

**THE PROCESS OF COPING AND SELF-MANAGEMENT
IN THE EXPERIENCE OF RECOVERING FROM
CHRONIC FATIGUE SYNDROME (CFS)**

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ABSTRACT

A hermeneutical model of doing research is adopted to investigate the process of coping and self-management in the experience of recovering from Chronic Fatigue Syndrome (CFS). Three research participants who consider themselves as recovering or recovered from CFS were interviewed to obtain data for analysis.

The findings are that once the participants cope with the uncertainty about the meaning of the onset of symptoms by defining themselves as ill in somatic terms, the participants use external social and treatment resources to cope with the onset of symptoms and being chronically ill with CFS. As a consequence of feeling stigmatised in relation to social and professional scepticism about initially being ill and subsequently, being chronically ill with CFS, the participants become uncertain about the meaning of having CFS. Coping shifts to using internal resources by adopting self-management practises. In this process, firstly, existing self-management shifts in such a way that the participants view themselves as recovering or recovered from CFS, and secondly, the participants come to the understanding that difficulties with self-management cause and maintain CFS.

The findings are discussed to conclude that CFS may be a misdiagnosis of difficulties with self-management. CFS itself may not be an 'objective' disorder, but a constituent of social processes. Becoming diagnosed with CFS arises as a consequence of the search for meaning in relation to the lay and professional assumption that psychological illness does not constitute 'real' illness, operating at both the levels of popular society and the doctor-patient relationship. Difficulties with self-management rather than the diagnosis of CFS provide a more adequate understanding of the participants' illnesses.

CHAPTER 1

LITERATURE REVIEW

1.1 INTRODUCTION

The aim of this research is firstly, to investigate the process of coping and self-management in the experience of recovering from CFS and secondly, for the results of this research to contribute to current understanding of CFS.

In the following literature review, current understanding of CFS is described in relation to research done on CFS from within the biomedical model. CFS is defined to indicate the nebulous nature of the condition. It is defined in the context of the controversy on how to biomedically conceptualise CFS. Research is presented to indicate the absence of an accepted conclusive understanding of the aetiology of CFS. In the absence of CFS being classified as a disease (Coetzer, Lockyer, Schorn, Boshoff, 2000), the understanding of CFS as a 'functional somatic illness' and/or a form of somatisation is presented.

The cognitive-behavioural model of CFS is described to present understanding of CFS from a biopsychosocial perspective.

Treatment for CFS is described and reveals that there is no commonly followed medical treatment for the condition. Coping as an area of research into CFS becomes

significant in view of its nebulous nature, the absence of an accepted conclusive understanding of aetiology, no commonly followed treatment, and the ineffective high utilisation of complementary therapies. The question of the impact of these factors on the process of coping over the course of the illness is raised. There is little research into the *process* of coping in CFS. Existing research into coping in CFS is based on a definition of coping by Folkman & Lazarus (1988). This definition defines coping as a process and not a static state. However, existing research is quantitative and hypothesis-testing, rendering coping as a static phenomenon.

A research finding that CFS serves as a catalyst for a major positive transformation in lifestyle (Ware & Kleinman, 1992) is presented. In addition, the reasons why this finding raises the question of self-management in the experience of recovering from CFS, will be presented. It is unlikely that CFS sufferers who are chronically ill with the condition will have experienced a major positive transformation of lifestyle. Thus, the aim of this research is to investigate the process of coping and self-management in the experience of recovering from CFS.

A hermeneutical model of doing research is adopted to explore and investigate the aims of this research in terms of the experience of three participants who view themselves as recovering from CFS, or as recovered from CFS.

1.2 WHAT IS CFS?

CFS is a descriptive term for a clinical presentation of a chronic illness characterised by self-reported persistent, relapsing, debilitating fatigue of at least 6 months duration, and accompanied by individualistic combinations of a variety of associated physical, constitutional and neuropsychological complaints. These complaints include difficulty concentrating, headache, sore throat, tender lymph nodes, muscle aches, joint aches, feverishness, difficulty sleeping, psychiatric problems, allergies, abdominal cramps, weight loss, rash, rapid pulse, weight gain, chest pain, and night sweats (Strauss, in Coetzer et al., 2000).

In terms of the prevalence of CFS, cases are reported world-wide, under different labels (Komaroff & Buchwald, 1998). It is twice as likely to occur in middle-class white women in their thirties, although cases in childhood and in middle age are described. It occurs in all ethnic, racial, and socio-economic groups (Mountstephen, in Coetzer et al., 2000).

In contrast to most patients with the presenting complaint of chronic fatigue, the onset of CFS is typically sudden, often with a flu-like illness, or it may follow a period of physical or emotional stress. The symptoms may vary in intensity, but are generally aggravated by stress and exertion (Komaroff & Buchwald, 1998; Straus, in Coetzer et al., 2000). The duration of CFS can be months or years. Some CFS sufferers show a marked improvement over time, while others remain ill or experience repeated

remissions and relapses of symptoms. This leads to a significant impact on quality of life and lifestyle (Farrar, Locke & Kantrowitz, 1995).

1.2.1 Origin of the term 'CFS'

In the United States of America, in 1968, it was discovered that the Epstein-Barr virus (EBV) causes mononucleosis (Wessely, Hotopf & Sharpe, 1998; Shorter, 1992). The symptoms of mononucleosis are chronic fatigue, aching legs, and depression. Mononucleosis becomes known as an infectious disease, chronic Epstein-Barr virus.

However, it was subsequently found that there is a poor correlation between those who have hematological evidence of chronic EBV infection and those who have the symptoms of chronic fatigue. In addition, it was discovered that EBV is found in varying amounts in all people (Wessely et al., 1998; Shorter, 1992). Consequently, in 1988 Gary Holmes along with coworkers at the United States Centers for Disease Control (CDC) renamed chronic Epstein-Barr virus, chronic fatigue syndrome (CFS) (Holmes, Kaplan, Gantz, Komaroff, Schonberger, Straus et al. 1988).

1.2.2 Definition of CFS

Holmes et al. (1988) outline the symptoms characteristic of CFS in their 'working case definition' which is an operational concept designed for research purposes. In addition, in the absence of classification as a disease entity for this condition, this definition became widely used by medical practitioners in diagnosing CFS.

According to this definition cases with any pre-existing or newly diagnosed psychiatric disease are grounds for exclusion. This criterion is criticised for its denial of the recognised prevalence of associated psychiatric morbidity in the majority of chronic medical conditions, for example, diabetes mellitus, chronic renal failure and heart disease. The associated psychiatric symptoms in these conditions do not cast doubt on the primary medical diagnosis (Lloyd, Hickie, Brockman, Hickie, Wilson, Dwyer & Wakefield, 1993). This contributes to a revision of the working case definition.

The CDC now defines CFS by two criteria (Fukuda, Straus, Hickie, Sharpe, Dobbins & Komaroff, 1994). The first criterion is the new onset of persistent unexplained fatigue that is not the result of ongoing exertion, is not alleviated by rest, and results in substantial reduction of previous levels of occupational, educational, social, or personal activities. The persistent fatigue is not attributable to any identifiable medical condition. The second criterion is the occurrence of four of the following symptoms that have persisted over six or more months: self-reported impairment in short-term memory or concentration; sore throat; tender neck or axillary nodes; muscle pain; multi-joint pain; headaches of a new pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours.

The exclusion criteria are: active, unresolved or suspected disease; psychotic, melancholic or bipolar depression (but not simple major depression); psychotic disorders; dementia; anorexia or bulimia nervosa; alcohol or other substance misuse; and severe obesity (Komaroff & Buchwald, 1998). Concurrent diagnosis of

somatoform disorder, anxiety disorder, nonmelancholic depression, or panic disorder does not preclude a diagnosis of CFS (Friedberg, 1996).

The original definition of CFS requires 8 out of 11 specific symptoms as opposed to 4 out of 8 in the current definition. Thus CFS is now defined by fewer reported symptoms. In addition, as mentioned, pre-existing or newly diagnosed psychiatric disease are no longer grounds for exclusion in definition and hence diagnosis.

According to information received from the Chronic Fatigue Immune Deficiency Syndrome (CFIDS) Association of America on their web site at www.cfids.org (October, 2001), another CDC meeting is being convened for the near future to revise the definition of CFS yet again.

1.3 CONTROVERSY REGARDING CFS

The problematic task of defining CFS for research purposes and hence diagnosing patients with CFS takes place in the context of two important issues. Firstly, as cited throughout the literature on CFS, there is controversy on how to biomedically conceptualise CFS. There are inconsistent and contradictory research findings regarding aetiology, treatment, and prognosis, in order to establish its disease status. There is controversy in medicine and the behavioural sciences over whether it is a physical disease (viral and/or immunological), or a psychiatric and/or psychological (depression, somatisation, personality factors, abnormal illness behaviour) problem. This conceptual controversy goes on into the present (Coetzer et al., 2000) and is

paralleled by the diagnostic controversy among clinicians (Farrar, 1995). The debate is polarised between those insisting on a purely biological explanation and those proposing that CFS is an entirely mental phenomenon.

Secondly, CFS assumes prominence in the mass media and public consciousness, portrayed as a major public health problem (Coetzer et al., 2000; Shorter, 1992; Wessely et al., 1998). CFS becomes an increasingly popular diagnosis (Shorter, 1992), which continues into the present (Coetzer et al. 2000). This is accompanied by support groups and national advocacy organisations that lobby for CFS to be recognised as a disease (Coetzer et al, 2000; Goudsmit, 1991; various CFS Action leaflets from the inception of CFS into the present). This occurs despite the fact that its scientific status, medical basis and pathophysiology remain unclear (Shorter, 1992; Coetzer et al. 2000).

The above-mentioned controversy is fuelled by various factors, including the lack of agreement on the label for the condition, uncertainty regarding its clinical validity, and the absence of definitive medical/laboratory tests confirming the diagnosis (Biccard, in Howlett & Lindegger, 1996), to be described below.

Since its inception, a wide range of names have been used to label this syndrome.

These names are descriptive of either:

- 1) the geographic locations where epidemics have been reported, for example, 'Icelandic Disease' (Friedberg, 1996);

- 2) supposed underlying medical aetiology, such as 'Chronic Epstein-Barr Virus' and 'Chronic Mononucleosis' (Shorter, 1992), 'Postviral/infectious Fatigue Syndrome' (Wessely, 1991), Myalgic Encephalomyelitis (ME) (Shorter, 1992);
- 3) supposed psychogenic nature of the condition, for instance, 'neurasthenia' (Wessely, 1991); and
- 4) the socio-economic group that the sufferers are thought to belong to, colloquially known as 'Yuppie-Flu' (Komaroff & Buchwald, 1998).

In the United States of America it has changed from chronic fatigue immune deficiency syndrome (CFIDS) to CFS. According to a current CFS Fact Sheet from the CFIDS Association of America, this association is currently addressing a need to change the name again because it is felt that CFS fails to reflect the serious physical nature of the condition. In those parts of the world where it is known as Myalgic encephalomyelitis (ME), the term CFS is now preferred because no consistent evidence of myopathy has been found to explain the Myalgia, and there is lack of consistent evidence for encephalomyelitis (Wessely et al., 1998).

With regard to the uncertainty of CFS as a clinically separate entity, it does not have any cardinal symptoms to distinguish it from other medical conditions. The constellations of symptoms pertaining to CFS resemble those of many other disorders. These include, multiple sclerosis, systemic lupus erythematosus and depression (Komaroff & Buchwald, 1998; Kruesi, Dale & Straus, 1989), Lyme disease and fibromyalgia (Kruesi et al., 1989; Coetzer et al., 2000). As such, there is much controversy as to whether CFS exists as a separate syndrome, and, as mentioned, if it

does, what the aetiology of this condition is. Many doctors do not diagnose CFS, not believing in its validity as a diagnosis (Coetzer et al. 2000).

1.4 REVIEW OF RESEARCH

Current understanding of CFS is based on the biomedical model of CFS and the cognitive-behavioural model of CFS. Most of the research on CFS is conducted within these two models, employing quantitative methodologies. In the light of the controversy over the biomedical conceptualisation of CFS, most of the research on CFS conducted within the biomedical model focuses on its aetiology. In addition, there is research into the treatment of CFS and coping with CFS. Before the biomedical model of CFS, the cognitive-behavioural model of CFS, and research into treatment and coping are presented, research into other areas of CFS include:

1. Research into sociocultural issues in CFS, and the comparison between the nineteenth century syndrome of neurasthenia and CFS (Farmer, Jones, Hillier, Llewelyn, Borysiewicz & Smith, 1995; Wessely, 1994; Wessely, (1990); Ware & Kleinman, 1992; Abbey & Garfinkel, 1991). This research has led many to understand that CFS is merely a new name for neurasthenia, including, Higgins (1992), Stewart (1990) and Richmond (1989). In 1990, Wessely maintains that although the social processes that govern neurasthenia and CFS remain obscure, "one may argue that they represent culturally sanctioned expressions of distress, in effect culture-bound syndromes" (p.50). The social processes still remain obscure and will be discussed in chapter 5.

2. Research with no definitive findings into cognitive functioning and neuropsychological deficits in CFS by, among others, Wearden & Appleby, 1996; Krupp, Sliwinski, Masur, Friedberg & Coyle, 1994; and Smith, Behan & Bell, Millar & Bakheit, 1993.
3. Research into quality of life in CFS by Schweitzer, Kelly, Foran, Terry, & Whiting (1995). Findings from this research highlight the importance of addressing the social isolation and loss of functioning experienced by CFS sufferers.

1.4.1 The biomedical model of CFS

The biomedical model is a scientific model, based on the assumptions of rationalism (Helman, 1990), in conjunction with the normative, taken for granted, usually implicit assumption of mind-body dualism (Helman, 1990, Scheper-Hughes & Locke, 1987). In terms of rationalism, symptoms of illness become 'real' only once they can become observed, measured, tested, and verified objectively (Helman, 1990). The assumption of mind-body dualism is an artificial, though useful, idea that separates the person into a concrete, material body, and an abstract mind (Scheper-Hughes & Locke, 1987).

