufferer attributes to significant people in their life.

Each scale was summed to obtain a scale score. These scales were treated independently so that a high score on the internal locus of control scale does not necessarily indicate a lower score on the chance locus of control scale, doctors locus of control scale or others locus of control scale. A high score on a scale indicates a participant attributes a high level of locus of control to that particular factor. In reverse, a low score on a scale indicates a participant attributes a low level of locus of control to that factor. Therefore, a high score on the internal locus of control scale is said to mean that a participant has a high internal locus of control.

Wallston, Stein and Smith (1994) report that the MHLC has validity. They suggest that a high test-retest reliability score would not be expected on the MHLC over an extended period of time as health beliefs would be expected to change, especially if a person's health status was to change. However, they reported stability coefficients between 0.35 for the others scale and 0.63 for the internal scale in a pre-and-post treatment study. Internal consistency values were internal; 0.87, chance, 0.82, doctors, 0.71, others, 0.71.

2.2.5 Shapiro Control Inventory (SCI) Shapiro, D., (1994). The Shapiro Control Inventory (SCI), is a 187 item questionnaire presented to the participant in four subscales, that measure everyday aspects of control. It differs from the MHLC in that it does not measure a person's control beliefs about a specific illness. Rather the SCI focuses on all aspects of a person's control profile. The scales range from a four, six or seven point Likert scale to an, A, B or C scale. Upon scoring the SCI the scales are broken down into fourteen separate scales, some including additional subscales.

The SCI measures an overall sense of control, which is made up of the positive sense of control and the negative sense of control scales. These scales measure the extent to which a person feels positively or negatively in control of their life and how much overall control they feel they have. The SCI also measures specific areas where people may feel they have or lack control. These include a person's body and mind; their inter-personal relationships; themselves; their career; the environment; and other, which measures a person's control with alcohol, drugs, gambling, smoking and violent behaviour. These specific areas are also summed to produce an overall domain specific sense of control scale. The SCI also measures a person's desire for control in their life; whether a person believes that they are a source of control; or whether other people are a source of control. The SCI measures a person's type of control, that is, the degree to which they have a positive or a negative assertive focus of control or the degree to which they have a positive or a negative yielding focus of control. The SCI then measures how satisfied a person is with their control, whether they would like to be more in control, less in control or remain the same.

The SCI manual provides standardised figures for a number of samples, both clinical and non-clinical. Each of the 14 SCI subscales were provided with standardised scores. The psychiatric clinical samples included eating disorders, Anorexia Nervosa and Bulimia Nervosa; Generalised Anxiety Disorder; Panic Attacks; Depression and

Borderline Personality Disorder. The at-risk group provided were adult children of alcoholics. The medical group included: Type A personality with 1 myocardial infarction treated with counselling, Type A personality with 1 myocardial infarction treated with (CBT) and breast cancer. The non-clinical unscreened samples provided were, senior citizens, meditators (very long term, long term and beginning), college students, middle managers and mental health workers and other professionals. A healthy control sample was also provided, consisting of non-psychiatric adults.

Studies reported by Shapiro (1994), show that the SCI has validity, in that it is able to distinguish between normal control groups and a number of clinical samples. Test-retest reliability alpha levels were recorded between 0.67 for the positive yielding scale to 0.93 for the overall domain specific scale. Internal consistency figures range from 0.70 for the negative sense of control and negative yielding scale to 0.89 for the overall sense of control and positive sense of control scale (Shapiro, 1994).

2.3 Procedure

Participants were recruited for the study in three ways. The first group were recruited by advertising through the Christchurch branch of the Chronic Fatigue Syndrome Support Group, which is a supportive and informative group for people suffering from CFS. Participants were then sought through the ANZMES magazine, which is a nation-wide magazine for people with CFS. A third attempt at recruiting was made through an appeal on the Internet. An email was sent to American Chronic Fatigue Support groups, where the appeal was sent to members of the groups, which resulted in twenty overseas participants being obtained.

Participants were selected to be part of the study if they identified themselves as having CFS. Participants were also required to indicate whether a health professional

supported their diagnosis of CFS. All participants included in the study were supported by a health professional in the diagnosis of CFS. Respondents who identified themselves as having Fibromyalgia (FM), were excluded from the study. Those few participants that identified themselves as experiencing a mental illness remained in the study, as the data collected from these particular participants did not appear substantially different from the rest of the sample.

Once participants had agreed to be involved in the study the questionnaires were sent out by mail. Questionnaires sent out at the initial stage included the Personal Circumstances Questionnaire, the FLP, the MHLC and the SCI. The Personal Circumstances Questionnaire, FLP and the MHLC specified that answers were to be given considering the participants' experience with CFS. Participants in the study were asked to evaluate each statement and to indicate how they felt about each statement in relation to their illness beliefs concerning CFS. Participants were requested to complete the questionnaires in four weeks. Participants from overseas followed a slightly different procedure. Potential participants emailed the researcher registering their interest in the study. They were then sent via email the Personal Circumstances Questionnaire, to complete. After completing the first step the participants were emailed the FLP, the MHLC, and the SCI. The overseas participants were given four weeks to complete the questions and either emailing or posting back their answers to the researcher.

After a period of six months the procedure was repeated. Participants from New Zealand and overseas were either mailed or emailed the Demographic Questions, the FLP, the MHLC and the SCI. Again, participants were given four weeks to complete the questionnaires before returning their responses, by post or email.

Correlations and *t* tests were used to ascertain the existence of significant relationships between the demographic variables and the MHLC and FLP scales. *t* tests were also used to establish whether there were any significant differences in functioning

on the FLP subscales between Time One and Time Two. Multiple regression analysis was then used to test for possible relationships between the MHLC subscales and the FLP change scores while controlling for the level of functionality at Time One. Standardised scores were used to ascertain significant differences or similarities on the SCI between the CFS sample and clinical samples. Significance levels were set to $p < 0.05$ unless otherwise stated.

[1] In the ambulation subscale the questions that were not included were questions two through to five and question 11. In the body care and movement subscale questions 13, 14, 17, 19, 20, 22, 24-31 and question 33 were deleted. Questions 36, 42 and 45 were excluded in the mobility subscale. Question 53 was removed from the household management subscale. No items were deleted from the recreation and pastimes or the social interaction subscales. Questions 89 and 92 were deleted from the emotion subscale. No questions were excluded from either the alertness or the sleep and rest subscales. In the communication subscale questions 120, 121 and 123 were removed. No items were removed from the work subscale.

3 Results

3.1 Demographic Data.

In order to establish the characteristics of the sample demographic information was recorded, including gender, age and the highest educational level achieved. Data specific to people suffering from CFS was also collected. This included the number and type of symptoms a participant experienced, whether the CFS was of a sudden onset (less than one month), or of a gradual onset (more than one month), how old the participant was at the onset of CFS and the causes to which the participant attributed their CFS. Table 1 shows the mean, standard deviation, minimum and maximum of scores for these variables. The total number of participants and the number of males and females in the sample have been reported in the method section (see appendix 4 for raw data).

3.2 t tests between the demographic data, the FLP and the MHLC.

Data from participants were split into two groups, males and females. This was done so as to investigate whether there were any differences in functioning between the genders. Results indicated that in some areas female participants experienced more functional impairment than males. Overall, on the FLP scales females reported significantly more impairment [$t = -2.32$, $df = 65$, $p < 0.02$]. Female participants also reported more impairment than male participants in areas of body care and movement [$t = -2.91$, $df = 65$, $p < 0.004$], physical dimension [$t = -2.73$, $df = 65$, $p < 0.008$] and sleep and rest [$t = -2.64$, $df = 65$, $p < 0.01$]. No significant differences were found for the remaining FLP scales (see Table 2). Table 3 shows the mean, standard deviation,

Table 1

Means, Standard Deviations, Maximums and Minimums for Demographic, Multidimensional Health Locus of Control and Functional Limitations Profile Data

Collected at Time One.

	Mean	SD	Minimum	Maximum
Age [a]	47.64	10.8	21	72
Education [b]	2.87	0.83	1	4
Number of symptoms	11.4	3.87	3	20
Number of causes	2.46	1.34	1	7
Length of illness [a]	13.71	11.14	1	51
Age at onset of illness [a]	33.66	12.68	6	61
Internal [c]	19.03	5.86	6	31
Chance [c]	18.31	6.51	6	34
Doctors [c]	7.82	3.5	3	18
Others [c]	7.5	3.2	3	15
Overall score [d]	33.45	13.23	4.26	71.46
Ambulation [d]	21.95	12.79	0	50.54
Body care & movement [d]	24.38	19.01	0	71.77
Mobility [d]	26.78	22.59	0	100
Household management [d]	37.16	22.11	0	88.82
Physical dimension [d]	27.74	14.57	2.15	61.86
Recreation & pastimes [d]	42.15	23.04	0	100
Social interaction [d]	27.35	17.34	0	72.61
Emotion [d]	20.16	23.75	0	100
Alertness [d]	61.11	29.89	0	100
Sleep & rest [d]	29.24	18.63	0	85.79
Psychosocial dimension [d]	35.66	16.19	2.36	82.09
Communication [d]	28.34	23.22	0	87.63
Work [d]	42.97	10.25	5.65	48.59

Notes: [a] Years

[b] Highest level achieved; Primary = 1, Secondary = 2, Tertiary = 3, Postgraduate = 4

[c] MHLC scale

[d] FLP scale

Table 2

Differences Between Male and Female Participant Scores on the Functional Limitations Profile at Time One.

	Mean male	Mean female	*t*-statistic	*df*	*p*
Overall	25.39	35.34	-2.32	65	0.02*
Ambulation	16.64	23.21	-1.56	65	0.12
Body care & movement	9.7	24.57	-2.91	65	0.00*
Mobility	15.89	28.8	-1.64	65	0.1
Household management	26.29	38.93	-1.76	65	0.08
Physical dimension	17.18	29.82	-2.73	65	0.00*
Recreation & pastimes	45.56	42.03	0.46	65	0.65
Social interaction	18.63	29.06	-1.78	65	0.08
Emotion	13.06	22.73	-1.16	65	0.25
Alertness	55.71	64.2	-0.85	65	0.4
Sleep & rest	15.57	31.96	-2.64	65	0.01*
Psychosocial dimension	28.31	37.7	-1.74	65	0.09
Communication	21	30.19	-1.19	65	0.24
Work	38.97	43.64	-1.39	65	0.17

Notes: * significant as indicated

Table 3
Means, Standard Deviations, Minimums and Maximums for Functional Limitations Profile
scales that Differed Significantly by Gender

	Mean	SD	Minimum	Maximum
Overall Male	9.7	10.01	0	25.81
Overall Female	27.57	18.86	0	71.77
Body care & movement Male	17.18	12.91	2.15	41.46
Body care & movement Female	29.82	13.63	2.54	61.86
Physical dimension Male	15.57	15.5	0	50.76
Physical dimension Female	31.96	18.53	0	85.79
Sleep & rest Male	25.39	13.59	4.99	48.82
Sleep & rest Female	35.34	12.33	4.26	71.46

minimum and maximum for the variables on which males and females significantly differed.

Participants' data were then split into two further groups, being by illness onset, i.e., whether participants indicated that their illness had a sudden or gradual onset. This allowed an investigation into whether illness onset was related to demographic variables, health locus of control or impairment. No significant differences were detected amongst the demographic variables between the sudden and gradual onset groups (see Table 4). One significant difference was found within health locus of control orientation and illness onset. Significantly more participants in the sudden onset group evidenced a greater chance health locus of control, than those participants with a gradual illness onset [$t = 2.64$, $df = 65$, $p < 0.01$].

A few significant differences were also found among functioning and illness onset. Those participants with a sudden illness onset reported significantly more impairment with mobility [$t = 2.32$, $df = 65$, $p < 0.02$]. Those participants with sudden illness onset also reported significantly more impairment on the physical dimension and the sleep and rest scale [$t = 2.39$, $df = 65$, $p < 0.01$]; [$t = 2.02$, $df = 65$, $p < 0.04$] respectively.

3.3 Correlations between the demographic data, the FLP and the MHLC

A further demographic variable investigated was the number of symptoms a participant reported. The number of symptoms reported correlated positively and significantly with all the FLP scales. As the number of reported symptoms increased the level of impairment in functioning across all scales increased (see Table 5). The strongest correlations occurred with the overall score ($r = .61$), ambulation ($r = .52$), and the

Table 4
Differences between Sudden and Gradual Onsets of CFS across Demographic, Multidimensional Health Locus of Control and Functional Limitations Profile Variables at Time One

	Sudden onset mean	Gradual onset mean
Gender	0.91	0.82
Age [a]	47.7	47.61
Education [b]	2.87	2.86
Number of symptoms	11	11.61
Number of causes	2.39	2.5
Length of illness [a]	12.74	14.24
Age at illness onset [a]	34.39	33.26
Internal [c]	18.22	19.09
Chance [c]	21.35	17.05
Doctors [c]	6.96	8.59
Others [c]	8	7.43
Overall [d]	36.27	32.59
Ambulation [d]	25.02	20.78
Body care & movement [d]	29.44	22.53
Mobility [d]	35.7	22.25
Household management [d]	43.2	33.83
Physical dimension [d]	33.46	25.05
Recreation & pastimes [d]	42.56	42.56
Social interaction [d]	28.27	27.11
Emotion [d]	19.59	22.17
Alertness [d]	63.75	62.51
Sleep & rest [d]	35.83	26.22
Psychosocial dimension [d]	37.49	35.67
Communication [d]	26.33	30.11
Work [d]	44.14	42.32

Notes: [a] Years
[b] Highest level achieved; Primary = 1, Secondary = 2, Tertiary = 3, Postgraduate = 4
[c] Multidimensional Health Locus of Control scale
[d] Functional Limitations Profile scale

Table 4 continued

	t-statistic	*df*	*p*
Gender	1.03	65	0.31
Age [a]	0.03	65	0.98
Education [b]	0.03	65	0.98
Number of symptoms	-0.613	65	0.54
Number of causes	-0.31	65	0.76
Length of illness [a]	-0.52	63	0.61
Age at illness onset [a]	0.34	63	0.73
Internal [c]	-0.57	65	0.57
Chance [c]	2.64	65	0.01*
Doctors [c]	-1.81	65	0.07
Others [c]	0.67	65	0.5
Overall [d]	1.11	65	0.27
Ambulation [d]	1.34	65	0.19
Body care & movement [d]	1.43	65	0.16
Mobility [d]	2.32	65	0.02*
Household management [d]	1.74	65	0.09
Physical dimension [d]	2.39	65	0.01*
Recreation & pastimes [d]	-0.00	65	1
Social interaction [d]	0.26	65	0.8
Emotion [d]	-0.41	65	0.68
Alertness [d]	0.16	65	0.87
Sleep & rest [d]	2.02	65	0.04*
Psychosocial dimension [d]	0.44	65	0.66
Communication [d]	-0.65	65	0.52
Work [d]	0.71	65	0.48

Notes: [a] Years
[b] Highest level achieved; Primary = 1, Secondary = 2, Tertiary = 3,
Postgraduate = 4
[c] Multidimensional Health Locus of Control scale
[d] Functional Limitations Profile scale
* Significant at level indicated

Table 5
Correlations Between the Functional Limitations Profile at Time One
and the Number of Symptoms Reported by Participants

	Number of Symptoms
Overall	0.61***
Ambulation	0.52***
Body Care & Movement	0.42**
Mobility	0.29**
Household Management	0.36**
Physical dimension	0.51***
Recreation & Pastimes	0.49***
Social Interaction	0.48***
Emotion	0.39**
Alertness	0.47***
Sleep & Rest	0.26**
Psychosocial dimension	0.59***
Communication	0.33**
Work	0.29**

Notes: ** $p < 0.05$
*** $p < 0.001$

physical dimension (r = .51). The weakest effects were recorded on the sleep and rest scale (r = .26), mobility and work both (r = .29).

The number of causes a participant reported in the development of their illness and a participants' age at the illness onset were investigated to identify any possible relationships that might exist with functioning. The only significant correlations with the number of causes identified by a participant was the FLP household management scale (r = .25) showing that the more causes a participant attributed to their illness, then the more impaired they were likely to be on the household management scale.

The participants' age at the onset of CFS significantly correlated with the following scales: alertness (r = -.39) and communication (r = -.33). Both produced moderate negative correlations. This shows that the younger a person is at the onset of CFS, then the pooper the functioning is likely to be in areas of alertness and communication. The psychosocial dimension and the overall score for the FLP gave weak negative correlations (r = –.29) and (r = –.26) respectively. This indicated that the younger a person was at the onset of CFS, the more impaired they were likely to be in areas of psychosocial dimension and overall functioning. The length of a participant's illness was not found to have significantly correlated with any of the FLP scales (Table 6).

Possible relationships between demographic data and the MHLC data were investigated to ascertain whether there were any significant correlations between the two sets of variables. The highest education level achieved by participants significantly correlated with MHLC doctors subscale (r = –.27), (education was coded as follows: completion of primary = 1, secondary = 2, tertiary = 3, postgraduate = 4). The correlation between MHLC doctors and education level suggests that there is a weak negative relationship between the education level of a participant and the amount of control they

Table 6

Correlations between Demographic Data and Functional Limitations Profile Time One Variables

	Age	Education	Number of causes	Length of illness	Age at illness onset
Overall	-0.11	0.13	0.10	0.18	-0.26*
Ambulation	0.13	0.11	-0.03	0.06	0.05
Body care & movement	-0.09	0.18	0.09	0.12	-0.17
Mobility	-0.02	0.19	-0.12	0.00	-0.01
Household management	-0.03	0.15	0.25*	0.21	-0.23
Physical dimension	-0.03	0.22	0.08	0.13	-0.14
Recreation & pastimes	0.08	0.02	0.18	0.20	-0.12
Social interaction	-0.14	-0.05	0.09	0.08	-0.20
Emotion	-0.07	0.08	0.16	0.09	-0.13
Alertness	-0.23	0.14	0.11	0.22	-0.39*
Sleep & rest	-0.08	0.13	-0.06	-0.09	-0.01
Psychosocial dimension	-0.17	0.08	0.13	0.15	-0.29*
Communication	-0.16	-0.02	-0.07	0.22	-0.33*
Work	0.21	0.01	-0.05	0.12	0.08

Notes: * $p < .05$

assign to their doctor. Specifically, the more highly educated a person is, the less likely they are to assign control of CFS to doctors.

The number of causes a participant attributed to their CFS was significantly correlated with the MHLC others subscale ($r = .29$). This correlation indicates a weak positive relationship between the number of causes a person identifies for their illness and the amount of control they assign to other people in their lives. This means that the more causes a person identifies as being responsible for their CFS then the more likely they are to attribute control of their illness to other people. The following factors did not significantly correlate with any of the MHLC subscales: current age of the participant, the number of symptoms a participant reported, length of the illness and the age of participants at illness onset (see Table 7).

The major findings from the demographic data, the MHLC and the FLP are that females experience more impairment in functioning than males in overall functioning, body care and movement, physical dimension and sleep and rest. A sudden illness onset is associated with greater impairment in areas of mobility, physical dimension and sleep and rest, and is associated with a greater orientation towards a chance health locus of control. As the number of causes identified by a participant increases, then the greater the impairment in household management and the more likely an others health locus of control orientation will be held. The younger the age is at the onset of CFS then the more likely there will be more impairment in functioning in alertness, communication, psychosocial dimension and overall functioning. An increase in the number of reported symptoms is associated with increased impairment across all areas. The higher the level of education a participant received, the less likely it is that they attribute health locus of control towards doctors.

Table 7
Correlations Between the Demographic Data and Multidimensional Health Locus of Control Scores at Time One

	Internal	Chance	Doctors	Others
Age [a]	0.17	-0.13	-0.15	0.07
Education [b]	-0.20	0.04	-0.27*	-0.22
Number of symptoms	0.00	0.01	0.24	0.13
Number of causes	0.22	-0.22	0.10	0.29*
Length of illness [a]	-0.08	0.16	-0.01	0.07
Age at illness onset [a]	0.19	-0.23	-0.13	-0.02

Notes: [a] Years
[b] Highest level achieved; Primary = 1, Secondary = 2, Tertiary = 3, Postgraduate = 4
* $p < 0.05$

3.4 Calculating Time One Data.

The relationship between health locus of control and functioning at Time One was investigated through a correlational analysis of the MHLC and FLP data (see Table 8). Correlations were computed between each MHLC and FLP scales and subscales for the data collected at Time One. A significant negative correlation was found between the MHLC internal subscale and the FLP subscale, alertness. This weak negative correlation (r = -.26) shows that the more internal locus of control a participant had the lower their impairment is likely to be on the FLP alertness scale.

Correlations between a chance health locus of control and the FLP scales show a positive association, which indicates functioning is poorer as orientation towards chance locus of control increases. The overall functioning scale on the FLP produced a weak positive correlation (r = .29) with a chance health locus of control. This suggests that a chance health locus of control is associated with a more impaired level of overall functioning.

Chance health locus of control was correlated (r = .30) with mobility suggesting that the more a participant attributes locus of control of their illness to chance, the more likely they are to be more impaired in areas of mobility. Physical dimension was weakly correlated (r = .27) with chance health locus of control suggesting again that as an orientation towards chance health locus of control increases then impairment on the physical dimension increases as well.

The social interaction subscale was a correlated (r = .27) with chance health locus of control, suggesting that a chance health locus of control is associated with poorer social interaction. Chance health locus of control was also correlated with sleep and rest (r = .31), psychosocial dimension (r = .25) and work (r = .28). These correlations show that a chance health locus of control is more likely to be associated with requiring more

Table 8

Correlations Between the Functional Limitations Profile and the Multidimensional Health Locus of Control Variables at Time One

	Internal [a]	Chance [a]	Doctors [a]	Others [a]
Overall [b]	-0.21	0.29*	0.22	0.23
Ambulation [b]	-0.05	0.13	0.05	0.17
Body care & movement [b]	-0.22	0.16	0.10	0.11
Mobility [b]	-0.14	0.30*	0.10	0.13
Household management [b]	-0.15	0.18	0.10	0.09
Physical dimension [b]	-0.20	0.27*	0.12	0.16
Recreation & pastimes [b]	-0.01	0.07	0.09	0.23
Social Interaction [b]	-0.15	0.27*	0.18	0.32*
Emotion [b]	0.06	-0.04	0.38*	0.31*
Alertness [b]	-0.26*	0.20	0.11	0.00
Sleep & rest [b]	-0.06	0.31*	0.21	0.20
Psychosocial dimension [b]	-0.16	0.25*	0.26*	0.27*
Communication [b]	-0.22	0.22	0.03	0.03
Work [b]	-0.12	0.26*	0.15	-0.01

Notes: [a] Multidimensional Health Locus of Control

[b] Functional Limitations Profile

* $p < 0.05$

sleep and rest, or suffering from unrefreshing sleep, more likely to be associated with more impairment in areas of psychosocial functioning, and poorer functioning in work or an inability to perform work tasks previously undertaken.