Taking the two assumptions together, because the body is material and more readily observable than mental phenomena, physical symptoms are considered to be more 'real' than mental phenomena. Symptoms of illness, be they physical, psychological and/or social, are first related to their underlying physical cause (Helman, 1990). The biomedical model focuses on the physical dimensions of illness. If there are objectively demonstrable physical changes in the body's function which can be

quantified by reference to 'normal' physiological measurements, these abnormal changes, or diseases, are seen as entities, with their own specific pattern of symptoms and signs (Helman, 1990). These then become 'real clinical facts'. The aim is to discover the logical chain of causal influences that lead to them. In this way, symptoms of illness can be diagnosed into symptoms of disease. Each disease is made up of a characteristic cause, clinical picture, results of clinical investigations, natural history, prognosis, and appropriate treatment (Helman, 1990). Diseases are assumed to be universal (Helman, 1990; Swartz, 1998).

Understanding of CFS in terms of research conducted on CFS within the biomedical model, follows.

i) Research into the physiology of CFS

Research has shown that although there may be an association between positive EBV and triggering CFS, the role of chronic infection in perpetuating CFS is doubtful (Mountstephen, in Coetzer et al., 2000). In Britain, the "hard" neurological and physical findings present in the "Royal Free Epidemic" cannot be found in those who suffer from its relabelled condition of benign ME (Shorter, 1992). Research has found that titres of antibodies to many infectious agents are elevated in-patients with CFS, such as herpes viruses, measles virus, rubella virus and Coxsackie virus B. However, their role as potential aetiological agents is inconclusive (Strauss 1998; Murray 1992). Various endocrine abnormalities have been found in CFS. Research into the possibility of immune dysfunction as a causative factor in fields of both humoral and

cell mediated immunity are inconclusive (Palca 1991, Read et al. 1988, & Strauss et al. 1989, cited in Murray 1992).

Further inconclusive research into the physiology of CFS includes the role of environmental or dietary and internally generated auto-intoxicants. Lifestyle, chronic hypoglycaemia, “total allergy syndrome” and chronic candidiasis have been hypothesised in the aetiology of CFS (Kim 1994; Stewart, 1990).

Research into the biological substrate(s) of CFS is unable to conclusively establish it as a disease entity. That is, not only can the physical changes or abnormalities in the body’s function in relation to CFS be objectively demonstrated, they do not form a specific, or characteristic, pattern in relation to cause, clinical picture, results of clinical investigations, prognosis and treatment. CFS remains a clinically defined condition (Coetzer et al., 2000). Regardless, those insisting on a purely biological explanation for CFS, understand CFS to be idiopathic, meaning that a cause is yet to be found (Farrar, 1995).

Further, in terms of the assumptions within the biomedical model, if no biological causes for symptoms of illness can be found, they must be looked for “in the mind”, which is considered to be less ‘real’ (Helman, 1990). Research into CFS as a psychiatric disorder and/or psychological disorder is presented.

ii) Research into CFS as a form of psychiatric disorder

There is a strong association between CFS and psychiatric disorder (Cleare & Wessely, 1997). David (1991), cited in Cleare & Wessely, (1997) established that one half of two-thirds of CFS patients have a co-morbid psychiatric disorder, usually depression, anxiety or somatisation.

The most common finding of a psychiatric kind is the incidence of depression in CFS (Powell, Dolan & Wessely, 1990; Ray, 1991). Mild to moderate depression is evident in about two-thirds of patients (Straus, 1998). However, there is debate over whether depression precedes or follows the onset of CFS. Many researchers have established the implication of a causal relationship between depression and CFS. They report evidence of depressive symptoms satisfying DSM-111-R (Diagnostic and Statistical Manual of Mental Disorders, Third Edition Revised, American Psychiatric Association) criteria for major depression before the onset of CFS (Kruesi et al., 1989; Manu, Mathews & Lane, 1988; Ray, 1991; Taerk, Toner, Sait, Garfinkel & Ozersky, 1987). The prevalence of depression in CFS exceeds that seen in other chronic conditions. On measures of depression, Howlett & Lindegger (1996) find that CFS patients are more like depressives than patients with chronic physical diseases. As such, some view CFS as fundamentally a psychiatric disorder and that the various neuro-endocrine and immune disturbances arise secondarily (Straus, 1998). Other researchers have concluded that affective disorder is reactive, a consequence of CFS (Hickie, Lloyd, Wakefield & Parker, 1990). Cleare & Wessely (1997) maintain that it is unlikely that CFS is the consequence of psychiatric disorder alone. They believe

that this concern limits an understanding of the role of psychological factors in CFS, such as personality and illness behaviour, to be considered next.

iii) Research into CFS as a psychological disorder

Patients with CFS often show personality traits, or attitudes, of perfectionism and over-achievement (Cleare & Wessely, 1997; Suraway, Hackman, Hawton & Sharpe, 1995; Puffer & McShane, cited in Suraway et al. 1995; Komaroff, 1988; Abbey & Garfinkel, 1990). Post-infectious fatigue that would be otherwise self-limiting may be exacerbated and perpetuated in persons with these personality traits (Sharpe, 1997). The common factor in such a vulnerable personality to situations of chronic adversity such as being over-stressed or being blocked in career, and depression consequent to loss, is an inability to perform or to achieve. These people may respond with assumptions of failure. In their assessment of 100 patients, Suraway et al. (1995) find that such experiential themes are illustrated by cognitive assumptions such as: "If I don't meet all my responsibilities to others all the time I am a failure"; "Unless I've achieved all my career aims I've failed"; and "I must never admit to difficulties". Repeated failed attempts to achieve their pre-morbid goals and levels of functioning lead to a state of chronic exhaustion, fatigue, frustration, and demoralisation, along with its physiological concomitants. Suraway et al. (1995) suggest that the symptoms of CFS result from the physiological changes accompanying chronic emotional distress and inactivity. In other words, they imply that personality factors play a causative role in CFS. This finding is controversial and it has not been established by further research.

CFS as a form of abnormal illness behaviour has been researched. Pilowsky (1986) describes illness behaviour as the ways in which individuals perceive, evaluate and respond to aspects of their own functioning, which they are predisposed to appraise in terms of 'illness' and 'health'. Abnormal illness behaviour describes "the persistence of an inappropriate or maladaptive mode of perceiving, evaluating or acting in relation to one's own health" (Pilowski, p.393). In terms of making sense of the physiological changes accompanying chronic emotional distress and inactivity, the symptoms may be attributed to a disease process. Disease conviction is described as the "affirmation that physical disease exists, symptoms preoccupation, and the rejection of the doctor's reassurance" (Pilowsky & Spence, 1983, p.3). The tendency of CFS patients to favour physical disease as the basis of their symptoms and to reject psychological explanations has been noted by among others, Matthews, Manu & Lane, (1989), Powell, Dolan & Wessely (1990), Suraway et al. (1995). Shorter (1992) and Coetzer et. al. (2000) view this tendency as a distinctive feature of CFS.

In their research on attributional style and illness behaviour in CFS, Howlett & Lindegger (1995) find that a distinctive characteristic of CFS patients which sets them apart from depressives and chronic pain patients is the high levels of disease conviction. There is no further research to establish that CFS is a form of abnormal illness behaviour.

Understanding of CFS in terms of research conducted on CFS within the biomedical model, follows.

The above review of research on CFS within the biomedical model indicates that the research is unable to reveal a biomedical explanation of CFS. As described above, firstly, research is unable to establish the biological substrate(s) of CFS. Secondly, research is unable to establish CFS as a form of depression and/or psychological disorder. Thus, CFS cannot be conceptualised as a disease of the body or the mind. Not only is CFS not a disease of the body, it is not a disease of the less 'real' mind. Regardless, as mentioned earlier, those insisting on a purely biological explanation for CFS understand CFS to be idiopathic. Those insisting on understanding CFS as an entirely mental phenomenon, view CFS as a 'functional somatic syndrome' and/or as a form of somatisation.

iv) CFS as a 'functional somatic illness'

Among others, Coetzer et al. (2000) and Sharpe (1997) consider CFS as a 'functional somatic syndrome'. In terms of mind-body dualism in the biomedical model, a disorder is either 'functional' or 'organic'. When the term 'functional' is used in its original sense of a disturbance of functioning the psychogenic implications of the alternatives of somatisation and somatoform are avoided (Sharpe, 1997). Conditions with uncertain scientific status, medical basis and pathophysiology are referred to as functional (Coetzer et al., 2000). CFS, fibromyalgia, irritable bowel syndrome, tension-type headache, chronic pain, non-cardiac chest pain, premenstrual syndrome fall into this category.

v) CFS as a form of somatisation

There are various and competing definitions of somatisation in the literature (Swartz, 1998; Kawanishi, 1992), depending on perspective. In terms of the biomedical perspective, a person who continues to claim somatic illness in the absence of physiological evidence is declared as one who is somatising psychological problems (Kawanishi, 1992). This is distinguished from psychosomatic disease (such as hypertension and duodenal ulcers). Here, somatic complaints do have a physiological evidential basis even though the causes often include psychological factors (Kawanishi, 1992). In terms of the assumption of mind-body dualism where it is conceptualised that the mind is experienced as separate from the body, it is considered that people ought to express their psychosocial distress in psychological terms and their physical afflictions in bodily terms (Kawanishi, 1992). Presenting bodily complaints as explanations for one's psychosocial problems and/or emotional distress is regarded as pathological and defined as somatisation. It is in this biomedical, psychiatric, sense, that CFS is considered as somatisation. The observation that CFS patients present mainly with bodily symptoms and have a tendency to favour physical disease as the basis of their symptoms and to reject psychological explanations has been cited above.

Shorter (1992) maintains that CFS is a form of somatisation in either one of two ways. Either the symptoms are entirely psychogenic, that is, in the context of stress and psychological problems CFS sufferers amplify their normal physical sensations into experience of them as somatic symptoms. Or, the response to physical symptoms is inappropriate or exaggerated; that is, physical symptoms are modeled to fit in with the

template of CFS. The template of CFS is publically made available through media broadcasting. CFS then becomes a personal reality by seeking medical help and confirmation from sympathetic physicians and patient support groups.

Coetzer et al. (2000) view CFS as a form of somatisation in a similar sense. Media broadcasting, CFS advocacy groups, patients presenting to doctors convinced of having an occult disease and self-diagnosing CFS, promote the medicalisation of CFS. Individuals with pre-existing, benign discomfort, some with an undiagnosed medical disorder, others re-labelling pre-existing bodily distress are supplied with a new disease attribution. Medicalisation and somatisation of CFS usher these individuals into the medical care system. Further discussion of CFS as a form of somatisation will be returned to in Chapter 4.

In order to address the conundrum of the mind-body debate driving research into CFS and possibly to overcome it, research by, among others, Wessely, David, Butler, Chalder (1989), Suraway et al. (1995), and Sharpe (1997) leads to a cognitive-behavioural model of CFS. According to Sharpe (1977) such a model assumes that 1) CFS is best understood using a perspective which considers biological, cognitive, emotional, behavioural and social components; and 2) these components interact so as to perpetuate the illness. Psychological and social factors are regarded not only as consequences of the disturbance, but also as causes of the disturbance. As such, the cognitive-behavioural model is a biopsychosocial model, which accommodates both the psychogenic and the biomedical approaches Sharpe (1977).

1.4.2 The cognitive-behavioural model of CFS

According to this model, the factors which may trigger CFS and contribute to early morbidity are distinguished from the factors which may perpetuate it in the long-term. For example, an ordinary viral infection occurring in the context of chronic stress in a vulnerable personality may precipitate fatigue, which in most cases resolves with the recovery from infection. However, in the cases where CFS is developed, perpetuating factors such as inactivity, inconsistent activity, symptom focussing in association with illness beliefs, fears about symptoms, depression and anxiety, and psychosocial stressors interact in vicious cycles to maintain and foster chronicity (Suraway et al., 1995).

Most patients who are disabled by CFS cope by avoiding activity or by actively pursuing rest. While rest is effective in the short-term it is counterproductive in the medium and long term. Over time, physical deconditioning occurs, where fatigue will be experienced at progressively lower levels of exertion. Inactivity therefore sustains symptoms and increases sensitivity to them (Demitrack & Abbey, 1996).

Many CFS sufferers are not persistently inactive. The desire to perform at pre-morbid levels of functioning lead to oscillations between rest and activity, with an associated exacerbation of symptoms in the form of relapse, without any progressive improvement in disability. This leads to a characteristic complaint of CFS sufferers that any activity must be “paid for” later by further fatigue and pain (Friedberg, 1996).

With regard to illness beliefs and fears about symptoms, in any illness this factor can influence disability, mood and behaviour (Cleare & Wessely, 1997). Inaccurate illness beliefs, reinforced by much ill-informed media coverage, include: 1) any activity that increases fatigue is damaging or impossible; 2) “doing too much” causes permanent muscle damage; 3) CFS is caused by a persistent virus infection or progressive immune disorder; 4) CFS is irreversible or untreatable; 5) rest is the only remedy; 6) disease conviction, i.e. believing that they have a purely organic disease that they can do little to influence and thereby minimising psychological and social aspects of their illness; and 7) activity-induced exacerbations of symptoms are interpreted as warning of impending “relapse” or “harm” (Suraway et al. 1995)

These illness beliefs and illness behaviour are confirmed and reinforced by increased focussing on symptoms. Concern about the meaning of symptoms, often interpreted as warning of impending relapse, is heightened by the unpredictable nature of CFS. Increased concern leads to heightened awareness, selective attention, and increased “body watching”. This can intensify the experience and perceived frequency of symptoms, thereby confirming illness beliefs and reinforcing illness behaviour (Suraway et al., 1995).

With regard to depression and anxiety in this model, Cleare & Wessely (1997) point out that regardless of the cause of these emotional states, they are strongly associated with fatigue and muscle pain, impaired memory and concentration, and reduced activity. Sharpe (1997) points out that these emotional states may be the biological consequences of avoidance of activity and oscillation of activity. These emotions

reinforce the beliefs about the illness which reinforce the avoidance and oscillation of activity. Hence the cognitive-behavioural perpetuating cycle which maintains and fosters chronicity.