The doctor subscale on the MHLC produced several significant positive correlations with various scales on the FLP. The first correlation was a moderate correlation ($r = .38$) between doctors and emotion. This suggests that attributing a health locus of control to a doctor was more likely to result in poorer emotional functioning. The doctors subscale also significantly correlated ($r = .26$) with the psychosocial dimension of the FLP. This indicates that those participants that attribute health locus of control of their illness to doctors are more likely to be more impaired in areas of psychosocial functioning.

The others subscale from the MHLC, which identifies the impact of attributing control to other people on a respondent's health, produced four positive significant correlations with the FLP. The first significant correlation ($r = .32$) was between the subscale others and social interaction. This indicates a weak correlation, which shows that a health locus of control towards others is associated with a poorer level of functioning on the social interaction subscale. The emotion subscale correlated ($r = .31$) with others, which indicates a poorer level of emotional functioning when a health locus of control is attributed to others. The psychosocial dimension correlated ($r = .27$) with the others subscale, suggesting that attributing health locus of control to others is associated with a poorer level of functioning on the psychosocial dimension.

Overall, the correlations between the MHLC and the FLP are able to distinguish relationships between locus of control and functioning. The overall pattern of correlations was negative for an internal health locus of control. Those participants who had an internal locus of control were more likely to function at a better level on the alertness scale. An internal health locus of control was the only orientation of control that was

associated with a better outcome in functioning. That is, those participants who had an internal health locus of control were less likely to be as affected by CFS as those participants who attributed control to chance, doctors or others. Those participants that had a chance, doctors or others health locus of control are more likely to function at a lower level and be more affected by CFS.

3.5 Functional Limitations Profile.

The FLP was administered during both phases of the study, which supplied information on any changes in functioning over the six-month period. *t* tests were performed on the two sets of data in order to ascertain whether there was any significant changes in functioning from Time One to Time Two (Table 9). All the subscales except the physical dimension changed significantly over time, indicating that there were significant changes in the levels of functioning at Time Two compared with Time One. In order to ascertain the direction and amount of improvement, change scores were computed by subtracting Time Two scores from Time One scores. A positive change score indicated an improvement in functioning from Time One to Time Two, while a negative change score indicated a worsening in functioning from Time One to Time Two (refer to appendix 5 for change scores). It should be noted that a high raw score at either Time One or Time Two indicates a severe degree of impairment, whilst a low raw score at either Time One or Time Two indicates a minor degree of impairment in functioning.

Correlations were calculated between the Time One data and the change score data. This enabled us to see if functioning at Time One was related to the amount of change, either an improvement or deterioration in functioning, that occurred by the time data were collected at Time Two. There were a number of significant positive correlations recorded for all the FLP scales. This shows that the more severe the

Table 9
t-tests Between the Functional Limitations Profile scores taken at Time One and Time Two

	t-statistic	*df*	*p*
Overall	-2.66	64	0.01*
Ambulation	14.03	64	0.01*
Body care & movement	10.56	64	0.01*
Mobility	8.96	64	0.01*
Household management	13.96	64	0.01*
Physical dimension	-0.81	64	0.42
Recreation & pastimes	15.37	64	0.01*
Social interaction	12.56	64	0.01*
Emotion	6.85	64	0.01*
Alertness	17.13	64	0.01*
Sleep & rest	12.91	64	0.01*
Psychosocial dimension	5.27	64	0.01*
Communication	10.2	64	0.01*
Work	34.69	64	0.01*

Notes: * significance as indicated

functioning indicated at Time One, the more improvement in functioning was recorded at Time Two. Thus, those participants that reported a severe level of impairment at Time One reported the greatest improvement in functioning at Time Two, while those participants who reported a lesser amount of impairment at Time One exhibited a smaller amount of improvement in functioning by comparison.

The correlations between the FLP data at Time1 and the FLP change scores are all positive, which indicates for all scales that the level of functioning at Time One is positively related to the amount of change recorded between Time One and Time Two. The improvement in functioning that was noted between Time One and Time Two scores may have been due to a regression to the mean, or could have occurred because of the variable nature of CFS.

Strong significant positive correlations were found for the mobility (r = .66) and emotion (r = .66) scales. These findings indicate that the higher the score at Time One for mobility and emotion the greater the associated improvement in functioning at Time Two. Moderate significant correlations were found between the FLP scores at Time One and the FLP change scores for sleep and rest (r = .58), social interaction (r = .56), recreation and pastimes (r = .53), household management (r = .51), communication (r = .49), physical subscale (r = .47), ambulation (r = .45), body care and movement (r = .45), psychosocial subscale (r = .41) and overall functioning (r = .41). Again these findings indicate that the higher the score on the above mentioned scales at Time One the greater the associated improvements in functioning at Time Two.

One weak correlation (r = .33) was found between scores at Time One and the change scores. This was for the alertness scale indicating that the higher the score in alertness at Time One the greater the improvement at Time Two. No significant correlation was found for the work scale, indicating a lack of a clear relationship between scores at Time One on the work scale and improvements at Time Two (see Table 10).

Table 10
Correlations Between the Functional Limitations Profile scores at Time One and Functional Limitations Profile Change Scores

	Overall chsc	Ambulation chsc	Body care & movement chsc	Mobility chsc	Household management chsc	Physical dimension chsc
Overall [1]	0.41*	0.22	0.34*	0.36*	0.24*	0.39*
Ambulation [1]	0.24*	0.45*	0.07	0.18	0.16	0.25*
Body care & movement [1]	0.27*	0.05	0.45*	0.25*	0.17	0.31*
Mobility [1]	0.40*	0.21	0.42*	0.66*	0.19	0.48*
Household management [1]	0.24*	0.08	0.19	0.17	0.51*	0.34*
Physical dimension [1]	0.38*	0.22	0.40*	0.43*	0.36*	0.47*
Recreation & pastimes [1]	0.26*	0.14	0.17	0.24*	0.17	0.24*
Social interaction [1]	0.39*	0.28*	0.19	0.28*	0.14	0.30*
Emotion [1]	0.15	0.10	0.15	0.13	-0.11	0.09
Alertness [1]	0.21	0.10	0.16	0.08	0.15	0.16
Sleep & rest [1]	0.35*	0.08	0.45*	0.48*	0.15	0.39*
Psychosocial dimension [1]	0.38*	0.20	0.28*	0.29*	0.15	0.31*
Communication [1]	0.29*	0.19	0.16	0.09	0.12	0.19
Work [1]	0.10	0.00	0.10	0.14	0.07	0.11

Notes: [1] Indicates scores at Time 1
[chsc] Indicates change scores
* $p < 0.05$

Table 10 continued

	Recreation & pastimes chsc	Social interaction chsc	Emotion chsc	Alertness chsc	Sleep & rest chsc	Psychosocial dimension chsc
Overall [1]	0.22	0.37*	0.40*	0.30*	0.31*	0.43*
Ambulation [1]	0.18	0.21	0.29*	0.24*	0.09	0.27*
Body care & movement [1]	0.22	0.23*	0.20	0.24*	0.15	0.28*
Mobility [1]	0.23*	0.26*	0.29*	0.27*	0.38*	0.37*
Household management [1]	0.19	0.26*	-0.02	0.14	0.10	0.21
Physical dimension [1]	0.27*	0.32*	0.23*	0.29*	0.24*	0.37*
Recreation & pastimes [1]	0.53*	0.25*	0.22	0.14	0.18	0.31*
Social interaction [1]	0.19	0.56*	0.36*	0.17	0.23*	0.41*
Emotion [1]	-0.14	0.08	0.66*	0.00	0.12	0.19
Alertness [1]	0.09	0.12	0.20	0.33*	0.17	0.26*
Sleep & rest [1]	0.06	0.25*	0.27*	0.16	0.58*	0.32*
Psychosocial dimension [1]	0.16	0.36*	0.45*	0.25*	0.33*	0.41*
Communication [1]	0.12	0.26*	0.28*	0.33*	0.17	0.32*
Work [1]	0.05	-0.01	0.06	0.07	0.02	0.06

Notes: [1] Indicates scores at Time 1
[chsc] Indicates change scores
* $p < 0.05$

Table 10 continued

	Communication [chsc]	Work [chsc]
Overall [1]	0.30*	0.00
Ambulation [1]	0.18	-0.09
Body care & movement [1]	0.18	-0.12
Mobility [1]	0.19	0.00
Household management [1]	0.10	-0.04
Physical dimension [1]	0.21	-0.08
Recreation & pastimes [1]	0.07	-0.07
Social interaction [1]	0.30*	0.11
Emotion [1]	0.19	-0.02
Alertness [1]	0.15	-0.07
Sleep & rest [1]	0.20	0.10
Psychosocial dimension [1]	0.27*	0.03
Communication [1]	0.49*	-0.06
Work [1]	0.14	0.15

Notes: [1] Indicates scores at Time 1
[chsc] Indicates change scores
* $p < 0.05$

As the correlations show 13 of the 14 scales at Time One and Time Two are related, this means that the higher the score at Time One the greater the improvement at Time Two.

3.6 Multidimensional Health Locus of Control and the Functional Limitations Profile

Multiple regression analyses were performed on the data from the FLP and the MHLC in order to ascertain whether health locus of control orientation could significantly predict impairment in functioning. The level of impairment at Time One was statistically controlled for as follows; Change Scores were used in conjunction with the Time One scores in an attempt to control for the relationship that existed between Time One and Time Two scores. FLP Change Scores were entered into the regression as the variable to be predicted. This enables the direction of change in impairment to be predicted. The FLP scores at Time One were entered into the model first, and then the MHLC scale scores were entered to see whether they would predict change. The use of the Change Scores along with the FLP Time One scores allowed impairment levels at Time One to be taken into account and therefore not impact on the value of the predictor variables. A number of significant results were found, most notably that the work scale was not significantly predicted by any variable, whilst a doctors health locus of control orientation was associated with less improvement in functioning.

The amount of change in overall functioning was found to be best predicted by overall functioning at Time One [$\beta = 0.47$, $t = 4.42$, $p < 0.01$] (Table 11 and 12) followed by doctors health locus of control orientation [$\beta = -0.28$, $t = -2.65$, $p < 0.01$] (Table 11 and 12). This indicates that overall functioning at Time One best predicted an improvement in overall functioning, whilst a doctors health locus of control orientation predicted less improvement in overall functioning from Time One to Time Two.