There may be psychosocial problems that contribute to the perpetuation of CFS (Suraway et al., 1995). For example, the prospect of returning to work after being chronically disabled, particularly if there are problems at work, and the loss of disability financial benefits may reinforce the condition. In other words, the loss of the benefits from being in the sick role, to be discussed in chapter 5, may impede recovery.

The above review covers most of the current understanding of CFS from research done on the subject. Motivation for the present research is done through presenting research into treatment and coping in CFS. This is presented next.

1.5 MOTIVATION FOR THE PRESENT RESEARCH

1.5.1 Research into the treatment of CFS

There is no treatment with proven efficacy for patients with CFS (Coetzer et al, 2000; Salit, 1996).

There is no commonly followed medical treatment for CFS (Coetzer et al., 2000; Wessely et al., 1998; Demitrack & Abbey, 1996). Treatment is directed at alleviating the symptoms. Non-steroidal anti-inflammatory drugs relieve the symptoms of

myalgia, arthralgia, headaches and feverishness, and non-sedating antidepressants improve mood and disordered sleep and thereby attenuate fatigue (Komaroff & Buchwald, 1998). Although immunologic therapies, corticosteroids and anti-viral therapies have been used these treatments have been proved to be of no value (Coetzer et al., 2000).

Psychological treatment for CFS includes various forms of psychotherapy, the efficacy of which is not established (Demitrack & Abbey, 1996). Berger (1993) describes psychotherapy for CFS patients from a self-psychological perspective. Taerk & Gnam (1994) describe psychodynamic psychotherapy with two patients with CFS, which culminates in their recovery from CFS. Simpson, Bennett, Holland (1997) provide an analytical psychological perspective for psychotherapy with CFS patients. The most widely recommended form of psychological therapy is cognitive-behavioural therapy (CBT), based on the cognitive-behavioural model of CFS, described above (Wessely et al, 1998; Demitrack & Abbey, 1996). Although more research is needed (Wessely et al. 1998), Sharpe (1997) points out that clinical trials find CBT to be more effective than medical care. However, as Wessely et al. (1998), and Demitrack & Abbey, (1996) point out, CBT for CFS patients requires specialised cognitive-behavioural therapists who are scarce even in first world countries.

Demitrack, in Coetzer et al. (2000), and Friedberg (1996), among others, note that although patients with CFS are among the high utilisers of complementary or alternative treatments, none of these are of proven efficacy.

1.5.2 Coping with CFS

Coping as an area of research into CFS becomes significant in view of its nebulous nature, the absence of an accepted conclusive understanding of aetiology, no commonly followed treatment, and the ineffective high utilisation of complementary medicine. How does experience of these factors impact on coping? Taking the course of the illness into account, experience of these factors is likely to change and hence so is coping likely to change. Thus, the question can be reformulated. What is the process of coping in the experience of having CFS? An investigation into this question will require a qualitative methodology in order to access the process of coping and the experience of having CFS. There is no published qualitative research into the process of coping in the experience of having CFS.

Existing research on coping in CFS includes quantitative research by: Blakely, Howard, Sosich, Murdoch, Menkes & Spears (1991); Ray, Weir, Stewart, Miller & Hyde (1993); and Knussen & Lee (1998). These studies identify various coping tendencies and strategies. The experience of persons with CFS is researched only insofar as it applies to static, empirically defined concepts of coping. In other words, coping is researched as if it is a static phenomenon, as opposed to coping as a process involving the dynamics of change.

For example, Blakely et al. (1991) researches psychiatric symptoms, personality and ways of coping in CFS. They use the Ways of Coping (WoC) inventory developed from Folkman & Lazarus's theory of coping (in Blakely et al. 1991). The inventory contains empirically defined categories of coping strategies which may be problem-

focused, directed toward resolution of the stressor, or emotion-focused, with efforts directed toward regulating distressing emotions to which the stressor gives rise. Their result in terms of ways of coping in CFS is that they find CFS patients have a mild tendency to use emotion-focused ways of coping such as Escape/Avoidance (females) and Distancing (males). According to Folkman & Lazarus (1988) 'Escape/Avoidance' describes efforts to divert attention away from the source of distress by escaping through wishful thinking, eating, drinking, smoking, using drugs or medications, or sleeping. In distancing, the person is able to acknowledge the problem but copes with it by not dealing with its emotional significance. It may be argued that one of the few uses of the research by Blakely et al. (1991) is that a negative CFS coping tendency is identified. Such a methodology is able to identify coping strategies but is unable to provide information on the context in which they are used, or how they may change as the context changes. This makes it difficult to use the findings in order to find out how to cope with CFS and it reveals very little about the phenomenon of CFS.

Ironically, Folkman & Lazarus (1988), on whose definition of coping the above research on coping in CFS is based, stress the need to view coping as a process and not a static state. They maintain that to view coping as static is to assume stable coping dispositions. To use the example from Blakely et al. (1991) mentioned above, an implication is that female CFS sufferers have a tendency to use Escape/Avoidance strategies across occasions, regardless of context. Folkman & Lazarus (1988, p.310) define coping as follows:

“Coping consists of cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. These cognitive and behavioural efforts are constantly changing as a function of continuous appraisals and reappraisals of the person-environment relationship, which is also always changing. Some of the changes in relationship result, in part, from coping processes directed at altering the situation that is causing distress (problem-focused coping) and/or regulating distress (emotion-focused coping), from changes in the person that are a result of feedback about what has happened, and from changes in the environment that are independent of the person.”

Coping as a process, reflected in the above definition, refers to “the changing character of what the person thinks and does during the unfolding of specific person-environment encounters and across encounters” (Folkman & Lazarus, 1988, p.310). However, the above research on coping in CFS does not take the changes involved in the coping process in relation to the changing person-environment relationship into account.

1.5.3 Self-management of CFS

One of the findings in research done by Ware (1993) and Ware & Kleinman (1992) is that for almost half of the subjects in two respective studies, CFS served as the catalyst for a major positive transformation in lifestyle from before CFS. Ware & Kleinman (1992, p.555) report that the participants in the research maintain that the experience of having CFS gave them the chance to “take stock and re-evaluate longstanding practices and priorities”. For example, “the sense of obligation to “to do for others” gave way to a determination to attend to one’s own needs.” In terms of this example, it appears that the self-management function of self-assertion is challenged by the experience of having CFS and that the shift from the tendency to be

submissive before having CFS to being more assertive during CFS may play a role in the transformation in lifestyle. This raises the question of self-management in the experience of recovering from CFS.

Masterson & Klein (1989) have a theory on personality structure. This is not of concern here. However, they use the term 'self-management' to refer to the way in which one manages one's life. Self-management is understood to be a reflection of developmental maturity in terms of the following functions and capacities: self-soothing, self-acknowledgement, spontaneity, self-activation, self-assertion, aliveness of affect, and creativity. For example, if someone has a history of avoiding negative feelings by becoming involved in self-destructive behaviour it may be assumed that the capacity to self-soothe is not maturely developed.

1.5.4 Focus of the present research

The two questions raised this far are firstly, the process of coping in the experience of having CFS and secondly, the process of self-management in the experience of recovering from CFS. Thus, the aim of this research is to investigate the process of coping and self-management in the experience of recovering from CFS.

In order to provide fruitful data to investigate the present research question it was decided to find research participants who view themselves as recovering from CFS or as recovered from CFS. Firstly, it was anticipated that participants who view themselves in this way would provide the opportunity to access data in order to study the dynamics of change in coping and self-management over the course of the illness.

Secondly, in order to investigate the process of self-management research participants who have experienced a positive transformation in lifestyle would be preferred. It is unlikely that CFS sufferers who are chronically ill with CFS will have experienced a positive transformation in lifestyle. It is more likely that CFS sufferers who view themselves as recovering from CFS or recovered from CFS will have experienced same. Thirdly, the perspective of hindsight (Kelly, 1994) of the person who has recovered from CFS may contribute to the richness of the data. For example, at the time of experiencing the onset of symptoms of CFS a participant may believe that she is not depressed. However, in hindsight, once she is recovering or recovered from CFS, she may understand that she was depressed at that time. The perspective of hindsight is discussed further in the next chapter on methodology.

CHAPTER 2

METHODOLOGY

2.1 RESEARCH OBJECTIVES

1. The aim of the following research is to investigate the process of coping and self-management in the experience of recovering from CFS.
2. In order to investigate the above the research aims to obtain an understanding of the experience of having CFS and the experience of recovering from CFS in terms of coping and self-management.
3. The research aims to access and investigate the dynamics of change in the process of coping and self-management in the experience of recovering from CFS.
4. Determined by the nature of the findings from the above, the findings will be discussed in terms of theoretical perspectives that reveal more about the findings than the findings themselves, to be explained below. In addition, the theoretical perspectives applied to the findings of this research will be determined by their potential to make it possible to think critically about current understanding of CFS. In this way, it is intended that the research may contribute to current understanding of CFS.

2.2 APPROACH

To achieve the above-mentioned research objectives, a methodology is required to enable the researcher to move from the point of accessing experience of coping and self-management in the experience of recovering from CFS to the point where the research is able to make a contribution to current understanding of CFS. The researcher considers that a hermeneutical model of doing research is appropriate for achieving the objectives of this research. This becomes clear in the following discussion of the hermeneutical functions of empathy and distanciation.

2.2.1 The hermeneutical function of empathy

Three research participants who consider themselves as recovering or recovered from CFS were interviewed to obtain data for analysis. This is to be subsequently described. Interviewing may be understood as the operation in research of 'understanding' as :

1. the hermeneutic principle of empathy, Dilthey (cited in Kelly, 1994);
2. the relationship 'speaking-hearing' (Ricouer, in Kelly, 1994); and
3. the empathic perspective of immediacy (Kelly, 1994).

In terms of the hermeneutic principle of empathy, Dilthey (cited in Kelly, 1994) proposes that in order to understand, for example, a research participant's 'lived experience' of having CFS, the researcher must engage in a method of empathic reliving of the participant's experience. The meaning of the participant's experience

of having and recovering from CFS can only be ascertained through access to the participant's subjective experience. In addition, according to Dilthey, the meaning of the participant's subjective experience can only be ascertained in relation to the context in which it occurs. In the interviews, the researcher attempts to do this through the questions that the researcher asks the participants. These are to be described below, in the section on data collection.

For Ricouer (in Kelly, 1994), immediate contact with a speaker, or the relation between speaking and hearing, is paradigmatic for 'understanding' a person. Here, the person speaks for the person who hears. In the interviews, the participant speaks for the researcher. Ricouer (in Kelly, 1994) says that speaking is distinctly contextual. In the interview, the meaning of what the participant says, may be questioned, clarified and confirmed by the researcher in relation to what is specifically meant by the participant. About Ricouer's point, Kelly (1994, p.4) says "speech has an ostensive sense which is set within the context of speaking, and in this respect the meaning of the utterance can be said to be identical to the utterer's meaning."

The hermeneutic perspective of empathy (Dilthey) and the relationship 'speaking-hearing' (Ricouer) corresponds with Kelly's (1994) empathic perspective of immediacy. In terms of the empathic perspective of immediacy, "other-knowing through empathy involves imaginative immersion in the immediacy of what is known to the experiencing subject" (Kelly, 1994, p.8). Kelly (1994) defines empathy as knowing within a horizon, or knowing within a perspective. In the interview, the researcher adopts an empathic stance in order to facilitate and obtain from the

participant a detailed description of the “textures within the lived world” (Kelly, 1994, p.8) of having and recovering from CFS. Thus, the content of the interviews are descriptions of the participants’ understanding of the textures within their lived world of the experience of recovering from CFS.

Kelly (1994) points out that in the human sciences, particularly phenomenology and ethnography, meaning is strictly embedded in subjective experience of situations and events, and emerges out of, in Dilthey’s sense, empathic immersion in a context. There is a tendency in the human sciences to say “the proper human reality emerges out of the perspective of the person who has the experience” (Kelly, 1994, p.7). Kelly (1994) points out firstly, that this leads to the supposition that the best test of veracity of research findings is to return these to the research participants for confirmation. Kelly (1994) goes on to say that if this is the case, attempts at understanding are reduced to a superficial and banal level. In terms of the hermeneutical function of empathy, understanding a research participant’s experience of recovering from CFS may be achieved merely through the method of interviewing. In this sense, the data speaks for itself and does not need to be analysed. However, the second point that Kelly (1994, p.5) raises, is the question of the “possibility of there being meanings existent within a context of speaking (or action), which the speaker (or psychological subject) is unaware of, and possibly unable to articulate, but which we can gain access to through interpretation.” Therefore, “we must move beyond the subjective appropriation of reality in seeking to understand” (Kelly, 1994, p.5). The data does not speak for itself. The data comes to be understood in terms of how it is analysed.

2.2.2 The hermeneutical function of distanciation

In this research the interviews are transcribed to provide data for analysis. Through the operation of the hermeneutical function of empathy in the interviews, the interview transcripts represent the research participants' arrogation of the meaning of their own experience. The analysis of the interviews/data, or the process of asking increasingly better questions, to be described below, may be understood as the operation in research of the hermeneutical function of distanciation, as developed by Ricouer (in Kelly, 1994), and the perspective of distanciation (Kelly, 1994).

Ricouer (in Kelly, 1994) distinguishes between 'understanding' and 'interpretation'. In seeking to understand a person in the communicative sense, described above, one is bound by the confines of the speaker's appropriation of reality. However, once the content of what the speaker says is layed down in text, for example, the interview transcripts of this research, one is no longer bound by the confines of the speaker's appropriation of reality. The content of what is said becomes available for everyone to read. It takes on a textual character and understanding this takes on a textual mode of interpretation. Once the content of what is said is layed down in text, the original intention of the speaker and the meaning of the text cease to coincide. "What the text says now is not necessarily what the author meant to say and the meaning of an inscribed (written) event surpasses the meaning contextualised in a situated event, i.e. the event in its specific context" (Kelly, 1994, p.4). This 'surplus of meaning' is a crucial feature of textuality. The break from immediate contextuality constitutes distanciation. Kelly (1994, p.4) regarding Ricouer on this point says "textuality allows interpretation to say more about the world to which the text refers than can be

ascertained in a dialogue with the speaker. In short, textuality in not being bound by the confines of the speaker's appropriation of reality, allows the reader to gain an understanding of the world beyond the speaker's appropriation thereof."

Kelly (1994) understands Ricoeur's model of the text to mean that distanciation has the function of disclosing the original meaning of the text in a way that surpasses the power of the context to disclose meaning of itself. In terms of this understanding Kelly (1994) describes a particular quality of the dialectical relationship between empathy and distanciation, which he refers to as the empathic perspective of immediacy, described above, and the perspective of distanciation. In terms of the empathic perspective of immediacy, the content of the interviews represent the views of the experiencing participants. Kelly's (1994) statement is mentioned above, that there is a tendency in the human sciences to say that the proper human reality emerges out of the perspective of the person who has the experience. Kelly (1994, p.7) suggests, however, that the "perspective of the standpoint of the experiencing subject is not a privileged standpoint from which to view the reality of the subject." A participant's subjective views of her experience is likely to be limited by the perspectival viewpoint of her subjectivity itself. Analysing this represents the researcher's view of the experience of recovering from CFS. Analysis of the data breaks out of the participant's horizontality or perspective of her experience. The participant's view is oriented, or revealed in relation to the perspectives in the form of questions that the researcher brings to the participant's view. The researcher may have access to the participant's experience of recovering from CFS in ways that the participant, immersed in her experience, does not have immediate access to. Kelly

(1994) states that the function of the observer, or the researcher, is seen as an epistemological function, which is fundamental to understanding. "This function is vital in the process of research and sets research apart from taken for granted understanding" (Kelly, 1994, p.8).

As will be seen below, the analysis of the data of this research involves a process of questioning of the participants' arrogation of the meaning of their own experience. Here, there is an increasing move away from the participants' subjectivity. Kelly (1994) states that this does not mean that there is a move towards an absolute objectivity. "It does seem legitimate to speak of a broader, deeper and more comprehensive perspective than the subject's own perspective, as being more objective, but the new perspective is not necessarily closer to 'nowhere'. It can be conceived of as a new standpoint which remembers the old" (Kelly, 1994, p.8). That the new perspective is not a view from 'nowhere' means that it is impossible to be absolutely objective about the subject's experience because the new perspective about the subject's experience is fundamentally determined and limited by the subject's perspective. Analysing the data undeniably loses the immediate sense of veracity of the participants' experiences. However, the interpretations made are nevertheless 'real' through being about these experiences.

Kelly (1994) uses Gadamer's discussion of distanciation to suggest that it is only through entering other horizons or viewing experience from other perspectives, that we can know a situation a better. Critical awareness of subjective perspectives may be developed only through the fusion of present horizons with new horizons. The

fusion of horizons refers to the interpretative process where the meaning of the participant's perspective emerges in the researcher's attempts to understand the participant's perspective. Here, the perspectives of the researcher fuse with the participant's perspectives. In this process of fusion, the researcher's new understanding transcends the original perspectives of the researcher and the subjective perspective of the research participant. "Whatever interpretive horizon we bring to a context, whether it be a map, a theory, or a theme derived from typicalities which endure across particular instances, or the perspective of hindsight, the hermeneutical function of distanciation undeniably allows us to know a situation better" (Kelly, 1994, p.9).

The participants in this research view themselves as recovering or as recovered from CFS. As such, the experience of having and recovering from CFS is researched from the participants' perspective of hindsight of their experience. At the end of chapter 1, it was mentioned that the participants' perspective of hindsight may contribute to the richness of the data. In terms of the above discussion, this means that the participants would have a distanced perspective of their own at the time of being interviewed. It is likely that each participant would have attributed new meanings to their experience. Or, they would have applied new horizons of understanding themselves to their own experience. The data may be richer in the sense that meanings which did not previously or at the time of the experience, exist, are in hindsight created in reverse sequence. Kelly (1994) says "in being attributed to a situation in hindsight, meaning should not necessarily be seen as imposed upon the situation, and such meaning may be claimed to be essentially true of the situation." While the perspective of hindsight

is important, the emphasis is rather, that the perspective being analysed, regardless of when the perspective is created, is the perspective of the research participant.

In terms of the above discussion, the interviews and the analysis of the data involve the operation of both the hermeneutical functions of empathy and distanciation. Through using this methodology and these hermeneutical functions, this research is able to have access to the experience of recovering from CFS. This experience becomes a reference, which poses limits on what can be said about this experience. At the same time, these limitations also inform one of the horizons, or the perspectivity, of the experience itself. Knowing this, the researcher is able to say more about the participants' experience of recovering from CFS. This is elaborated below, in the section on the analysis of data.

2.2.3 The 'grounded' hermeneutic research approach

The methodological process of this research contains features of the 'grounded' hermeneutic research approach (Addison, 1992), specifically, the idea that research questions should be allowed to develop during the course of doing research. The development of research questions is intrinsic to the process of doing research. The literature review and the research questions, that is, the projected pre-understandings of the phenomenon to be investigated, provide a starting place for research. Packer (1989) goes on to say that in this way research is conceived of as a means of asking more meaningful and useful questions. This is a reflective process of engaging with the data, during which the questions guiding the research are re-examined and reformulated (Mergendoller, 1989). In this way the data does not speak for itself.

Rather, questions are asked about the data leading not to results, but to better ways of thinking about the phenomenon under investigation, and further questions. Thus, it may be said that a hermeneutical model is exploratory, discovery-oriented and theory-generating rather than hypothesis-testing (Elliot, 1989).

In addition, the methodological process of this research contains features of the 'grounded theory' approach suggested by Glaser & Strauss (1967).

2.2.4 The 'grounded theory' approach

The researcher "jointly collects, codes, and analyses his/her data" (Glaser & Strauss, 1967, p.45). In this way, the research does not proceed in a linear manner from introduction to conclusion. Rather, the questions asked, the data collected and the interpretative account, are intertwined. In the process of doing the research these develop together in the sense that they mutually inform each other. In this research, interpretation of the data began with reflections made by the researcher during the initial interviews. The literature review evolved as questions guiding the data interpretation evolved. The emerging interpretative account and the literature reviews continued to influence each other until the point of completion.

2.3 DATA COLLECTION

2.3.1 Research participants

In order to provide an interpretative account that may be used to say something in general about CFS, from the process of coping and self-management in the experience

of recovering from CFS, it must be characteristic or typical of such experience. It was decided that the experience of three people who are recovering or have recovered from CFS would provide sufficient variation in order to this.

Criteria for selection of participants was firstly, that they had to have been medically diagnosed as having had CFS and secondly, that they consider themselves to be recovering or recovered from the condition. This emphasis, of the second criterion, is explained at the end of chapter 1.

The participants were drawn from patients in private medical practices. The researcher approached four medical practitioners individually. They were informed about the research questions. They were requested if they would be prepared to assist the researcher in the process of finding participants for the research. All were willing to assist. They were asked if they had any patients diagnosed with CFS who are recovering or have recovered in their practices. One medical practitioner did not. Three medical practitioners did. They each approached one of their patients who had recovered from CFS. The patient was informed about the research question, and that it was being conducted by a Rhodes University student, doing a Master's degree in Clinical Psychology. The patients were prepared to have their names and telephone numbers given to the researcher in order for the researcher to make contact with them. Each participant was telephoned and informed that participation in the research would entail a series of three separate audio-taped interviews. A date and time for the first interview was established for each participant. Prior to the commencement of the first interview each participant completed a consent form.

2.3.2 Interviews

A series of three separate, semi-structured interviews of approximately 90 minutes duration each was conducted with each participant.

Seidman (1991) describes a model of in-depth, phenomenological interviewing. It is a three-series structure of interviewing where each interview provides a foundation of detail, which illuminates the next. The first interview establishes the context of the participants' experience under investigation. This corresponds with Dilthey's (in Kelly, 1994) idea that the meaning of the participant's subjective experience can only be ascertained in relation to the context in which it occurs, mentioned earlier. This contributes a historical dimension to an understanding of the experience of the phenomenon under investigation. "The interviewer's task is to put the participants' experience in context by asking him or her to tell as much as possible about him or herself in light of the topic up to the present time" (Seidman, 1991, p.11). The second interview allows participants to reconstruct the details of the phenomenon within the context in which it occurs. The third interview requires that the meaning of the phenomenon for the participant be explored. In this research, Seidman's (1991) model was used as a guide.

In accordance with Seidman's (1991) model, the first interview of this research with each participant focused on the context of having CFS where the participant's experience prior to the onset of CFS was explored. Where it was necessary to understand the context, the appropriate aspect of the participant's life history was explored. These interviews were audio-taped, but not transcribed. From listening to

the audio-taped interviews the researcher compiled reports of the context of having CFS for each participant. See Appendix 1 for these reports.

The second interview focused on the experience of the onset of symptoms, and the chronic phase of having CFS. It was found that the participants' reconstruction of their experience was already imbued with meaning. The meaning was explored at the same time. Therefore, instead of having a separate third interview for the exploration of the meaning of the experience for each participant, as suggested by Seidman's (1991) model, the researcher used the third interview to focus on the experience and the meaning of recovering from CFS. Please see Appendix 2 for the interview questions used in these interviews. The interviews were audio-taped and transcribed in order to provide the data for analysis. As an example, the transcribed interviews of the third interview for each participant can be found in Appendix 3.

2.4 DATA ANALYSIS

The following methodological procedure systemically transformed the audio-taped interview material to the point where it yielded an account of the process of coping and self-management in the experience of recovering from CFS.

The 'reading guide' method used by Brown, Tappan, Gilligan, Miller & Argyris (1989) was adapted for analysing the interview material. This method is a way of structuring the process of interpretation, from reducing the data to the discussion stage. It is a method of textual interpretation developed for taking from the text those

features of the text which clarify the meaning of the text in terms of particular questions. The development of a reading guide begins with formulating a set of questions through which the textual material is to be read. A reading guide brings an ordering to the interview material. Further development of the reading guide or the development of second and third order reading guides facilitates further exploration of the material. Using the 'reading guide' method involves the hermeneutical function of distanciation, as discussed earlier.

The sequence of the data analysis:

Step 1:

Development of first interpretative reading guide:

Each transcript was read as many times as was necessary to obtain an understanding of each participant's experience in terms of the researcher's understanding of CFS as reflected in the literature review.

The construction of the subsequent reading guide involved returning to the literature review and reflecting on the interview data so that the emerging reading guide was appropriate to the aims of this research while at the same time remained true to the data that was collected.

In consideration of each of the participant's experience together, it was found that the experience of recovering from CFS could be viewed as occurring in three phases:

1. The onset of symptoms.
2. Being chronically ill with CFS.

3. Recovering from CFS.

Questions to extricate features of coping and self-management were formed in relation to each of these phases.

2.4.1 First interpretative reading guide

1. How does the participant cope with the experience of the onset of symptoms?
2. How does the participant cope in terms of her experience of being chronically ill with CFS?
3. How does the participant cope in terms of her experience of being chronically ill with CFS such that she arrives at the point where she is able to view herself as having recovered from CFS?

Step 2:

Application of first interpretative reading guide:

The reading guide was applied to the interview material of each participant by reading the data of each participant in terms of each question in the reading guide. Firstly, data relating to each reading was extricated from each of the transcripts. Secondly, interpretations were made by formulating meaning from the process of asking the data the questions of the reading guide. Please see Appendix 4 for the end result of this methodological step. Application of the first reading guide constitutes the first phase in distancing from immediate contextuality, or the participants' subjectivity.

Step 3:

Development of second interpretative reading guide:

The development of the second interpretative reading guide involved moving from the particular experience of each participant to the general experience of all the participants. This is explained below, in step 4. The following reading guide is the same as the first reading guide with the exception that it is applied to each of the participants at the same time, and a further question, question 5, is included.

2.4.2 Second interpretative reading guide

1. How do the participants experience the onset of symptoms?
2. How do the participants cope with the onset of symptoms?
3. How do the participants cope in terms of their experience of being chronically ill with CFS?
4. How do the participants cope in terms of their experience of being chronically ill with CFS such that they arrive at the point where they are able to view themselves as having recovered from CFS?
5. How do the ways in which the participants cope during recovery differ from ways in which they cope during the chronic phase of having CFS?

Step 4:

Application of second interpretative reading guide:

The first reading guide was applied to the interview material of each of the participants at the same time. This meant taking each question and reading 'across' the text of each participant in terms of the question asked. Reading 'across' the text

of each participant involved asking what is typical about the particular experience of each participant concerned in the question being asked. For example, in relation to question 4 of this reading guide, P1 goes through a phase of self-confrontation, P2 experiences gradual self-confrontation supported by psychotherapy, and P3 undergoes holistic treatment from a physiotherapist. The particular experience of each participant is different from the other. However, the experience of self-reflection is typical of the particular experience of each participant. Thus, moving from the particular to the general, in the way just described, allows for further interpretation. Application of the second reading guide constitutes a second phase in distancing from immediate contextuality, or the participants' subjectivity. As such, it is a step further from the participants' subjectivity than the first phase of the application of the first reading guide.

The interpretation yielded in terms of the above reading guide constitutes the account of the process of coping and self-management in the experience of recovering from CFS. This is presented in the form of 'results' contained in the chapter 3.

Step 5:

Development of third interpretative reading guide:

In this last phase of interpretation, or of the process of distancing from the participants' subjectivity, the limitations of the participants' experience are considered with an invitation to new horizons of understanding, or other perspectives, of the participants' experience. For the researcher, the findings that emerge from the first

and second reading guides, in the form of ‘results’ in chapter 3, invite the following reading guide.

2.4.3 Third interpretative reading guide

What do the interpretations of the first and second interpretative reading guides mean in terms of:

1. a function of discourse (Shotter, 1992);
2. a medical anthropological perspective of the social relations of sickness (Helman, 1990);
3. Levin’s (1987) postmodern perspective of disease; and
4. current understanding of CFS?

Step 6:

Application of third interpretative reading guide:

The application of the third reading guide is described in chapter 4, the discussion of the research findings.

CHAPTER 3

RESULTS

The following is an interpretative account of the process of coping and self-management in the experience of recovering from CFS. This account is the outcome of the methodological process pertaining to the application of the second interpretative reading guide, as outlined in chapter 2.