Table 11

Multiple Regression Between the Functional Limitations Profile and Multidimensional Health Locus of Control Variables at Time One showing the Beta, t and p values

		Beta	*t*	*p*
Overall [chsc]	Overall [a]	0.47	4.42	0.01*
	Doctors [b]	-0.28	-2.65	0.01*
Ambulation [chsc]	Ambulation [a]	0.47	4.69	0.01*
	Doctors [b]	-0.27	-2.69	0.01*
	Internal [b]	0.23	2.27	0.03*
Body care & movement [chsc]	Body care & movement [a]	0.5	4.69	0.01*
	Doctors [b]	-0.18	-1.7	0.09
	Internal [b]	0.16	1.45	0.15
Mobility [chsc]	Mobility [a]	0.69	7.73	0.01*
	Doctors [b]	-0.16	-1.76	0.08
	Internal [b]	0.12	1.27	0.01
Household management [chsc]	Household management [a]	0.52	5.26	0.01*
	Doctors [b]	-0.22	-2.23	0.03*
Physical dimension [chsc]	Physical dimension [a]	0.52	4.99	0.01*
	Doctors [b]	-0.26	-2.55	0.01*
	Internal [b]	0.14	1.3	0.2
Recreation & pastimes [chsc]	Recreation & pastimes [a]	0.57	5.99	0.01*
	Doctors [b]	-0.23	-2.26	0.03*
	Others [b]	-0.16	-1.49	0.14
Social interaction [chsc]	Social interaction [a]	0.61	6.57	0.01*
	Doctors [b]	-0.32	-3.46	0.01*
Emotion [chsc]	Emotion [a]	0.72	7.51	0.01*
	Doctors [b]	-0.15	-1.61	0.11
Alertness [chsc]	Alertness [a]	0.36	3.26	0.00*
	Doctors [b]	-0.23	-2.07	0.04*
Sleep & rest [chsc]	Sleep & rest [a]	0.67	6.74	0.01*
	Doctors [b]	-0.22	-2.24	0.03*
	Internal [b]	0.15	1.45	0.15
	Chance [b]	-0.12	-1.17	0.25
Psychosocial dimension [chsc]	Psychosocial dimension [a]	0.48	4.49	0.01*
	Doctors [b]	-0.26	-2.47	0.01*
Communication [chsc]	Communication [a]	0.49	4.81	0.01*
Work [chsc]	Others [b]	-0.24	-1.99	0.05
	Work [a]	0.18	1.53	0.13
	Internal [b]	0.17	1.4	0.17

Notes [a] Functional Limitations Profile scale

[b] Multidimensional Health Locus of Control scale

[chsc] Functional Limitations Profile change score

* significant at indicated level

Table 12

Multiple Regression Between the Functional Limitations Profile and Multidimensional Health Locus of Control Variables at Time One

showing the R^2, $R^{increment}$ and F values

		R^2	$R^{increment}$	F
Overall [chsc]	Overall [a]	0.24		
	Doctors [b]	0.17	-0.07	7.01**
Ambulation [chsc]	Ambulation [a]	0.31		
	Doctors [b]	0.23	-0.07	7.21**
	Internal [b]	0.26	-0.05	5.14*
Body care & movement [chsc]	Body care & movement [a]	0.25		
	Doctors [b]	0.22	-0.03	2.93
	Internal [b]	0.25	0.02	2.1
Mobility [chsc]	Mobility [a]	0.46		
	Doctors [b]	0.44	-0.02	3.11
	Internal [b]	0.45	-0.01	1.62
Household management [chsc]	Household management [a]	0.33		
	Doctors [b]	0.26	-0.05	4.96**
Physical dimension [chsc]	Physical dimension [a]	0.29		
	Doctors [b]	0.22	-0.07	6.51*
	Internal [b]	0.29	0.01	1.7
Recreation & pastimes [chsc]	Recreation & pastimes [a]	0.39		
	Doctors [b]	0.35	-0.04	5.11**
	Others [b]	0.37	-0.02	2.22
Social interaction [chsc]	Social interaction [a]	0.41		
	Doctors [b]	0.31	-0.1	11.98***
Emotion [chsc]	Emotion [a]	0.45		
	Doctors [b]	0.43	-0.02	2.6
Alertness [chsc]	Alertness [a]	0.16		
	Doctors [b]	0.11	-0.05	4.27*
Sleep & rest [chsc]	Sleep & rest [a]	0.4		
	Doctors [b]	0.4	0.04	5.02**
	Internal [b]	0.39	-0.01	1.12
	Chance [b]	0.35	-0.05	2.98
Psychosocial dimension [chsc]	Psychosocial dimension [a]	0.24		
	Doctors [b]	0.17	-0.07	6.1**
Communication [chsc]	Communication [a]	0.24		

Notes

[a] Functional Limitations Profile scale

[b] Multidimensional Health Locus of Control scale

[chsc] Functional Limitations Profile change score

* $p < 0.01$

** $p < 0.05$

*** $p < 0.001$

Improvement in ambulation from Time One to Time Two was best predicted by ambulation at Time One [$\beta = 0.47$, $t = 4.69$, $p < 0.01$] (Table 11 and 12). Internal health locus of control predicted an improvement in ambulation from Time One to Time Two [$\beta = 0.23$, $t = 2.27$, $p < 0.03$] (Table 11 and 12). Significantly less improvement in ambulation was best predicted by a doctors health locus of control orientation [$\beta = -0.27$, $t = 2.69$, $p < 0.01$] (Table 11 and 12). This shows that ambulatory functioning at Time One and an internal locus of control are related to improvement in functioning, whilst a doctors health locus of control is related to less improvement in ambulatory functioning.

A positive change in body care and movement functioning was found to be best predicted by body care and movement functioning at Time One [$\beta = 0.5$, $t = 4.69$, $p < 0.01$] (Table 11 and 12). An internal health locus of control was also associated with improvement in functioning on the body care and movement scale, but did not reach significance (Table 11). A doctors health locus of control orientation led to less improvement in functioning in body care and movement, but also did not reach significance (Table 11).

An improvement in mobility from Time One to Time Two was found to be significantly predicted by functioning on the mobility scale at Time One [$\beta = 0.69$, $t = 7.73$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control orientation was found to be associated with less improvement in functioning over time, but did not reach significance (Table 11). An internal health locus of control was found to lead to an improvement in the mobility scale, but also did not reach significance (Table 11).

Functioning in household management was significantly related to two factors, household management at Time One and doctors health locus of control. Household management at Time One predicted an improvement in functioning from Time One to Time Two [$\beta = 0.52$, $t = 5.26$, $p < 0.01$] (Table 11 and 12). Doctors health locus of

control predicted less improvement in functioning over time [$\beta = -0.22$, $t = -2.23$, $p < 0.03$] (Table 11 and 12).

The improvement in physical dimension was positively predicted by the physical dimension at Time One [$\beta = 0.52$, $t = 4.99$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control had a negative impact on the amount of improvement over time [$\beta = -0.26$, $t = -2.55$, $p < 0.01$] (Table 11 and 12). Internal health locus of control had a positive impact on physical functioning over time, but did not reach significance (Table 11).

Functioning in recreation and pastimes was significantly associated with two factors, recreation and pastimes at Time One and doctors health locus of control, while a third factor others health locus of control, did not reach significance. Functioning at Time One on the recreation and pastimes scale predicted a positive change in functioning over time [$\beta = 0.57$, $t = 5.99$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control orientation predicted significantly less change in functioning over time in the recreation and pastimes scale [$\beta = -0.23$, $t = -2.26$, $p < 0.03$] (Table 11 and 12). An others health locus of control orientation had a negative impact on the direction of change on the recreation and pastimes scale, but did not reach significance (Table 11).

A change in social interaction functioning was predicted by two factors, social interaction at Time One and a doctors health locus of control. Social interaction change was positively predicted by social interaction functioning at Time One [$\beta = 0.61$, $t = 6.57$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control predicted a less improvement in functioning on the social interaction scale [$\beta = -0.32$, $t = -3.46$, $p < 0.01$] (Table 11 and 12).

A change in emotional functioning could also be predicted by two factors, emotional functioning at Time One and a doctors health locus of control. Emotional functioning at Time One predicted an improvement in functioning [$\beta = 0.72$, $t = 7.51$, $p < 0.01$] (Table 11 and 12). While a doctors health locus of control orientation predicted less

improvement in emotional functioning over time, but did not reach significance (Table 11).

A change in alertness functioning was significantly predicted by two variables, alertness functioning at Time One and doctors health locus of control. Functioning on the alertness scale at Time One predicted a positive change in functioning over time [$\beta = 0.36$, $t = 3.26$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control orientation predicted less improvement in functioning on the alertness scale [$\beta = -0.23$, $t = -2.07$, $p < 0.04$] (Table 111 and 12).

Change in sleep and rest functioning over time was predicted by several variables, sleep and rest functioning at Time One and doctors, internal and chance health locus of control. Sleep and rest functioning at Time One predicted an improvement in functioning over time [$\beta = 0.67$, $t = 6.74$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control orientation predicted significantly less improvement in functioning in sleep and rest over time [$\beta = -0.22$, $t = -2.24$, $p < 0.03$] (Table 11 and 12). Both an internal and chance health locus of control predicted a change in functioning over time, but both failed to reach significance. An internal health locus of control predicted a positive change in functioning, whilst a chance health locus of control predicted less improvement in functioning.

The psychosocial dimension could be predicted by two variables namely, functioning at Time One on the psychosocial dimension and doctors health locus of control. Functioning on the psychosocial dimension at Time One predicted an improvement in functioning over time [$\beta = 0.48$, $t = 4.49$, $p < 0.01$] (Table 11 and 12). A doctors health locus of control predicted less improvement in functioning over time [$\beta = -0.26$, $t = -2.47$, $p < 0.01$] (Table 11 and 12).

The last two functioning scales were communication and work. A change in communication was only predicted by functioning on the communication scale at Time

One, which predicted an improvement in functioning over time [$\beta = 0.49, t = 4.81, p < 0.01$] (Table 11 and 12). The work scale was not significantly predicted by any variable, although an others health locus of control orientation did predict less improvement in functioning over time (Table 11). Functioning on the work scale at Time One and an internal health locus of control predicted an improvement in functioning over time to a non-significant level (Table 11).

Results from the multiple regression analyses have shown that functioning at Time One is the best predictor of improvement over time in ten of the individual subscales, as well as the physical and psychosocial dimensions and overall functioning score. Controlling for levels of functioning at Time One a doctors health locus of control was found to be significantly negatively correlated with the change scores for overall functioning, household management, recreation and pastimes, social interaction, alertness, sleep and rest and the psychosocial dimension. The more that CFS participants attributed control of their illness to doctors, the less the positive improvement from Time One to Time Two. An internal health locus of control was found to predict an improvement in functioning in ambulation.

3.7 Shapiro Control Inventory.

The standardised figures provided in the SCI, from previous research conducted by Shapiro (1994) included both clinical and non-clinical samples, these were compared with the CFS sample scores. First, CFS scores were standardised using Shapiro's (1994) procedure (described below). The psychiatric clinical samples included were: Anorexia Nervosa and Bulimia Nervosa; Generalised Anxiety Disorder; Panic Attack; Depression; and Borderline Personality Disorder. The at-risk comparison group were adult children of alcoholics. The clinical control sample was comprised of three groups: Type A

personality with 1 myocardial infarction treated with counselling; Type A personality with 1 myocardial infarction treated with CBT; and breast cancer. The non-clinical unscreened samples included for comparison were, senior citizens, meditators (very long term, long term and beginning), college students, middle managers and mental health and other professionals. A healthy control sample was also provided, which was made up of psychiatrically screened adults.

Standardised scores were used to compare the SCI scale scores between the different groups. The formula used to obtain the scores was;

$$S = (10*((X-M_h)/SD_h))+50$$

Where X = raw score
M_h = Mean for the healthy control group
SD_h = Standard Deviation for the Healthy Control group.