3.1. SELF-DEFINITION OF BEING ILL

The life context in which each participant becomes ill is characterised by chronic psychosocial distress. For examples, see illustration below.

Illustration re psychosocial distress:

Participant 1

Central to P1's life situation at this time are her ways of attempting to cope with her divorce two year's previously. She describes her divorce as the most stressful time in her life. Her first intimate relationship since her divorce ends in "disaster".

Participant 2

Central to P2's life situation is living by her re-commitment to her marriage, her unsuccessful attempt at in vitro fertilisation to become pregnant, and adjusting to a new environment. This is after a lengthy period of instability in her marriage.

Participant 3

The central issue in P3's life is her efforts to repair her problematic relationship with her father. She is upset about his anger and disappointment in her for dropping a subject at school. She becomes anxious when she realises that she is failing in her attempts to repair their relationship by doing well academically at school.

As mentioned above, the life context in which each participant becomes ill is characterised by chronic psychosocial distress. However, the language that the participants use to describe their experience of becoming ill and their understanding of this contain no reference to experience of the distressing psychosocial contexts in which the onset of symptoms occurs. Their language is in somatic terms only. The participants are uncertain about the meaning of the onset of symptoms. They cope with the uncertainty by defining themselves as ill with “something” in somatic terms. The meaning of the experience of the distressing psychosocial context in which each participant becomes ill appears to play no role in attempts to understand the illness, as reflected in the self-definition of being ill. The participants perceive their illnesses as “something” which is external and separate from themselves.

Illustration re:

- **somatic language and understanding of onset of symptoms**
- **uncertainty about meaning of self-definition of being ill**

Participant 1

Description of the experience of the onset of symptoms:

“For me, it was like my body could not overcome the flu that I had. Normally, when I had flu in the past, my body would deal with it in a way that it made me forget that I had flu. I would just recover. But this time, I’d just be getting back into things and wham! I’d be stopped dead in my tracks. I’d feel so sick, be so tired and feverish that I’d just collapse into bed. I couldn’t continue with normal living. Like I’d be back at work rearing to go and I’d have to end up going home. It was on and off like that the whole time.”

Description of the understanding of the experience of the onset of symptoms:

“Well, I thought that there must be something wrong with me that I just couldn’t get over this flu. There must be something major going on. I began to panic. I had been on antibiotics for this flu. So, when it felt like I hadn’t got over it, it was scary. Perhaps I had glandular fever I thought. The thought of Aids

crossed my mind, but I knew I couldn't have that. But I was very worried because it felt like I was being taken over by something."

Participant 2

Description of the experience of the onset of symptoms:

"When I was having in vitro fertilisation, the incredible doses of hormones that I had to have made me incredibly moody and mad, but knowing where it came from helped. During the first few weeks of feeling this change, being very tired, I got bronchitis. I don't think I ever really got over it. I was in bed more than out, for weeks afterwards. Getting an incredibly sore throat has always been a big symptom for me. At night, mainly, I'd frequently get temperatures, feeling feverish. I felt very stiff, my whole body, and it ached, even after the bronchitis was over. For about three months after having bronchitis I'd keep on trying to be well when I wasn't. At the first moment of feeling any sign of feeling better, I was so happy, I'd just be getting into doing things, and I was ecstatic about catching up, when then I would be taken over by this terrible exhaustion. It would just immobilise me and I'd literally collapse in a heap."

Description of the understanding of the onset of symptoms:

"I knew that I was sick, and that it had nothing to do with the in vitro that I had gone through. I had to find out what it was. I was afraid of what might happen if I didn't get it diagnosed and treated as soon as possible."

Participant 3

Description of the experience of onset of symptoms:

"Being tired was never a problem for me before I got ME. I could always psyche myself out of everyday tiredness. But this time, it was after I had a bad case of flu in my September holidays, that was the end of standard 9, which hit me hard, it was quite frightening. I just didn't get better. And I so badly wanted to, there was so much to be done. Every time when I'd feel, okay, this is finally going now and I'd muster my energy to rear ahead, I was getting behind in everything, no sooner than I'd be doing this, then I'd feel horribly sick again. Flu'ie, you know, my muscles and joints felt paralytically weak, sore, and stiff. And, quite striking was the absolute exhaustion, like I had been drained of my life blood. The worst was, before being diagnosed, fighting to ignore these symptoms and pushing painfully along despite feeling so sick."

Description of the understanding of the experience of onset of symptoms:

"I didn't understand it. I simply couldn't handle it. It was frustrating, and I began to worry. "This is not normal", kept niggling in the back of my mind until well, eventually, I had to admit that there was something seriously wrong

with me. This is all I knew, yes, definitely I had something, and also, it had to do with the flu that I had initially.

3.2 USING EXTERNAL RESOURCES

The participants use external resources to cope with the onset of symptoms. Firstly, they use external social resources to cope with being ill. Secondly, and subsequent to being diagnosed with CFS, they use external treatment resources. This is elaborated below.

3.2.1 Using social resources

The participants use external social resources to cope with being ill by expressing their experience of illness with others in their social networks. They do this in order to justify their illness behaviour to others and to be understood by others as being ill. However, others attribute their illnesses to psychological problems. This gives them the impression that they are perceived as not being ill. They feel stigmatised. The participants feel misunderstood by others. The participants cope with this by consulting medical practitioners in a further attempt to justify their illness behaviour to others and to be understood as being ill. The participants receive medical diagnoses of psychological problems, depression, and stress, respectively. They perceive these diagnoses to be not 'real' illnesses. As such, the participants perceive that they are being misunderstood as being not ill, and accused of pretending to be ill. Consequently, they continue to feel stigmatised.

Illustration re:

- expression of illness with others
- psychological illness attribution of others
- impression from others that participants are not ill
- participants feel misunderstood
- participants feel stigmatised

Participant 1

In relation to her parents, P1 says the following:

"They believed it was psychosomatic."

"My hectic socialising since the divorce and my new boyfriend which ended in disaster and being so busy at work. They believed that my symptoms were as a result of this stress."

In relation to her friends and colleagues at work, P1 says the following:

"It was kind of the same thing."

"They also believed it was stress"

P1 describes her response to the illness attributions of others as follows:

"I was very angry, upset by this suspicion that I wasn't really ill. I wasn't pretending. They were not allowing me to be sick."

P1 consults a doctor with the tension created by others not believing in the reality of

her illness, in mind. She says:

"I was sure that by this time [the doctor] must be getting quite tired of me and I went to see him with this in mind."

"I had the impression that he thought I was just not coping with life, you know, from the previous times I had seen him about being off work. Then, when I suggested to him that I had ME he was hesitant and sceptical."

P1's illness is diagnosed as psychological in origin. She defensively resists this and

feels misunderstood. P1 describes this experience as follows:

"I mean the evidence was there that I had a physical disturbance. I felt blatantly insulted and in no uncertain terms did I let him know it."

"It was incredibly frustrating being misunderstood like that by everyone, even my own parents."

Participant 2

P2 consults her doctor who refers her to a specialist physician. He finally tells her "there is nothing wrong with you". P2 consults additional medical professionals with this in mind. Several of her consultations with medical professionals result in the diagnosis of depression. The participant vehemently denies the possibility of depression. She feels misunderstood.

P2: "It irritated me a lot, that talk about you are depressed."

"It was quite clear that I wasn't being listened to. I was rather insulted."

"I was mad about this. The fact that my real complaints ... were not taken at face value, was like a real slap in the face. These symptoms were just not addressed. It was bizarre."

Participant 3

P3 consults her doctor who finally attributes her symptoms to stress. P3 says the following:

"The worst was that a lot of people thought that I was just trying to get a second chance for failing myself."

"The most tragic thing for me was my parents, my father. I was just not in his good books, hadn't been for years, and he was outright with that accusation, "bullshit" he said. That was devastating for me. And in that state I had to try and clear my name, get myself understood."

P3 consults a doctor with the tension created by the attribution of others that she is not really ill, in mind. In relation to the possibility that she may exclude the distress in relation to her father in her consultations with the medical profession P3 says:

"Ja, it could have led me to emphasise my symptoms to the doctors. I mean, can you imagine, if I told them the whole story about my father. Well, I just knew what the psychiatrists were making of this, it's the kind of things they look for. They were suspicious, I could pick it up from the questions and in the general tone."

P3 feels misunderstood by the medical profession.

"It was the battle of my life to get a diagnosis. It kills me to think about that time. How frustrating it was not being heard. I mean I couldn't believe it. How I felt, it was like being accused for a crime you didn't commit." My father, other people, from their point of view, yes, I could understand why they could accuse me of pretending. But, it was the end of the world for me really, that the custodians of our health, that even they just couldn't understand."

The participants network the medical profession for a personally and socially acceptable diagnosis. This means that when a diagnosis received from one medical practitioner is not satisfactory to the participant, the participant moves to the next medical practitioner, thus networking the medical profession until a personally satisfactory diagnosis is received. In this process, the participants become medically diagnosed as having CFS. The diagnosis of CFS firstly, provides certainty about the meaning of being ill with the onset of symptoms. Secondly, the tension created by the contradiction from others in their social networks and the medical profession that they are not ill is resolved. They are relieved. The participants experience the diagnosis of CFS as a justification of their illness behaviour and an understanding from others that they are ill.

Illustration re the experience of being diagnosed with CFS:

P1: "Eventually, many months into it all, when I got diagnosed with ME, it was a hell of a relief. There was something else going on and I wasn't pretending and now I could be ill without having to worry about the possibility that they were right. It felt great to be able to tell people now that I had ME, you know, like when people would ask me what was wrong with me."

"And then, I could stay at home in peace. My folks came round and were really concerned and helpful."

P2: "When I got diagnosed it was good to know what I've got. That uncertainty was over,"

"It was most certainly better for me to tell people that I had CFS and not depression. CFS is a real illness whereas depression as an illness is rather frowned upon. I certainly would not have felt so comfortable retiring to bed. It was relieving to find that the other doctors who diagnosed me with depression were actually wrong."

P3: "I just burst into tears. Not only because I felt relieved, my integrity was returned, but because of the traumatic battle it was for me. All the suspicion it was terrible for me."

3.2.2 Using external treatment resources

The participants cope with being chronically ill with CFS by networking the health system for effective treatment. They rely on external treatment resources. These refer to treatments offered by agents in the health system, such as doctor, homeopath, reflexologist, magazine articles, the ME Association of South Africa (MESA).

Illustration:

*P1: "At first I relied very much on anything any doctor would recommend."
"I even accepted referrals to psychiatrists, took anti-depressants. There were many alternative treatments that I tried."*

*P2: "I spent a great deal of time looking for something or someone to help me."
"I wanted to believe that there was something out there and if I looked hard enough I'd find it."
"this cost me a fortune in all the various medical consultations and other therapies."*

*P3: "the support group that I joined was my hugest coping mechanism."
"People in the group would talk about what was happening to them and advice was discussed. We tried everything suggested."*

One of the participants excludes the medical profession in her search for effective treatment. The “traumatic” experience of searching for a diagnosis left her feeling alienated from the medical profession.

Illustration:

P3: “I just burst into tears. Not only because I felt relieved, my integrity was returned, but because of the traumatic battle it was for me. All the suspicion it was terrible for me.”

“Once diagnosed I got the distinct impression that I was not welcome to return to the medical arena. I didn’t want to go back and I haven’t been to see a doctor since.”

The more these treatments are experienced as ineffective the more desperate they become for help, and the more they network the health system.

Illustration:

P1: “I’d often go to the doctor in a desperate state and I’d just break down in his office.”

“I even accepted referrals to psychiatrists, took anti-depressants.”

P2: “if I could just buy it, I would have paid anything.”

P3: “I even went on a detox diet, basically starved, it was suggested somewhere that our immune systems can’t cope with all the toxins.”

They experience cycles of hope and disappointment at each treatment resource used and found to be ineffective.

Illustration:

P1: “if I think of all the things I tried and did, it began to wear me down, you know, being disappointed all the time.”

“You’re always onto something else, hopeful, searching for something which would cure you and then prove that you aren’t just depressed.”

P2: “But, after all that time of getting optimistic and then being disappointed, it was like that, in cycles, in the end it became boring, pointless, and I got too tired of being frustrated.”

*P3: "Each time, I'd feel excited, now this is it"
 "The terrible realisation that I'm not getting any better. Nothing worked."*

In their search for effective treatment the participants once again experience social and professional scepticism about being ill. Whereas before they experience scepticism about being ill, this time it is about the validity of CFS as a 'real' illness. The certainty that the meaning of the diagnosis of CFS gives to the initial uncertainty about the meaning of being ill gives way once again to uncertainty. All of the participants become uncertain in their confusion about the meaning of CFS. The two participants who include treatment resources from the medical profession in their search for treatment also become alienated from the medical profession. These two participants become depressed. All of the participants stop networking the health system for treatment.

Illustration re:

- **Social and professional scepticism about validity of CFS as a 'real' illness**
- **uncertainty about the meaning of having CFS**
- **alienation from the medical profession**

Participant 1

P1 is alienated from the medical profession and is confused about the meaning of CFS.

P1: "Some doctors don't take the physical symptoms seriously, believing that it's just stress. Those that do take them seriously are unable to treat it. The psychiatrists don't take the physical symptoms seriously. It left me feeling rather out in the cold"

*"for me, living with ME has had a lot to do with living with depression"
 "but then, it would always come back to the feeling of actually having a physical disease, suffering physically which felt as if it had nothing to do with what was going on in my mind."*

P1 is alienated from others in her social network, is uncertain about the meaning of CFS, and becomes depressed.

P1: "But it gets a bit much when people ask you again and again how such and such a treatment has worked, and you say that nothing changes, you are still very ill, but you don't look too bad."

"It's hard to live with this yourself let alone get others to understand it. People, myself included, began to doubt the reality of ME. What's the point of having a diagnosis when it gets you nowhere? So, in the end, the relief of having the diagnosis of CFS sort of went back to the confusion before I got diagnosed. And it was so hard trying to make sense out of it when all I came up against was doubt about the reality of ME."

"It seemed that now that I was also a psychiatric patient what my friends and family thought about my illness initially was right. Maybe ME is all in the mind."

"Maybe it is a form of depression. For a while I really felt it to be like this. And other people treated me like ME is in the mind."

"But then, it would always come back to the feeling of actually having a physical disease, suffering physically which felt as if it had nothing to do with what was going on in my mind."

"I didn't want to carry on this way and many, many times I would just want to die rather than to live this life of illness."

"Having to come to terms with, at the end of the day, that no matter what you tried, you weren't getting better. It all seemed so pointless really. And I gave up hope eventually that there was going to be anything that could help me."

"In the end I just lost hope in everything that I originally had hoped and automatically expected could help me conquer this illness."

Participant 2

P2 is alienated from the medical profession, is uncertain about the meaning of CFS, and becomes depressed.

P2: "I couldn't accept that I must just go home and rest. That's not treatment. It's like, just put her in file 13, the waste-paper basket, that's most of the medical profession.

P2: "When I withdrew into this shell and just couldn't get up anymore, I was dangerously depressed, most people, there was an awkwardness with me, and my husband told me that his family were saying that yes, it's actually depression after all. I didn't care about that anymore. I didn't know what to make of CFS anymore. For the first time in my life I found out what it was like to be depressed. This is when I needed psychiatric help. I went into psychotherapy for three years."

Participant 3

P3 experiences uncertainty about the meaning of CFS.

P3: "After a while, a lot of people with CFS, certainly myself, because of all I went through, having to cope with what many people think, you know, that it's not a real illness, and that there is nothing to help you, nothing ever changes.

3.3 USING INTERNAL RESOURCES

The context of the experience of CFS at this stage is the chronicity of the illness, the inability to find help in the form of treatment to control the illness, the confusion about the meaning of CFS, and feeling isolated in relation to the alienation from the health system. In this context, the participants experience self-reflection. P1 goes through a phase of self-confrontation. P2 experiences gradual self-confrontation, supported by psychotherapy. P3 attributes the turning point in her experience of having CFS to holistic treatment she receives from a physiotherapist.

Illustration:

P1: "Being sick, with there being nothing more to try, left me just being with myself. It was scary, to have no option but to live with yourself. I had become so isolated with this illness, I couldn't do anything. No more attempts at treatments, activities and people to escape into. It was hell. I was left with no option but to think ... and the questioning. What have I done wrong? Why have I got this illness? What must I do now to break through, so that next time round, the next life maybe, I don't have to go through this again?"

"Having CFS forced me to look in, to recognise my faults and losses, things that I did not like, and to deal with them. CFS was the catalyst. To come out of it accepting my faults and to work with them. Getting over CFS had a lot to do with this, for me"

"I couldn't rely on anyone or anything to kind of fix me. I learned to take responsibility for my illness.

P2: "I don't think I would have been able to get to where I am today as a person and as a person with CFS if it wasn't for psychotherapy."

"I can come out and clearly state that if I hadn't worked on myself as a person, I will not have recovered from CFS."

"I could choose to not work with this illness. I had to take responsibility for recovering. No one else was going to do this."

P3: "The fact that without really being aware of it, I was less and less seeing myself as a person who has CFS. I was getting caught up in, how can I describe it, the magic of getting better, and learning to do it myself, relying on myself and doing it myself."

"After a while, a lot of people with CFS, certainly myself, because of all I went through, having to cope with what many people think, you know, that it's not a real illness, and that there is nothing to help you, nothing ever changes. Having CFS to explain my situation was just getting me nowhere. It came to mean something else. I can't really express myself clearly, but it got to the point where it meant very little. Which is why when I realised what Keta [physiotherapist] was doing, not ever referring to CFS, it made sense. Also, trying to get a normal life again presented so many more immediate challenges, I was beginning to do what I needed to do, and it did not involve having to think CFS, CFS."

The participants emerge from these experiences of self-reflection with a perception of being responsible for their illnesses. Initially they perceive their illnesses as "something" they have which is external and separate from their self-identity, and they cope by using external social and external treatment resources. With the shift in perception of having CFS, their coping style changes accordingly. The focus of coping shifts to using internal resources in that the participants adopt self-management practises to cope with having CFS.

The participants' existing self-management is challenged by the physical limitations of having CFS. The focus of coping is finding out how to manage themselves in order to prevent relapses of symptoms into CFS.

Illustration re focus of coping:

P1: "And then, if I've got to be there from 5 to 10 then I'll make sure that I don't tax my body in the day, just taking it easy and make sure that I don't have too many commitments that day and have time to rest and sleep. If I don't do this, if I push myself, then I know that there will be a relapse."

P2: "Even small things, like if my mother-in-law comes to visit, she thinks that getting on with me is about telling me all about her complaints. She tries to get me to do things in this twisted round-about way. There I am, having to listen to her and getting more and more uptight as I realise how she is trying to manipulate me. Then, I feel symptoms coming, headache, that's the first sign, and then I know something's not right. I'm not handling this correctly.

P3: "I'm not as healthy as I used to be in the sense that I've got physical weaknesses. I'm forced to be aware of it. Before, I could go on full steam ahead without having to be aware of my body and its reactions. As soon as I start running away with myself, or I forget myself, like if I'm doing too much and getting worked up over things, warning bells start ringing. I start getting flu symptoms and then I've got to make emergency plans and center myself again."

The participants find that existing self-management in the context of having CFS precipitate relapses into symptoms of CFS, to be illustrated below. In other words there is tension between existing self-management and the experience of relapses. The participants find that this means that existing self-management practises cause chronic illness with CFS. In order to resolve the tension between existing self-management and the experience of relapses by preventing relapses, the participants accommodate self-management to the physical limitations of having CFS. In this process existing self-management practises shift to the following:

3.3.1 The self-management practise of self-acknowledgement

Prior to having CFS the participants unconsciously show a tendency toward self-effacement. P1 does this by automatically complying with the demands of others. P2 does this by automatically tolerating the demands of her husband's family. P3 does this by automatically complying with her father's expectations. The participants

report that in order to avoid precipitating relapses, they have had to learn to acknowledge their own thoughts in such situations. Instead of responding to the needs of others before acknowledging their own thoughts about these, the participants make a point of considering their own thoughts first, and subsequently responding to the needs of others accordingly.

Illustration re self-management practise of self-acknowledgement:

P1: "Most of the time I was feeling obliged to do things. I mean I know I allowed this to happen, people always knew that they could call on me. I have to stop myself and ask do you want to do such and such. I'm more aware of how I feel. And, I include this in making decisions about what to do."

P2: "And this is where the challenge is, not feeling that I have to do things, and that's a huge pressure in my husband's polite, colonial-type family. And I've got to the point where I can say to myself that I cannot and do not have to listen to this."

P3: "If I feel that I can't do something, something that my father expects me to do, I've learned to admit it to myself and to say that I can't without feeling it's the end of the world. Previously, it would be out of the question entertaining the possibility of not wanting to do it."

3.3.2 The self-management practise of self-assertion

The participants show a tendency toward being submissive in relation to significant others prior to having CFS. P1 finds it "too complicated" to assert herself, for example, in situations regarding her daughter to her parents. P2 finds it difficult to express her feelings to her husband about his dynamics with his mother which negatively affect their relationship. P3 refers to situations in relation to her father where she finds herself being submissive for fear of disappointing him if she asserts herself. The participants all refer to "the stress" that they experience in these situations, and its link with having subsequent relapses if managed in the usual way. To resolve the tension between the tendency to be submissive in important

relationships and the probability of precipitating a relapse if they continue to be this way, the participants adopt the practise of self-assertion in these situations. This is illustrated below.

Illustration re self-management practise of self-assertion:

P1 remembers one of the principles of Feng Shui, a complementary health treatment, that she tries during her search for treatment. It prompts her to question why she is “stuck in the rut of this illness”? She believes that living with her parents and all that this entails is “blocking” her potential to recover from CFS. She makes the decision to move out of her parents house and to make a new life in another town.

“Working it out was one thing, but then making these changes was difficult and where I’ve learned the most.”

“I guess the big jump came when I had to tell people what I was doing, and to do this within the limits of my illness, not to rush, panic, and worry.”

“I mean it took a lot of courage for me – not to ask my parents and to get into debates and possible problems, that whole trip. I just refused to go there. It was a matter of telling them I was leaving, no fussing. Just demonstrating that I am the boss of my life.”

P2: “Usually, if something’s not right, like there’s something that I’m upset about, like if I bottle up my feelings about how my husband is being false with his mother and he is seething about being manipulated, and it starts affecting our relationship, my body just can’t hold the tension. I start getting sick. Then I have to confront it, as hard as it is for me, but I do. I feel much better and then the downward spiral is avoided. I’ve realised it’s all about nipping things in the bud.”

P3: “Living at home, being with my father all the time, it wasn’t good for me. I, on purpose, chose to keep him, my parents at bay. And I just haven’t allowed him to get to me. He has got a way, he knows how to get to me, to make me feel bad, like I’m doing the wrong thing. Just from what he says about my new career, herbalism and aromatherapy. He thinks it’s a lot of nonsense. I mean he really wanted me to be a doctor, and his disappointment still rings loud. When I was at school, I could not tell him that I had dropped Latin. I suffered in the face of the inevitable. Obviously the time came for him to find out. And

what he thinks of my boyfriend, they are so different. Before, it would have freaked me out if he didn't like one of my boyfriends. Now, I still have him as my boyfriend. But before CFS, I probably wouldn't. And I don't try to explain myself, why I like him to my father. That's the way it is, it's a pity, but what can I do. I just don't let it get to me any more. I think that what I went through, it makes you stronger. I've learned also not to alienate people, to be more constructive. One side of me just wants to freak out, but the stress it is just not good for me. Inevitably I'll become symptomatic again. Keeping focused on what's good for me, and I know now, instinctively, what is and what isn't.

3.3.3 The self-management practise of self-soothing

The practise of self-soothing is adopted to tolerate negative feelings rather than avoid them. The practise of self-soothing resolves the tension between the tendency to avoid negative feelings and the relapse into symptoms that such behaviour will probably precipitate.

Illustration re self-management practise of self-soothing:

Instead of compulsively avoiding negative feelings "by burying myself in my work, and in other people's demands of me" and self-destructively acting-out negative feelings by "going drinking and partying", P1 adopts the capacity to tolerate depressive feelings.

P1: "Okay, you see, it's like the person I was then, I wouldn't have allowed myself to be depressed. I was just too busy with things to actually stop and face myself. I mean now I just physically can't go drinking and partying, and burying myself in work and other people's demands. Now, if I'm depressed, well, it's not pleasant, but I cope, I'll get over it, look at what the problems are and try my best to solve them. Otherwise, I will feel consumed and get CFS again."

Instead of avoiding depressive feelings by becoming "sick", P2 learns to regulate her feelings by addressing her problems constructively. In relation to her experience of depression P2 says the following:

"It was serious having to live through it and learn to feel that it's okay to be depressed. I mean when I grew up, you just weren't allowed to be depressed,"

"Being depressed was like being a failure."

"I see now why I was so angry when I was diagnosed with depression. You see, I just couldn't get it then. I couldn't be depressed, so I got sick instead."

"For me, learning how to cope with CFS has been a lot about how to cope with my feelings. Watching when I get relapses and instead of avoiding it, rather, looking at what's going on in my life at the time. And I've learned to read it so well now,"

P3 learns to soothe her anxiety in the face of her father's disapproval, rather than "freaking out" and subsequently feeling guilty about it. In relation to her father, P3 says the following:

"Before it would have freaked me out if he didn't like one of my boyfriends."

"And I don't try to explain myself, why I don't like him to my father. That's the way it is, it's a pity, but what can I do? I just don't let it get to me anymore."

"One side of me wants to freak out, but the stress, it is just not good for me. Inevitably I'll become symptomatic again."

The self-management practises described above prevent relapses. The process of coping with their illnesses by adopting and maintaining self-management practises contributes to firstly, the perception of having recovered from CFS. Secondly, the experience of a positive shift in self-identity and positive transformation in lifestyle. An illustration which is indicative of all the participants is provided.

Illustration re shift in self-identity:

P3: "The lifestyle I have made now – it's a different me. I'm no longer trying to be a hero out to please her father. I was too busy trying to be someone I was not. Looking back, and it's only now that I can say this, afterwards, that CFS, I mean I was asking for it. All that missioning and pressure to get A's and be involved in everything. It wasn't really me. CFS is probably one of the best things that could have happened to me. CFS forced me to make a new life for myself and it made me do things I would ordinarily not have done."

Thirdly, the participants find meaning in their illnesses. From the time of onset of symptoms until prior to adopting self-management practises, the participants are

uncertain about the meaning of being ill and having CFS, and they are unable to consider the role of distressing psychosocial factors in the meaning of having CFS. However, in the process of realising that firstly, existing self-management practises precipitate relapses, and secondly, accommodating self-management to the physical limitations of having CFS prevent relapses, psychosocial factors are included in the meaning and self-management of having CFS. The participants come to understand that problematic self-management practises cause and maintain CFS.

3.4 SUMMARY OF INTERPRETATIVE ACCOUNT

The process of coping and self-management in the experience of recovering from CFS is about the development of meaning in relation to coping with :

1. the uncertainty about the onset of symptoms;
2. feeling stigmatised as a consequence of social and professional scepticism about initially being ill, and subsequently, being chronically ill with CFS; and
3. uncertainty about being ill with CFS.

3.4.1 Self-definition of being ill

The participants cope with the uncertainty about the meaning of the onset of symptoms by firstly, defining themselves as ill in somatic terms. The meaning of the experience of the distressing psychosocial context in which each participant becomes ill appears to play no role in attempts to understand the illness, as reflected in the self-definition of being ill.

The participants cope with the uncertainty about the onset of symptoms by secondly, using external social resources.

3.4.2 Coping by using external social resources

The participants use social resources by expressing their experiences of being ill with others in their social networks. They do this in order to justify their illness behaviour to others and to be understood by others as being ill. However, others attribute their illnesses to psychological problems. This gives them the impression that they are perceived as not being ill. The participants feel misunderstood by others. They feel stigmatised. To cope with this, the participants consult medical practitioners in a further attempt to justify their illness behaviour to others and to be understood as being ill. The participants receive medical diagnoses of psychological problems, depression, and stress. They perceive these diagnoses to be not 'real' illnesses. As such, the participants perceive that they are being misunderstood as being not ill, and accused of pretending to be ill. Consequently, they continue to feel stigmatised.