By using this formula the Healthy Control group always had a score of 50 and the other groups had standardised scores that could easily be compared.

The scores for the CFS group were converted into standardised scores and *z*-tests were performed to ascertain the significance, if any, between the CFS and the SCI samples. For the means, standard deviations, minimums and maximums for the CFS sample see Table 13.

On six scales the CFS sample was found to score outside Shapiro's (1994) healthy range, which is set to the level achieved by the SCI healthy control sample. On the specific sense of control scale (domain specific sense of control) the CFS score was 28.07, thus scoring significantly lower than the healthy control sample. The CFS sample recorded a significantly different score of 31.18 on the domain specific sense of control body subscale, again significantly lower than the healthy control sample. The CFS sample also significantly differed from the healthy control group on the interpersonal relationships in the specific sense of control scale, with a score of 23.03, which was significantly lower than the healthy control sample to the ($p < 0.01$) level.

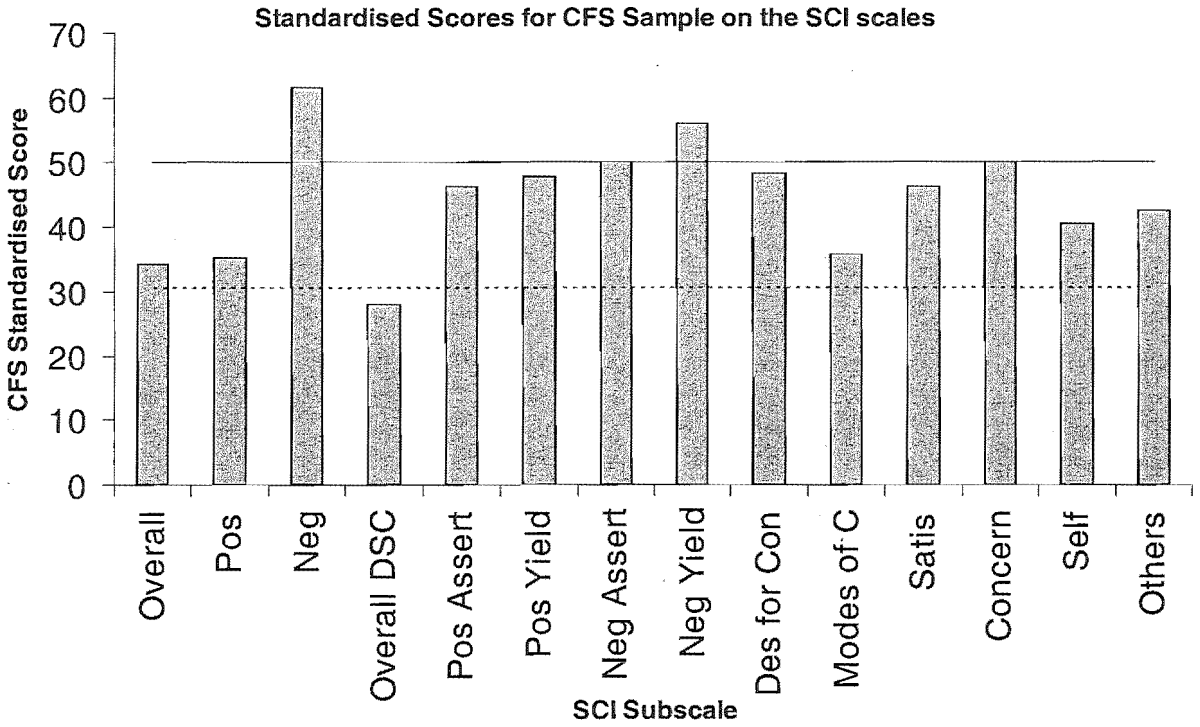
Table 13
Means, Standard Deviations, Minimums and Maximums for the Shapiro Control Inventory scales

	Mean	SD	Minimum	Maximum
1 Overall sense of control	31.53	7.69	12	46
2 Positive sense of control	55.23	8.91	33	73
3 Negative sense of control	16.3	4.13	8	29
4 Overall domain specific sense of control	103.53	16.19	70	136
a) Body	22.34	6.1	6	34
b) Mind	14.84	3.72	7	21
c) Personal relationships	14.53	4.77	4	24
d) Self	4.27	1.21	1	6
e) Career	11.57	3.45	4	18
f) Environment	4.51	1.41	1	6
g) Other	31.47	6.2	4	36
5 Positive assertive	43.23	8.69	25	61
6 Positive yielding	35.76	5.78	21	49
7 Negative assertive	25.14	6.5	15	48
8 Negative yielding	8.81	3.45	5	28
9 Desire for control	49.93	9.43	27	74
10 Modes of control	112.93	13.69	85	152
11 Satisfaction	48.27	18.24	0	100
12 Concern (B+C)	47.19	19.26	0	100
a) Change/Alter (B)	28.81	14.8	0	64
b) Acceptance (C)	18.38	14.86	0	76
13 Self as a source of control	5.55	1.2	3	7
14 Others as a source of control	12.08	4.03	4	23

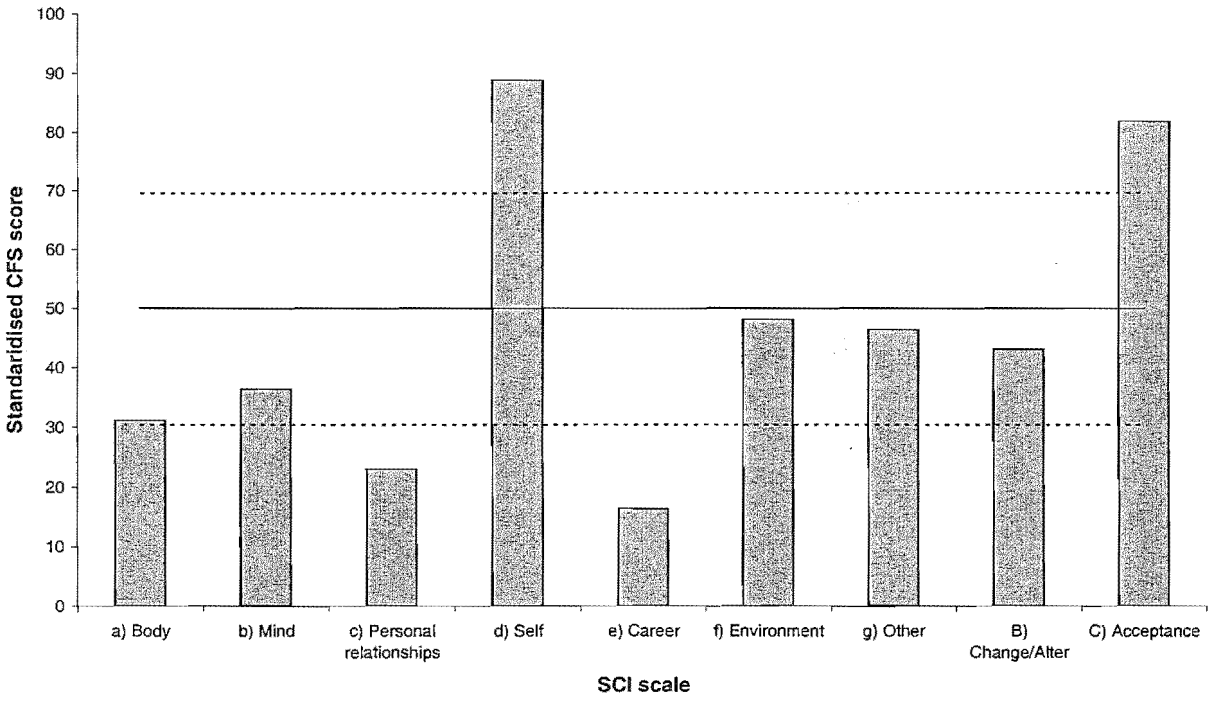
The self subscale in the specific sense of control grouping was also significantly different from the healthy controls, with a score of 88.77 ($p < 0.01$) which was significantly higher than the healthy control sample. The CFS sample scored 16.31 ($p < 0.01$) on the subscale career and this was significantly lower from the healthy control group.

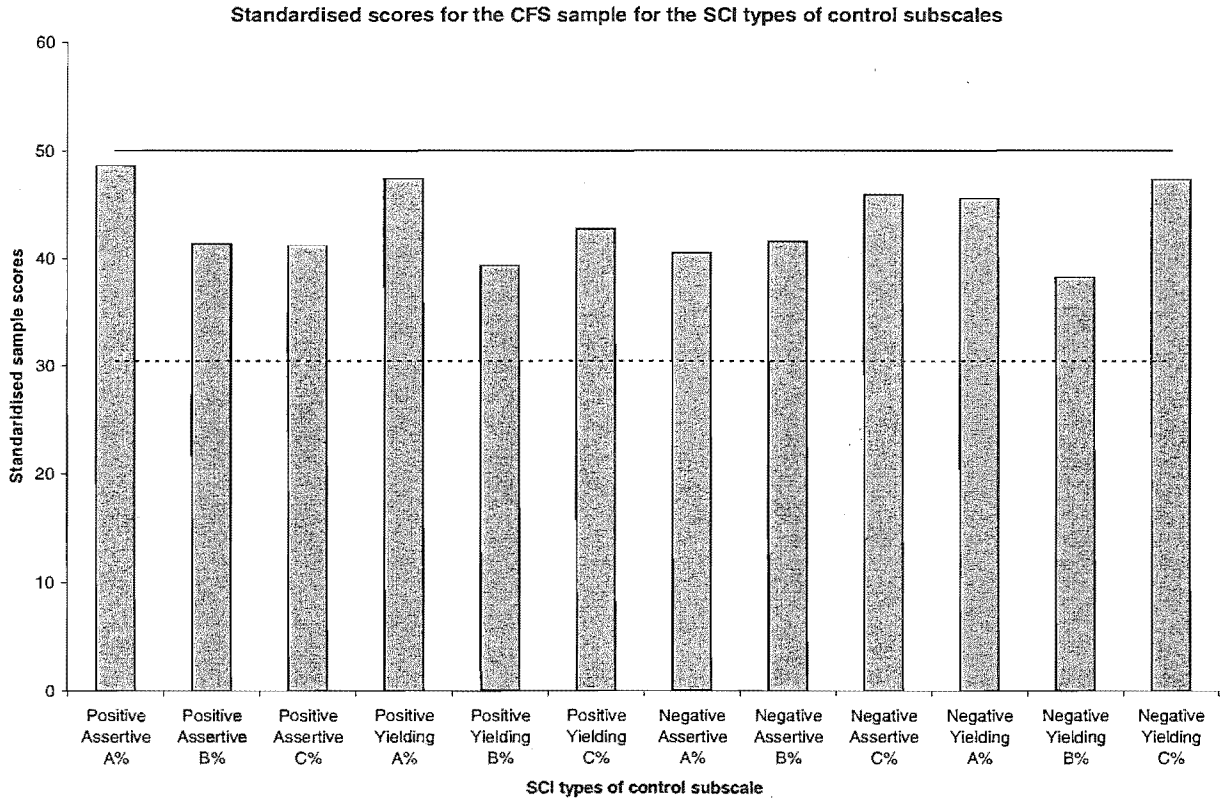
The other significant difference between the healthy control group and the CFS group was in the acceptance subscale, which is part of the specific parameters scale. This corresponds to the statements in the specific sense of control scale. The specific parameters scale assesses how satisfied or dissatisfied a person is with specific areas of their life. The acceptance subscale measures how satisfied a person is with the following seven areas, body, mind, personal relationships, self, career, environment and other. The CFS sample differed significantly from the healthy control group with a score of 81.82, ($p < 0.01$). None of the other SCI scales showed any significant differences between the CFS sample and the healthy control sample, which means that the CFS scores all fell within the normal range of answers in the other scales (see graphs 1, 2 and 3).