The participants network the medical profession for a personally and socially acceptable diagnosis. In this process the participants become medically diagnosed as having CFS. The diagnosis of CFS provides certainty about the meaning of the onset of symptoms. The tension created by the contradiction from others in their social networks and the medical profession that they are not ill is resolved. They are relieved. The participants experience the diagnosis of CFS as a justification of their illness behaviour and an understanding from others that they are ill.

The participants cope with being chronically ill with CFS by using external treatment resources.

3.4.3 Coping by using external treatment resources

The participants network the health system for effective treatment. However, one of the participants excludes the medical profession in her search for effective treatment. The “traumatic” experience of searching for a diagnosis left her feeling alienated from the medical profession. The more these treatments are found to be ineffective, the more desperate they become for help, and the more they network the health system. They experience cycles of hope and disappointment at each treatment resource used and found to be ineffective. In this process the participants once again experience social and professional scepticism. In this instance it is scepticism about the legitimacy of CFS as a ‘real’ illness. Consequently, the participants experience uncertainty once again. In this instance it is uncertainty about the meaning of CFS. The two participants who include the medical profession in their search for treatment also become alienated from the medical profession. These two participants become depressed. All the participants stop networking the health system for effective treatment.

The first participant goes through a phase of self-confrontation. The second participant experiences gradual self-confrontation, supported by psychotherapy. The third participant receives holistic treatment from a physiotherapist.

The participants emerge from these experiences of self-reflection with a perception of being responsible for their illnesses. Initially they perceive their illnesses as “something” they have which is external and separate from their self-identity, and they cope by using external social and external treatment resources. With the shift in perception of having CFS, their coping style changes accordingly. The participants cope with the uncertainty about the meaning of having CFS by using internal resources in that the participants adopt self-management practises to cope with having CFS.

3.4.4 Coping by using internal resources/adopting self-management practises

The participants’ existing self-management practises are challenged by the physical limitations of having CFS. The participants find that existing self-management practises such as tendencies toward self-effacement, being submissive in relations to significant others, and avoiding negative feelings, precipitate relapses into symptoms of CFS. In other words there is tension between existing self-management and relapses. The participants find that this means that existing self-management practises cause chronic illness with CFS. In order to resolve the tension between existing self-management and the experience of relapses by preventing relapses, the participants accommodate self-management to the physical limitations of having CFS. In this process, existing self-management practises shift toward self-acknowledgement, self-assertion in relation to significant others, and self-soothing in the face of negative feelings. These self-management practises prevent relapses. The process of coping with their illnesses by adopting and maintaining self-management practises contributes to firstly, the perception of having recovered from CFS. Secondly, the

experience of a positive shift in self-identity and positive transformation in lifestyle. Thirdly, the participants find meaning in their illnesses. From the time of onset of symptoms until prior to adopting self-management practises, the participants are uncertain about the meaning of being ill and having CFS, and they are unable to consider the role of distressing psychosocial factors in the meaning of having CFS. However, in the process of realising that firstly, existing self-management practises precipitate relapses, and secondly, accommodating self-management to the physical limitations of having CFS prevent relapses, psychosocial factors are included in the meaning and self-management of having CFS. The participants come to understand that problematic self-management practises cause and maintain CFS.

CHAPTER 4

DISCUSSION

The following discussion is an outcome of the methodological process pertaining to the application of the third interpretative reading guide as outlined in chapter 2.

The aim of the following discussion is to formulate an understanding of the phenomenon of CFS from the interpretative account on the process of coping and self-management in the experience of recovering from CFS, yielded in chapter 3. The use of external social and external treatment resources to cope with the onset of symptoms and being chronically ill with CFS will be discussed in terms of a function of discourse (Shotter, 1992) concurrent with a perspective of the social relations of sickness (Helman, 1990). The shift in coping from using external resources to using internal resources will be discussed in terms of Levin's (1987) postmodern perspective of disease. To conclude, interpretations from the discussion will be considered in terms of current understanding of CFS described in the literature review.

4.1 A FUNCTION OF DISCOURSE (SHOTTER, 1992)

The aim of this section is to present a function of discourse as described by Shotter (1992). The idea of discourse is 'grounded' in social constructionist thought. A description of social constructionist thought is not intended. However, to

contextualise the idea of discourse, a brief background of this body of thought will be given.

Central within philosophy and related social science disciplines empiricist assumptions are undergoing rampant questioning. Moves in this way of thinking are labeled post-structuralist, post-empiricist, postmodern, interpretative, social constructionist, and hermeneutic (Gergen, 1991).

Postmodern thinking makes the assumptions inherent in the paradigm of knowledge problematic. These are usually taken for granted, or treated as immutable givens in the modern way of life. Such thinking adopts a critical stance against Western metaphysics, epistemology and normative assumptions, which underlie the concepts, rules and meanings in our practices, routines, and institutions (Levin, 1987). For example, and to be discussed later, postmodern thinking questions the assumption which is based on Cartesian dualism, that disease is indicative of an objectively observable malfunctioning of the body alone (Levin, 1987).

Social constructionism challenges the objective basis of conventional knowledge. The degree to which a given form of understanding prevails, or is sustained across time, is not fundamentally dependent on the empirical validity of the perspective in question, but on the vicissitudes of social processes (Gergen, 1985). In other words, knowledge is cut away from an ontological base within the head, or from entities in the 'objective' world, and placed within the process of social interchange. Here knowledge is understood as constituents of social process.

Shotter (1992) states that social constructionism is concerned with the social processes by which theoretical and descriptive accounts come to be accepted as legitimate representations of reality. The way the world is understood depends upon the on the way it is spoken about, that is, on the discourses and how they are used. Language is so structured as to produce sets of meanings, or discourses, that operate independently of the intentions of speakers. In other words, the process of making sense produces meaning rather than represents meaning (Henriques, Hollway, Urwin, Venn & Walkerdine, 1984)

Discourses operate at discursive levels in social practises. For example, in the 1960s and 1970s the production of social scientific knowledge, 'sociologese' and 'psychologese' filtered into every discourse of administration and management of human activity. In putting the discourses into practice – that is their discursive function – the agencies of social regulation, like the family, work, health system, the social sciences and social administration grew into a mutually productive relationship (Henriques et al. 1984). This, according to Foucault (in Henriques et al. 1984), is how knowledge and therefore power, is produced and maintained at a discursive level.

The following function of discourse, cited in Shotter (1992), will be used in the attempt to understand the social process of being ill with CFS, in the next section. An assumption contained within a discourse takes on the appearance of a definition in the social practices where it operates, that is, at the discursive level of the discourse. In social process meaning contained within the assumption is produced, the discourse is maintained. At the same time, the illusion is created that the assumption is

representative of reality in an 'objective' sense. People respond to the assumption as if it is an 'objective' fact. This will become clear in the next section.

4.2 THE SOCIAL RELATIONS OF SICKNESS

4.2.1 The health system

Various institutions exist in mutually productive relationships to regulate society. The health system is one of these institutions or social systems that regulate and perpetuate the way in which people deal with health and illness (Helman, 1990). Even though the health system has its own concepts, rules and social organisation according to the functions that it performs, it still reflects the values or dominant ideology of the larger culture (Helman, 1990).

Becoming ill immediately places the person in a relationship with the health system. The health systems of Western societies are characterised by medical pluralism. In terms of Helman's (1990) definition of the health system, the agents likely to be involved in the social relations of sickness are those from the three different sectors, the popular/lay sector, the professional sector, and the folk/complementary sector. There are many divisions within each sector although they coexist. Each sector and/or individuals therein have their own characteristic modes of explaining and treating illness. These are described in the following sections.

4.2.2 Definition of illness as a social process

Kawanishi (1992) points out that “illness is not simply an attribute of an individual but is defined by the social situation and imputed to the individual through social processes” (p.25). In other words, Kawanishi (1992) maintains that “an illness does not become an illness unless it is defined socially” (p.27). Helman (1990) maintains that “people are defined as ill when there is agreement between their perceptions of impaired well-being and the perceptions of those around them. In that sense, becoming ill is a social process which involves people besides the patient.” (p.93). Illness as a social process involves both subjective experiences of physical and/or emotional distress, and the confirmation of these by others (Helman, 1990).

Firstly, the definition of illness as a social process is discussed in terms of the experiences of the participants in this research, below.

Secondly, in the conclusion, the existence of CFS as a disorder is discussed in terms of the understanding of CFS that emerges from the experience of CFS as a social process. The identification and definition of CFS as an existing disorder is dependent on its acceptance by professional and popular society at large, which is a social process. This is evident in the description of the origin of the term CFS, its definition by the CDC, and the polarised debate among clinicians regarding its aetiology, as described in chapter 1.

4.2.3 The ill person in relation to the lay sector

It is in the context of, and in relation to others in, the lay sector that the person becomes ill. Illness is first recognised, defined, and treated in the lay sector (Helman,

1990). The popular/lay sector is essentially the community excluding the professional and complementary sectors. It includes the family and others already linked to the patient, self-help groups, churches, other people with experience of the same complaint, that is, support groups, and the media. Treatment is based on lay beliefs about the body, causes and nature of illness (Helman, 1990).

It is in relation to others in the lay sector that the complex process of the negotiation of meaning and/or the construction of explanatory models of the symptoms of illness will occur on the part of the ill person and others related to about the symptoms (Helman, 1990). An explanatory model is defined as the explanation held by any of all of those in relation to the ill person, including patients and doctors, regarding the ill person's symptoms and their treatment (Kleinman, in Helman, 1990). It casts personal and social meaning on the experience of the illness and guides choices among the options for treatment. Explanatory models are used to explain, organise and manage illness.

As stated earlier, illness as a social process involves both subjective experiences of physical and/or emotional distress, and the confirmation of these by others (Helman, 1990). Before social confirmation of illness is sought, the person must perceive symptoms and signs as abnormal.

In this research the participants perceive their symptoms as abnormal and experience uncertainty about their meaning. For each participant, the context in which the onset of symptoms occurs is characterised by psychosocial distress. For example, one

participant describes the divorce she did not want as the most stressful time in her life. Immediately prior to the onset of symptoms of the illness in question, her first intimate relationship since her divorce ends in “disaster”. It may be significant that, however, the participants do not include any reference to the meaning of their experience of the distressing psychosocial context in which they become ill, in their self-definition of being ill. This is indicated by their descriptions of the experience of the onset of symptoms, their understanding of this, and their self-definition of being ill. These are in somatic terms only.

Nemiah and Sifneos, cited in Taylor (1992), introduced the construct of alexithymia, the description of which, according to Taylor (1992), includes difficulty identifying and describing feelings and having constricted imaginative processes. This means that some people may have difficulty in making sense or meaning out of feelings because of the difficulty in identifying and describing them. In chapter 1 it was cited that Taerk & Gnam (1994) describe psychodynamic psychotherapy with two patients with CFS, which culminates in their recovery. In this psychotherapy, the patients recover from CFS once alexithymic features are overcome. In the therapy, the patients discover that the symptoms of CFS exacerbate or relapse at times of emotional distress. Having difficulty identifying and describing the emotional distress, the patients are able to articulate the somatic concomitants of the emotional distress but have difficulty articulating the emotional distress itself. Through the psychotherapy, they recover from CFS once they learn to better identify, label, and describe the emotional distress in both emotional and physiological terms, and to regulate the emotional distress.

In this research, the participants recover from CFS in the process of adopting self-management practises. The self-management practises of self-acknowledgement, self-assertion and self-soothing, as articulated in chapter 3, involve the ability to identify and describe feelings and the ability to make meaning out of feelings. This appears to support the understanding of CFS as a form of somatisation, described in chapter 1. However, the finding in this research that the participants' understanding of being ill does not include meaning of experience of psychosocial distress, in which the onset of illness occurs, may not be an intrapsychic inability to do so, but a process of cognitive interpretation, to be explained next.

According to Kirmayer (cited in Kawanishi, 1992) alexithymic behaviour is more commonly the outcome of the social interaction between the psychotherapy patient and the psychotherapist and on the part of the patient, the causal attributions of distress to somatic or social events rather than intrapsychic emotional experience. Kirmayer (cited in Kawanishi, 1992, p.19) says "the capacity to focus on and talk about what is 'inside'... Alexithymia is the projection onto one member in a interacting dyad of failure to meet in the construction of a shared symbolic world. From this perspective, alexithymia is irreducibly social." Accordingly in the following discussion, the finding that the participants' understanding of being ill does not include meaning of emotional distress, in which the onset of illness occurs, may be more an outcome of the social process of being ill than an alexithymic inability to identify and describe feelings.

Cultural factors will influence which symptoms or signs will be perceived as abnormal (Helman, 1990; Shorter, 1992). As mentioned in chapter 1, the cultural assumptions of rationalism and mind-body dualism contained within the biomedical model consider physical symptoms to be more 'real' or legitimate than less 'real' mental phenomena. These assumptions persist in the popular notion that legitimate symptoms are ascribed to an underlying organic disease, beyond the individual's control, for which the person cannot be blamed (Showalter, 1997; Wessely, 1993; Ware, 1993). Illegitimate ones, like psychological symptoms, are considered to be less 'real', or imaginary and therefore worthy of blame. In research done by Blackwell (in Kawanishi, 1992) it is found that the more an illness is seen as psychological the less likely the sufferer is to be assigned the sick role. Psychological disorder is stigmatised (Kirmayer, in Ware, 1993; Wessely, 1993). Therefore, there is "cultural pressure" (Shorter, 1992, p.x) on the part of the ill person to present legitimate symptoms, and as will be seen below, "cultural pressure" will be placed on the person who presents illegitimate symptoms.

In this research, the participants cope with the uncertainty about the meaning of the onset of symptoms, by firstly, defining themselves as ill in somatic terms. In terms of the popular notion that physical symptoms are more legitimate than psychological symptoms, presenting themselves as ill in somatic terms is culturally legitimate.