The SCI scale showed that the CFS sample scored significantly lower on four scales, domain specific sense of control, body, interpersonal relationships and career. However, the CFS group scored significantly higher than the healthy control sample on the self scale and the acceptance scale. The CFS sample scored within the normal range on the other 17 scales.


Standardised Scores for CFS Sample on the SCI scales
CFS Standardised Score
70
60
50
40
30
20
10
0
Overall
Pos
Neg
Overall DSC
Pos Assert
Pos Yield
Neg Assert
Neg Yield
Des for Con
Modes of C
Satis
Concern
Self
Others
SCI Subscale

CFS sample scores on the SCI domain specific subscales and the concern about control subscales




Standardised scores for the CFS sample for the SCI types of control subscales
Standardised sample scores
60
50
40
30
20
10
0
Positive Assertive A%
Positive Assertive B%
Positive Assertive C%
Positive Yielding A%
Positive Yielding B%
Positive Yielding C%
Negative Assertive A%
Negative Assertive B%
Negative Assertive C%
Negative Yielding A%
Negative Yielding B%
Negative Yielding C%
SCI types of control subscale

4 Discussion

The aim of the present study was to investigate the relationship between health locus of control and functioning in individuals suffering from a chronic condition. Health locus of control is important in health and illness because it defines the control orientation a person has towards their health. Health locus of control has been found to be an important factor in the positive adaptation to illness and engagement in health beneficial behaviour (Shapiro et al. 1996, Stein et al. 1984). The aims of the study were addressed through a repeated-measures design, where participants suffering from CFS were questioned about their health locus of control beliefs and functional impairment twice, six months apart, using the MHLC to investigate health locus of control beliefs and the FLP to investigate impairment in functioning. The SCI was also used at both times to provide a set of scores for comparison with other sample sets. Characteristic information about the sample was collected, as well as information regarding each participant's illness experience with CFS. This information enabled comparisons to be made between information such as the onset of CFS (sudden or gradual), the causes that a participant attributed to their illness and the number of symptoms they suffered with the information gathered by the MHLC and the FLP. The information collected at Time One was analysed using correlations and *t*-tests, while multiple regression analysis was used to examine the relationship between the amount of change in impairment between Time One and Time Two and health locus of control orientation. The major results from the study showed that the health locus of control was related to functioning. An internal health locus of control, that is assigning control of CFS to internal causes, was associated with improvement in levels of functioning over the six-month period of the study, whilst a doctors locus of control orientation, that is assigning control of CFS to doctors was associated with less improvement in functioning over the period of the study.

The use of multiple regression analysis, which allowed functioning at Time One to be statistically controlled for showed that an internal health locus of control affected functioning for individuals with CFS. An internal health locus of control was linked to an improvement in functioning, thus supporting the hypothesis of the study, which was that those participants with an internal locus of control are more likely to improve in levels of functioning over time. However, an unexpected result was that a doctors health locus of control was linked to less improvement in functioning over a six-month period. These findings suggest that those people with CFS who have a strong internal health locus of control have less impairment than those people who have a lower level of internal health locus of control. Participants with a high internal health locus of control made more improvements in functioning between Time One and Time Two than those participants that attributed control of CFS to doctors.

An internal health locus of control was associated with an improvement in functioning in ambulation. The participants who attributed control of their illness to their own actions recovered to a greater degree in ambulatory functioning than those participants that did not have a high sense of internal health locus of control. On the other hand those participants that attributed control of their illness to a doctor reported less improvement over six months in a number of functioning areas, most notably overall functioning, ambulation, mobility, household management, physical dimension, recreation and pastimes, social interaction, emotion, alertness, sleep and rest and psychosocial dimension.

These findings are similar to those of Knussen and Lee (1998), where a perceived lack of control over CFS was associated with more severe symptoms. Using multiple regression analysis Ray et al. (1997) found that internal health locus of control,

attributing control of CFS to one's own actions was able to significantly predict improvement in functioning over a one-year period in participants with CFS. However, in an earlier study Ray at al. (1995) and Cope et al. (1996) concluded that health locus of control does not influence the maintenance or precipitation of CFS. This is contrary to the findings of this research, which points toward health locus of control playing an important part in the maintenance or recovery of CFS.

Although Heijmans and De Ridder (1998) did not use the MHLC to identify whether attributing control of CFS to doctors influenced functioning in CFS, they did find that confidence in doctors was associated with feelings of a lack of control over CFS. Therefore, the findings of this study, that is attributing control of CFS to doctors was related to poorer functioning over a six-month period, supported the study by Heijmans and De Ridder (1998). This area requires further research to verify that attributing control of CFS to doctors has a negative impact on functioning. Thus, the findings from this research support earlier research that has found that health locus of control is a central factor in CFS.

4.2 Health locus of control and functional impairment at Time One in CFS

Analysis of the FLP and MHLC data collected at Time One also yielded some interesting findings. Attributing control of CFS to one's own actions (Internal health locus of control), was found to be negatively associated with alertness. That is, those participants who reported an internal health locus of control were more likely to experience less impairment in alertness functioning. These results support a conclusion that attributing control of CFS to one's own actions is associated with significantly better functioning on the alertness subscale and overall functioning. It is possible that internal health locus of control may play a protective role in the development of CFS. A high

sense of internal health locus of control may protect people with CFS from being as impaired as people who have a low sense of internal health locus of control. This is indicated by the results from those participants that attribute control of CFS to their own actions. This group of participants functioned better on alertness scales at Time One. In order to test the direction of the relationship between functioning and health locus of control, baseline levels would need to be measured followed by the application of a therapeutic regime aimed at increasing a participant's internal health locus of control. Post-treatment measures of health locus of control and functioning should be obtained in order to see if internal health locus of control scores had improved and if functioning scores had significantly improved.

While attributing control of CFS to one's own actions, was correlated with an improvement in functioning, all other health locus of control scales (chance, doctor, and others) were negatively correlated with improvement in functioning. A chance health locus of control, that is, attributing control of CFS to fate, was associated with a worsening in overall functioning, mobility, physical dimension, social interaction, sleep and rest, psychosocial dimension and work. A doctors health locus of control was associated with a deterioration in functioning on the emotion and psychosocial dimension. An others health locus of control, where control of CFS is attributed to significant people in a sufferer's life, was correlated with a deterioration in social interaction, emotion and psychosocial dimension functioning. These results suggest that high levels of chance health locus of control, attributing control of CFS to fate, or attributing control to either a physician or other people, such as friends and family members are associated with a poorer level of functioning in CFS.

However, previous research by Ray et al. (1997) found no significant differences in CFS participants with regards to external health locus of control that is, attributing control of CFS to causes that are external to the sufferer, or powerful others attributing

control of CFS to people that play a significant role in a sufferer's life and impairment. While their findings differ somewhat from the findings in this study, it should be noted that Ray et al. (1997) were using a different form of the MHLC. The form that they used did not include a chance health locus of control or doctors health locus of control scale, but instead external health locus of control was measured, and this incorporated chance locus of control. In the MHLC form that was used in this study external health locus of control is conceptualised as the opposite of internal health locus of control. Therefore, a low score on the internal health locus of control scale indicates the presence of a high external health locus of control. Another difference between the MHLC scale that Ray et al. (1997) used and the MHLC scale used in this study is that the powerful others scale has been broken down into two separate scales, doctors and others. The breaking down of this scale may increase the sensitivity of the items, which may have led to the results that were obtained in this research. Therefore the findings from this study, which found that an internal sense of control and attributing control of CFS to doctors, require replication with the four-scale MHLC in order to verify the reliability of these results.

Whilst functioning and locus of control were the primary factors under investigation in this study it should be noted that data from other factors investigated also yielded significant results. These add to the picture of CFS emerging from research conducted by health psychologists. One such finding was that functioning as measured in the participants over the six-month period of the research revealed significant changes. Participants recorded a change in functioning in all scales the except the physical dimension showing significant improvement over the six-month follow up period. All the FLP scales exhibited a significant change over the research period, showing a significant amount of improvement between Time One and Time Two. The work subscale also indicated improvement, but not to a significant level. Moreover, the greater the severity of dysfunction at Time One the more improvement that had been made by Time Two.

The important factor about these changes and improvements in functioning is that there was no intervention or treatment as part of the research. From these findings it could be concluded that CFS is a variable illness and functioning is likely to improve over time, regardless of treatment or lack thereof, or that there was a regression effect, which may have been due to the variable nature of CFS. In order to clarify this finding longitudinal research would need to be undertaken, with impairment levels taken at regular intervals so that a comprehensive picture of CFS could be drawn.

This finding is in opposition to that of Johnson et al. (1999) where over an 18 month time frame only 17% of participants reported an improvement in symptoms. The findings support in part research by Ray et al.'s (1992), which found that 55% of participants with CFS felt that they were improving over time. Figures from this study are much higher, but still support the general trend that, is also reported by the CDC (1994b) that people with CFS improve in functioning and symptom severity given enough time. Another finding was that the number of symptoms reported by a participant was found to correlate positively with the amount of impairment experienced by a participant.

4.3 Personal characteristic differences in functioning in CFS

A number of personal attributes were found to have significant relationships with functioning and health locus of control. Females were significantly more impaired on the body care and movement, sleep and rest subscales, physical dimension and overall functioning than male participants. Research into gender differences in CFS is lacking and the findings from this research indicate that gender differences in CFS do exist and therefore should be investigated further. However, these results could be due to reporting

differences in men and women. It could be that men are less likely to report symptoms that they experience. It may be important to note that gender differences exist within CFS when proposing appropriate support for sufferers. Females may require more assistance in areas of body care, physical functioning and overall functioning. Treating physicians need to be aware that their female patients may be experiencing more problems with regards to sleep and rest than their male counterparts.

A somewhat unexpected result was that participants who were of a younger age at the onset of their illness had higher levels of impairment in functioning on the alertness, communication, psychosocial dimension and overall functioning than those participants who were older at the onset of CFS. This is an area that needs further study to ascertain why this occurred. In terms of treatment, people who develop CFS at an earlier age may require more support and assistance than those people who develop CFS at an older age.

Another surprising result was that education levels were found to be negatively associated with attributing control of CFS to doctors. This suggests that those participants with a higher level of education were less likely to assign control of their illness to a doctor than those participants with lower education levels. In a practical sense, this may mean that the participants who were more highly educated were more likely to review and be more sceptical of the treatment advice recommended by their physician, and these sufferers might adjust their recommended treatment courses to suit their beliefs.

A sudden illness onset of CFS was associated with a significantly higher belief in a chance health locus of control, where control of CFS is attributed to fate. It was also found that those participants with a sudden illness onset were more likely to experience greater levels of impairment on the functioning scales; mobility, sleep and rest and the physical dimension than those participants who reported a gradual onset. Ray et al. (1998) also investigated illness onset in CFS. They found that a gradual illness onset was

associated with a longer illness duration, while a sudden illness onset was associated with a shorter illness duration. However, Russo et al. (1998) found that people with CFS who did not recover were older, less educated, had a long illness duration and suffered from a greater number of symptoms. Nevertheless the present study failed to replicate those findings. No significant association was found between illness onset and illness duration. Further study in this area may clarify these discrepancies.

The number of attributes that a participant identified as causing their illness was significantly correlated with poorer functioning only on the household management scale. This relationship between the number of causes that a person suffering from CFS attributes to their illness and the amount of impairment does not appear to have been investigated in previous studies. Other studies have investigated whether the type of causes that CFS participants attribute to their illness is associated with functioning (Ray et al. 1997). Thus, due to the findings of this research, which found that the number of causes a participant attributes to CFS correlates to functioning in household management, further studies should be conducted in order to investigate the nature of this relationship. That is, a relationship between the types of causes identified by a person and the amount of impairment suffered, needs to be investigated in order to determine whether or not a person with CFS who attributes a greater number of causes to their illness experiences more impairment than those people who attribute fewer causes to their CFS.

4.4 Shapiro Control Inventory

The SCI was used to further investigate issues of control amongst the CFS sample. While the MHLC was able to identify the health locus of control orientation of each participant the SCI was able to provided a more in depth investigation into issues of control within participants' lives. The SCI examined areas of overall control, including

positive and negative aspects, desire for control, satisfaction or concern about control, specific areas of control and types of control. The SCI also provided scores which enabled the CFS sample scores to be compared with previously collected clinical samples, including individuals with eating disorders, depression, anxiety disorders, Breast Cancer and Myocardial infarction, and the adult children of alcoholics. The CFS sample was also compared to a range of non-clinical samples, which included college students, senior citizens, meditators, middle managers and mental health workers and other professionals. Also included in the SCI normative data was a sample of psychiatrically screened, healthy controls. These samples provided in the SCI enabled a comparison to be made with the participants in the present study, in order to see if there were any significant differences or similarities between the clinical and non-clinical samples and the CFS sample.

The SCI showed that the CFS sample lay within the normal range across a wide range of control scales when compared to clinical and healthy control groups. The CFS sample scored significantly lower than the healthy control group on three of the SCI scales, and scored significantly higher than the healthy control group for two scales. The CFS sample registered significantly lower than the healthy control on the domain specific sense of control scale (which is a summary of the specific areas of control scales that included mind, body, interpersonal relationships, career, environment, self and areas of drug and alcohol usage). The CFS sample scored similarly to the adult children of alcoholics and Generalised Anxiety Disorder samples in the area of domain specific sense of control. The CFS sample scored significantly lower on the personal relationships subscale of the domain specific sense of control scale. The CFS sample was similar to the Depression, adult children of alcoholics and beginning meditators samples in control levels concerning personal relationships. The CFS sample also scored significantly lower on the career subscale of the domain specific sense of control. On this scale the CFS

group scores were similar to the those diagnosed with Generalised Anxiety Disorder, Panic Attack and Borderline Personality Disorder and to the adult children of alcoholics.

The CFS sample scored significantly higher on the self-subscale of the domain specific sense of control scale. In this scale all the comparison groups except the healthy controls scored less than 50. Therefore the CFS sample was not similar to any of the comparison groups. The CFS group also scored significantly higher than the control group on the acceptance subscale of the concern scale. The CFS sample group was similar in this respect to college students, the very long term meditators, the long term mediators and the breast cancer control groups. While the CFS sample was similar to the psychiatric comparison groups on only three scales it should be pointed out that the Depression, Generalised Anxiety Disorder, Borderline Personality Disorder and adult children of alcoholics comparison groups all scored significantly lower than the CFS sample in a range of scales. This strongly suggests that the CFS sample is not similar overall to the psychiatric comparison groups, nor is the CFS sample similar overall to the other comparison groups in aspects of control.

4.5 Generality of the results and methodological problems

It is likely that the findings of this study can be generalised to the CFS population. A wide range of participants were recruited for the research, although the number of males was low (12 at Time One and 10 at Time Two). The average age of participants was just under 48 years and ranged from 21-72. The average age of CFS onset was in the mid 30s, which is consistent with previously reported research (Johnson et al. 1999). There were 23 cases of sudden illness onset and 44 cases of gradual illness onset. Taken together, these attributes of the sample suggest reasonable representativeness.

A recognised problem area within CFS research is the recruitment of participants. Moss-Morris et al. (1996) suggest that recruiting participants through self-help or support

groups may bias any findings of a study. Their sample was made up of participants who were members of a CFS self-help/support group, while most other research has been conducted with participants recruited through clinical practises. Most participants in this study were recruited from self-help/support groups.

Ax et al. (2001) identified another potential problem. They suggest that the different diagnostic criteria existing in a number of countries results in CFS samples being different across countries. Therefore, accurate international comparisons may not be able to be made. For example participants from the USA are likely to be diagnosed according to the CDC criteria, whilst the UK participants are likely to be diagnosed according to the Oxford criteria (Ax et al. 2001). This is particularly relevant to this study as almost 50% of participants were from overseas, some from the USA and UK, and the diagnostic criteria for these participants was not known. While data from participants was not analysed for any differences that might exist between participants from different countries the examination of the sample through box plots and histograms yielded no significant outliers, suggesting any such differences did not impact on this sample.

Participants in this research were not assessed for the presence of CFS, rather participants' affirmation that they had been diagnosed or had their diagnosis confirmed by a medical practitioner was set as the benchmark for inclusion. In Ax's (1999) study participants were not assessed in terms of their CFS diagnostic criteria for inclusion; rather participants were asked who made the CFS diagnosis. It was assumed that those who were diagnosed by physicians met the criteria for the illness, as it was considered likely that the physician was familiar with CFS and the criteria for diagnosis.

There were some methodical concerns in the present study. One problem was recruiting participants for the study. As the study used a repeated-measures design, participants were required to be committed to the study for a period of six months. Although the dropout rate for the study was quite small (only seven participants dropped

out between Time One and Time Two), it is not known how many potential participants did not respond to recruitment advertisements because they felt unable to complete the study. The number of males that participated in the study was quite small but this is consistent with other research in the area of CFS. Another problem that occurred was that a number of participants failed to complete all the items on the questionnaires. Participants were given a second chance to answer the missing items. In some cases participants may have failed to understand the question, as quite a few participants missed the same questions in the SCI (questions 49, 50, 53, 74, 75 and 78 were frequently missed). At other times the illness may have impacted on participants' concentration levels as random questions throughout the questionnaires were missed and in some cases whole pages of questions were missed. In an attempt to avoid these problems relatively brief questionnaires were chosen. A possible compounding problem with the study was that no information was collected concerning treatment received by participants during the time of involvement. Therefore, it is conceivable that the improvement in functioning over the follow-up period may be due to treatment that participants were receiving at the time of the research.

It is also likely that the nature of the questions asked on the FLP impacted on the outcome of the study. The questions in the FLP asked participants to think of themselves in the last month when giving answers. It is possible that participants, especially those that were experiencing many memory and concentration problems, had difficulty in accurately remembering themselves and their symptom experience in the last month. Thus accurate information may not be reflected in the answers of the participants.

In a number of cases, mean differences were observed which were expected to be statistically significant, but were not, and some predicted relationships failed to emerge. Multiple regression performed between the FLP and the MHLC showed that both chance and others health locus of control orientation failed to affect functioning significantly. It

may be that there was not enough statistical power given the sample size to reach significance on these variables. However, it could be that as a sample the CFS participants do not hold strong chance or others health locus of control orientations. As significant results were obtained for both internal locus of control (attributing control to one's own actions) and doctors health locus of control (attributing control of CFS to doctors), it seems that the second reason is more likely to be the case.

Overall, the results from this research indicate that health locus of control is an important factor in CFS. Particular attention should be given to the impact that doctors have on their patients and the outcome of their CFS. The present study indicates that a high doctors health locus of control orientation is detrimental to people with CFS. Until now the relationship between doctors and functioning in CFS has not been examined. However a number of researchers have noted that clients' feelings surrounding the medical profession has not been positive.

4.6 The role and impact of Doctors in CFS

Wessely (1995) reports that in long-term cases of CFS there is a significant risk of suicide, especially when there is a lack of sympathy or support from friends, family and doctors. Wessely (1995) also reports that CFS is often mistaken for Depression, Phobia and Somatization Disorder. He concludes that doctors and psychological practitioners need to be educated about CFS so that misdiagnosis does not occur and so that people with CFS get the treatment and support that they require.

Heijmans and De Ridder (1998) found that people with CFS made more visits to non-medical professionals, were more intense in their self-care activities, had a higher number of co-morbid conditions, used less prescription medicine and were less confident about doctors than people without CFS. They also suggest that people with CFS are highly motivated and well informed about their illness. They propose that this may be due

to support groups and similar patient organisations which can influence people's illness representations to some extent. Kisely (2002) cautions that people with CFS can be exposed to a wide range of information on the world-wide-web and the lack of regulation and quality control of such information may mean that people with CFS may be misinformed about their illness and treatment. He reports that information on the world-wide-web comes from a range of sources including medical and scientific research as well as anecdotal reports and self-help groups.

Green, Romei and Natelson (1999) produced some of the earliest work into the role of doctors in CFS. They found that among doctors there is stigma and disbelief surrounding the physical nature of CFS. They found that the attribution of physical symptoms to psychological causes by the medical profession was viewed by people with CFS as a negative label causing distress. Further investigation by Green et al. (1999) revealed that over 50% more male doctors attributed CFS symptoms to psychological causes, compared to female doctors. Male doctors were five times more likely to recommend psychotherapy as treatment for CFS. Green at al. (1999) found that 77% of participants with CFS felt that they were exposed to psychological labelling by doctors with regard to their CFS. Green at al. (1999) also found that some medical practitioners were hesitant about using the term CFS because they viewed it as a self-fulfilling prophecy with disabling consequences. However, participants with CFS viewed a diagnosis of CFS as enabling, as it provided an alternative to personality factors as a cause of CFS.

Moore (2000) reported that whilst research into CFS has increased the knowledge and understanding for some practitioners, there is still a widespread ignorance and lack of understanding surrounding CFS. This can lead to difficulties in the diagnosis and treatment of CFS. These difficulties may then result in the patient with CFS feeling isolated and discredited.

In a study investigating the medical care received by participants with CFS, Deale and Wessely (2001) found that 62% were dissatisfied with their care and only 38% were happy with the care that they were receiving. A gender breakdown of these findings showed that 67% of female participants and 52% of male participants were dissatisfied with the care they were receiving from their doctor. Deale and Wessely (2001, p 1862) also report

> Dissatisfied patients were more likely to describe delay, dispute or confusion over diagnosis; to have received an unacceptable psychiatric diagnosis for symptoms; to perceive doctors as dismissive, sceptical or lacking in knowledge about CFS; and to feel that the advice given was inadequate or conflicting. In contrast, satisfied patients were more likely to perceive doctors as caring, supportive and interested in their illness; to state that they did not expect their doctors to cure CFS and to identify their GP or hospital as the source of greatest help during their illness.

A doctors health locus of control orientation was found to impact on impairment in functioning in CFS. Attributing control of CFS to doctors was associated with more impairment in a number of functioning areas. Therefore, doctors should be aware of the impact that they can have on their CFS patients. A lessening of the amount of control that a patient attributes to their doctor may go some way to combating this negative effect. Doctors may wish to acknowledge their patients' feelings and beliefs about the illness and thus reduce patients' fears, generating a more positive approach. Another strategy may be to actively involve the patient in discussion and decision-making about the treatment of the illness, and work within the patients' goals for recovery and or management of CFS.

4.7 Future research

Areas of future research that should be considered is the comparison of the MHLC and the SCI in order to determine the relationship between health locus of control

in CFS and more generalised areas of control as assessed by the SCI. The relationship between the control as measured on the SCI and functioning should also be examined in order to determine whether such a relationship between these two factors exists and the nature of such a relationship. Further research should also include the examination of relationships between the types of causes that a person attributes to CFS, control and functioning. None of these areas were investigated because of the complexity of the analysis and a lack of available time required to undertake such analyses. It would however, have further advanced the hypothesis of this study and the understanding of control in CFS.

This research has established that a health locus of control, particularly attributing control of CFS to one's own actions and attributing control of CFS to doctors, plays a significant role in functioning. An internal health locus of control was found to be significantly associated with improvement in functioning over time, whilst attributing control of CFS to doctors was associated with significantly less improvement in functioning over time. CFS participants were also shown to fall within the normal ranges in areas of control, as assessed by the SCI. However, CFS participants were found to have lower than normal levels of control, in areas of control over their body, personal relationships and career. The CFS participants were found to have higher than normal levels of control, in areas of control over themselves and acceptance of their situation. In terms of the treatment and understanding of CFS, it may be useful for clinicians to use the SCI to pinpoint areas that an individual with CFS feels is a concern, and or out of control and then incorporate these factors into the treatment plan. This may increase a client's sense of internal health locus of control, which has been shown to be beneficial in the outcome of CFS. Therefore, treatment plans for CFS can be tailored to suit each client, which would ideally produce greater rates of recovery in CFS.

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7 Appendices

7.1 Appendix One (Personal Circumstances Questionnaire)

Name:

Phone number:

Postal Address:

Have you ever been diagnosed with Glandular Fever, if so when?

When did your illness CFS first begin?

Was there a diagnosis straight away from any medical professionals, if not, how long was it before a diagnosis was made?

Who initially diagnosed CFS?

How long have you had CFS?

7.2 Appendix Two (Demographic Questionnaire)

1) Please indicate whether you are male or female.

2) Please state your present age.

3) Please state your highest education level (e.g., Secondary / Tertiary / Post Graduate).

4) What do you personally think or believe was the cause(s) of your CFS? Please choose from the following;

A) Physical (e.g., viral illness)

B) Chemical sensitivity / allergies (e.g., Aerial sprays)

C) Medical (e.g., complications after surgery, reaction to medication)

D) Trauma (e.g., car accident)

E) Stress (e.g., highly stressed, taking on too much)

F) Psychological (e.g., personality, mental health)

G) Other (please state)

If possible please elaborate further on categories, for example, please give the name of the viral illness, if known, that caused your CFS.

5) Do you consider your CFS illness to be of a sudden onset (e.g., one month or less), or of gradual onset (e.g., more than one month)?

6) Please indicate which of the following symptoms you have experienced in the last nine months that are attributable to your CFS.

Sore throat

Tender neck / lymph nodes

Swollen glands

Coughing

Runny nose and / or streaming / weeping eyes

Muscle pain

Joint pain

Unusual headaches

Persistent, unexplained fatigue, which has resulted in a reduction in levels of activity.

Unrefreshing sleep

Post exertional malaise

Cognitive impairment (e.g., lack of concentration / impaired memory)

Depressed mood (e.g., feeling down / flat, negative thought patterns)

Lack of motivation, difficulty focussing on tasks

Mood swings / heightened emotionality

Obsessional thoughts

Inability to obtain enjoyment from previously pleasurable activities

Lack of appetite

Increased appetite

Newly developed intolerance of certain foods

7.3 *Appendix Three (Altered version of the Functional Limitations Profile)*

Functional Limitations Profile.

Ambulation Items

The following statements describe walking and use of stairs. Remember, think of yourself **in the last month.** Only tick by the number of the statement if you agree with it, **and if it is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

1. I walk shorter distances or often stop for a rest.
2. I do not walk at all.
3. I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg.
4. I walk only with help from somebody else.
5. I go up and down stairs more slowly; for example, one step at a time or I often have to stop.
6. I do not use stairs at all.
7. I walk more slowly.

Body care and movement items

The following statements describe how you move about and dress yourself **in the last month.** Only tick by the number of the statement if you agree with it, **and it is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

8. I only stand for short periods of time.
9. I do not keep my balance.
10. I only stand with someone's help.

11. I am very clumsy.

12. I stay lying down most of the time.

13. I spend most of the time partly dressed or in pyjamas.

14. I dress myself, but do so very slowly.

15. I only get dressed with someone's help.

Mobility items

These next statements describe how you get about the house and outside **in the last month.** Only tick by the number of the statement if you agree with it, **and it is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

16. I stay in one room.

17. I stay in bed more.

18. I stay in bed most of the time.

19. I do not use public transport now.

20. I stay at home most of the time.

21. I do not go into town.

22. I only stay away from home for short periods.

Household management items

The following statements describe your daily work, around the home. When you answer, think of yourself **in the last month.** Only tick by the number of the statement if you agree with it, **and if is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

23. I only do housework or work around the house for short periods of time or I rest often.

24. I do less of the daily household chores than I would usually do.

25. I do not do any of the household chores that I would usually do.

26. I do not do any of the maintenance or repair work that I would usually do in my garden.

27. I do not do any of the shopping that I would usually do.

28. I do not do any of the cleaning that I would usually do.

29. I do not do any of the clothes washing that I would usually do.

30. I do not do heavy work around the house.

31. I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts.

Recreation and pastime items.

The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself **in the last month.** Only tick by the number of the statement if you agree with it, **and it its due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

32. I spend shorter periods of time on my hobbies and recreation.

33. I go out less often to enjoy myself.

34. I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less.

35. I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read.

36. I am doing more inactive pastimes instead of my other usual activities.

37. I take part in fewer community activities.

38. I am cutting down on some of my usual physical recreation or more active pastimes.

39. I am not doing any of my usual physical recreation or more active pastimes.

Social interaction items

These statements describe your contact with family and friends **in the last month.** Only tick the number beside the statement if you agree with it, **and it is due to your health.** Otherwise leave the number blank and move on to the next statement.

40. I go out less often to visit people.

41. I do not go out at all to visit people.

42. I show less interest in other people's problems; for example, I don't listen when they tell me about their problems; I don't offer help.

43. I am often irritable with those around me; for example, I snap at people or criticise easily.

44. I show less affection.

45. I take part in fewer social activities than I used to; for example, I go to fewer parties or social events.

46. I am cutting down the length of visits with friends.

47. I avoid having visitors.

48. My sexual activity is decreased.

49. I often express concern over what might be happening to my health.

50. I talk less with other people.

51. I make many demands on other people; for example, I insist that they do things for me or tell them how to do things.

52. I stay alone much of the time.

53. I am disagreeable with my family; for example, I act spitefully or stubbornly.

54. I frequently get angry with my family; for example, I hit them, scream or throw things at them.

55. I isolate myself as much as I can from the rest of the family.

56. I pay less attention to the children.

57. I refuse contact with my family; for example, I turn away from them.

58. I do not look after my children or family as well as I usually do.

59. I do not joke with members of my family as much as I usually do.

Emotion items

The next statements describe your feelings and behaviour. Again think of yourself **in the last month.** Only tick the number beside the statement if you agree with it, **and it is due to your health.** Otherwise leave the number blank and move on to the next statement.

60. I say how bad or useless I am; for example, that I am a burden on others.

61. I laugh or cry suddenly.

62. I often moan and groan because of pain or discomfort.

63. I have attempted suicide.

64. I behave nervously or restlessly.

65. I am irritable and impatient with myself; for example, I run myself down, I swear at myself, I blame myself for things that happen.

66. I talk hopelessly about the future.

Alertness items

These statements describe your general alertness **in the last month.** Only tick the number by the statement if you agree with it, **and it is due to your health.** Otherwise leave the number blank and move on to the next statement.

67. I am confused and start to do more than one thing at a time.

68. I have more minor accidents; for example, I drop things, I trip and fall, or I bump into things.

69. I react more slowly to things that are said or done.

70. I do not finish things I start.

71. I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things.

72. I sometimes get confused; for example, I do not know where I am, who is around, or what day it is.

73. I forget a lot; for example, things that happened recently, where I put things, or to keep appointments.

74. I do not keep my attention on any activity for long.

75. I make more mistakes than usual.

76. I have difficulty doing things which involve thought and concentration.

Sleep and rest items

These statements describe your sleep and rest activities **in the last month.** Only tick the number by the statement if you agree with it, **and it is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

77. I spend much of the day lying down to rest.

78. I sit for much of the day.

79. I sleep or doze most of the time, day and night.

80. I lie down to rest more often during the day.

81. I sit around half asleep.

82. I sleep less at night; for example, I wake easily, I don't fall asleep for a long time, or I keep waking up.

83. I sleep or doze more during the day.

Communication items

The following statements describe how much you talk to other people and write. Please think about yourself **in the last month.** Only tick the number by the statement if you agree with it, **and it is due to your health.** Otherwise leave the number blank and move on to the next statement.

84. I have trouble writing or typing.

85. I often lose control of my voice when I talk; for example, my voice gets louder or softer or changes unexpectedly.

86. I carry on a conversation only when very close to other people or looking directly at them.

87. I speak with difficulty; for example, I get stuck for words, I stutter, I stammer, I slur my words.

88. I am understood with difficulty.

89. I do not speak clearly when under stress.

Work items

The next group of statements has to do with any work you usually do other than managing your home. By this we mean anything that you regard as work that you do on a regular basis. Think of yourself **in the last month.** Circle the answer that best fits you or tick the number by the statement if you agree with it, **and it is due to the state of your health.** Otherwise leave the number blank and move on to the next statement.

Do you usually do work other than managing your home? YES NO

If YES, complete the work section (Q. 90-98).

If NO:

(A) Are you retired? YES NO

(B) If you are retired, was your retirement due to your health? YES NO

(C) If you are not retired, but are not working, is this due to your health? YES NO

If YES to question (C) above, please tick item 90 and skip the rest of the items in this section.

If NO to question (C) above, please skip all the items in this section.

90. I do not work at all (includes retired because of health).

91. I do part of my job at home.

92. I am not getting as much work done as usual.

93. I often get irritable with my workmates; for example, I snap at them or criticise them easily.

94. I work shorter hours.

95. I only do light work.

96. I only work for shorter periods of time or often stop to rest.

97. I work at my usual job but with some changes; for example, I use different tools or special aids or I swap jobs with someone else.

98. I do not do my job as carefully and accurately as usual.

Functional Limitations Profile Summary scoring sheet

	Sum of items scores (a)	Maximum score (b)	Total Score (a/b x 100)
Ambulation		556	
Body care and movement		620	
Mobility		530	
Household management		617	
Physical dimension		**2323**	
Recreation and pastime		383	
Social interaction		1289	
Emotion		578	
Alertness		811	
Sleep and rest		591	
Psychosocial dimension		**3652**	
Communication		380	
Work		743	
Overall FLP		**7098**	