The participants cope with the uncertainty about the meaning of the onset of symptoms, by secondly, using external social resources. They express their experiences of being ill with others in their lay networks. Helman (1990) maintains

that the ill person begins to seek alleviation of symptoms through self-treatment and home remedies, seeking out information and advice concerning the symptoms from family, friends, others with the same complaint, and the media (Helman, 1990). Within and across these various social contexts, it is likely that the ill person and the lay other is negotiating meaning and/or an explanatory model of the illness (Helman, 1990). In this process provisional validation of the sick role is requested (Helman, 1990). If granted, the person is temporarily allowed to be sick (Wolinsky, 1988). Accordingly in this research, in the process of expressing their experiences of being ill with others in their lay networks, the participants begin the attempt to find meaning and/or construct their explanatory models regarding their illnesses. In addition, they attempt to justify their illness behaviour to others and to be understood by others as ill. In other words, they aim to obtain confirmation of illness from others, thereby being granted provisional sick role status.

4.2.3.1 The sick role

By virtue of being human and thus beyond individual control, an individual occupies a variety of different social roles. These roles each have their normative expectations for behaviour, the adequate performance of which contributes to the smooth functioning of society. Deviation from the normal performance of these roles, of which illness represents one such form of deviance, has a negative impact on society. If normal role obligations fail to be met, even if this failure is due to illness, it is deviant because the person is not behaving as expected and thereby creates a problem for society and those around them (Wolinsky, 1988). Social control mechanisms arise to minimise the occurrence of deviance. In the context of illness, the person is

temporarily allowed to occupy the sick role. In order to occupy this socially acceptable way of being deviant in illness, that is, the sick role, confirmation from others is implicitly and/or explicitly sought (Helman, 1990). This is done not only because a person naturally shares some experiences with others, but also in order to justify occupation of the sick role (Wolinsky, 1988).

If occupation of the sick role is dependent on confirmation of illness from others, the presentation of illness or language of distress becomes significant. According to Helman (1990) this bridges the gap between subjective experience of illness and its social acknowledgement. The ill person's language of distress will be influenced by the ill person's explanatory model, and to whom the distress is being expressed. Cultural factors will influence which symptoms or signs will be perceived as abnormal; they help to shape these diffuse illness changes into a socially recognisable and acceptable pattern. They become illness entities, the first stage of becoming ill.

As mentioned earlier, in terms of the popular notion that physical symptoms are more legitimate than psychological symptoms, the language of distress that the participants in this research use to present themselves to others in their lay networks is in culturally legitimate somatic terms. However, others in the lay sector respond to the participants by attributing their illnesses to psychological problems and not granting them provisional sick role status. In other words, others in the lay sector respond to the participants in terms of the popular assumption that psychological problems are not 'real', illegitimate, and not worthy of the sick role. In this social process, the assumption takes on the appearance of a fact. Others respond to the participants as if

it is an 'objective' fact that psychological problems do not constitute 'real' illness. The discourse about the popular notion that psychological problems are not 'real', illegitimate, and not worthy of the sick role is called forth and put into action by lay others in their response to the participants' presentation of illness.

Defining oneself as ill, is not enough (Helman, 1990). Wolinsky (1988) maintains that if others are not able to confirm the person's illness, as is the case in the response of others to the participants in this research at this stage of their illnesses, the person risks the following consequences:

1. not being taken seriously, for example, in this research, in response to one of the participant's self-definition of being ill, her father in disbelief says "bullshit";
2. feeling misunderstood; and
3. being viewed as a malingerer i.e. pretending to be sick in order to receive secondary gains, the privileges of being in the sick role (Wolinsky, 1988). For example, one participant says "I was very angry, upset by this suspicion that I wasn't really ill. I wasn't pretending. They were not allowing me to be sick."

In this research, the consequences of the inability of lay others to confirm the participants' illnesses are that the participants get the impression that they are not 'really' ill and the participants feel misunderstood. There is tension contained within the contradiction between their own attributions of being ill with a physical condition and the attribution of others that they have psychological problems.

Being in the sick role means that the person has rights as well as obligations (Wolinsky, 1988). One has a right to not be held responsible for the condition and a

right to be exempt from normal task and social role obligations. Conversely, not being granted sick role status implies that one may be held responsible for the condition. In this research the participants feel blameworthy or stigmatised for their illnesses. For example, one participant says “it was like being accused for a crime you didn’t commit.”

The participants are drawn into the discourse that psychological problems do not constitute ‘real’ illness at a discursive level (i.e. operation of the discourse in social practice) by, in turn, also responding to this assumption as if it is an ‘objective’ fact. As mentioned above, the consequences of the inability of lay others to confirm the participants’ illnesses are that the participants get the impression that they are not ‘really’ ill, they feel misunderstood and stigmatised. For the participants it is no longer only a question of the quest for meaning in their symptoms in terms of having a physical condition, but also, that to be recognised as ill, their illnesses should not be psychological. In other words, the participants are drawn to dealing with the imposition of the meaning of the response of others in their quest for understanding regarding their illnesses. As a consequence, the ‘cultural pressure’ to present their illnesses in somatic terms is reinforced. This has a bearing on their language of distress in their presentation of illness to medical practitioners, the significance of which is discussed in the next section.

The participants deal cope with the impression that they are not really ill, feeling misunderstood and stigmatised by consulting medical practitioners. They do this in the trust that a medical diagnosis will be accurate and thereby prove that they are

'really' ill and not malingering for the benefits of the sick role. In this process the assumption contained within the discourse that psychological illness is not 'real' illness is maintained and is in action at a discursive level. It is carried over in the participants' quest for meaning in their illnesses, from its operation at the discursive level of the ill participants in relation to the lay sector, to operate at the discursive level of the doctor-patient relationship.

4.2.4 The ill person in relation to the professional sector

The professional sector consists of the various medical and paramedical specialities, such as medical doctors, nurses, psychologists, physiotherapists and pharmacists (Helman, 1990). This sector's way of explaining and treating illness is based on modern scientific medicine. The biomedical model has various interpretative methods, viral, immunologic, psychodynamic, to name but a few (Helman, 1990). The biomedical model which guides diagnostic and treatment practice in professional medicine has been described in chapter 1.

This sector is officially sanctioned and therefore its institutional practices have significant social (assignment of the sick role) and economic (determination of financial benefits) effects (Helman, 1990). Although the ill person may have been temporarily given sick role status by the lay referral system, the person does not become a bona fide occupant of the sick role until the illness is legitimised by a medical practitioner in the form of a diagnosis and treatment. Medical practitioners are traditionally and legally regarded to be the legitimate social agents controlling assignment of the sick role (Wolinsky, 1988). What this means is that regardless of

the assignation or denial of provisional sick role status by the lay sector, society is legally bound to treat people according to the medical sector's assignation or denial thereof. In this research, as will be shown below, regardless of the denial of provisional sick role status by others in the lay sector, once the participants are diagnosed as having CFS by medical professionals, others in the lay sector acknowledge the participants as ill.

4.2.4.1 The doctor-patient relationship

Cassell (in Helman, 1990) and Eisenberg (in Scheper-Hughes & Locke, 1987) make a distinction between 'illness' and 'disease' in order to make the point that when patient and doctor meet, they will have different perspectives or explanatory models regarding the patient's symptoms. A person experiences an illness that the medical practitioner decodes into a disease.

"Illness is the subjective response of the patient, and of those around him, to his being unwell; particularly how he, and they, interpret the origin and significance of this event; how it effects his behaviour, and his relationship with other people; and the various steps he takes to remedy the situation. It not only includes his experience of ill-health, but also the meaning he gives to that experience." (Helman, 1990, p. 91)

Thus, prior to consultation with the doctor, the ill person is likely to have an explanatory model of illness, constructed within and across each social context in the lay sector. Kleinman (cited in Helman, 1990, p.95) maintains that

"lay explanatory models tend to be idiosyncratic and changeable, and to be heavily influenced by both personality and cultural factors. They are partly conscious and partly outside of awareness, and are characterised by vagueness, multiplicity of meanings, frequent changes, and lack of sharp boundaries between ideas and experience".

Helman (1990) makes the point that even if lay perspectives are influenced by concepts borrowed from the media and from the medical model, possibly based on scientifically incorrect premises, they have a coherence which helps the patient find meaning in their symptoms. In other words, the point is that the ill person has a subjective understanding of his/her illness, regardless of what any one else may understand the illness to mean.

It was mentioned earlier that the participants in this research consult the medical profession as a consequence of the stigmatisation in relation to being treated as not ill by others in the lay sector. They consult the medical profession in the trust that a medical diagnosis will confirm that they are 'really' ill and not malingering for the benefits of the sick role. They consult medical practitioners with the explanatory model of illness in mind that they are suffering from a physical condition and that their illnesses are not psychological in origin.

The medical professional relates to the patient's symptoms from the perspective of the biomedical model, described in chapter 1. The medical professional's ability to 'decode' the patient's illness is complicated by the fact the main concern in relation to understanding and interpreting the patient's language of distress is with the aim of diagnosing and treating physical dysfunction, rather than understanding the patient's subjective meaning of the illness (Helman, 1990).

Regardless of their different perspectives, and as noted by Helman (1990) the differences in power, both social and symbolic, the patient and doctor enter a

dialogue. The doctor-patient relationship is not egalitarian. The doctor usually determines the form and course of the dialogue in a way that fits his personal style and medical training.

In the process of the dialogue, the patient presents the illness to the doctor. The doctor translates the patient's language of distress into a diagnosis and prescribes treatment which is acceptable to both patient and doctor (Helman, 1990). This process involves negotiation of meaning. Regardless of whether the participants' explanatory model of being ill and the premises on which it is based are 'correct' or not in terms of the medical diagnosis thereof, the ability to appeal to the participants' subjective meaning of the illness has significant implications. As mentioned, medical professionals are social control agents of the sick role. The assignation or denial of the sick role will effect the meaning of the illness for the participants and that of others connected to them, as well as the subsequent illness behaviour of the participants and society's subsequent treatment of them.

From the literature cited below, it may be said that there are various factors with the potential of creating barriers of communication between patient and doctor. On the part of the patient, there are factors that may influence the doctor-patient interaction.

Firstly, the patient may not be willing to disclose personal feelings regarding the symptoms to the doctor. The patient may be expressive of emotions in other contexts,

for example, with friends. While the doctor may not be a stranger to the patient, the doctor is usually not a friend (Kawanishi, 1992).

Secondly, the patient may emphasise the physical experience of symptoms to the doctor as opposed to the psychological experience of them that may be emphasised in relation to the psychiatrist (Wallen et al., in Kawanishi, 1992).

Thirdly, physical complaints may be consciously or unconsciously presented in disguise, in place of emotional distress to gain a more legitimate sick role in the face of the stigmatisation of mental illness (Kawanishi, 1992). In this research, the participants feel stigmatised in relation to being understood as suffering from psychological problems and therefore not being granted provisional sick role status by others in the lay sector. In this face of this, it is highly likely in the doctor-patient consultation that the participants' somatic language of distress is consciously emphasised and the feelings of stigmatisation are not directly expressed.

Using the biomedical model to translate or 'decode' the participants' presentation of illness, the participants' medical practitioners diagnose psychological problems, depression, and stress, respectively. The assumption contained within the discourse that psychological illness is not 'real' illness is called forth independently of the intentions of the medical practitioners. In terms of this assumption, the participants perceive these diagnoses as not 'real' illnesses. The participants perceive that they are being misunderstood as not ill, and accused of pretending to be ill. They react defensively to the diagnoses. The tension contained within the contradiction between their own attributions of being ill and those in their social networks is not resolved in

consultation with the medical profession. Rather, it is reinforced. As such, the current discourse is maintained at the discursive level of the doctor-patient relationship. The participants have responded as if the assumption that psychological problems are not 'real' is an objective fact.

On the part of the doctor there are factors that may influence the doctor-patient interaction. Firstly, the doctor may have a lack of interest or skills in eliciting psychiatric symptomatology. It is the doctor's task to make emotional experience "visible amidst somatic noise" (Kawanishi, 1992, p.24). In this research, the fact that the medical practitioners make diagnoses of psychological problems, depression, and stress indicate that they elicit psychiatric symptomatology. As will be shown below, the medical practitioners fail to ascertain and appeal to the participants' feelings of stigmatisation in relation to these diagnoses.

Secondly, the doctor may fail to observe and take metaphoric and non-verbal forms of expression into account (Kawanishi, 1992). The way in which a person verbally and non-verbally articulates symptoms of illness varies. Verbal expression may be direct or more symbolic and metaphoric, or a blend of these. Non-verbal expression usually refers to body language, but it may also include what is not verbally expressed, yet implied in verbal and non-verbal expression. In this research, it is clear from the nature of the diagnoses made by medical practitioners that the implication of non-verbal expression of the context of the experience of emotional distress in relation to psychosocial distress in which the onset of symptoms occurs is observed.

Thirdly, incorrect timing of giving the patient a diagnosis. The trust of the patient must be obtained before a full explanation of the diagnosis. If the diagnosis is given before trust is established, the patient may react defensively (Kawanishi, 1992). In this research, the participants' defensive reaction to their medical practitioners diagnoses may be as a consequence of the manner in which the diagnoses are disclosed and/or that the medical practitioners disclose the diagnoses before trust is established with the participants.

Fourthly, bearing the perception of the doctor as an authority figure in mind, failure to be sensitive about the impact the diagnosis may have on the patient's sentiments (Henderson, 1934). Addressing doctors, Henderson (1934, p.822) says "that the patient will eagerly scrutinise and rationalise what you have to say, that he will carry it away with him, that he will turn your phrases over and over in his mind, seeking persistently for shades of meaning that you never thought of."

With regard to the participants' defensive reaction to the medical diagnoses, feeling misunderstood by, and in the case of one participant, feeling alienated from, the medical profession, Henderson (1934) and Kawanishi (1992) make relevant points, described below, regarding the doctor-patient relationship.

In 1935, with regard to his experience as a medical practitioner, Henderson's (1935) following statements appear relevant in terms of the participants' interactions with their medical practitioners in this research:

"A multitude of important new facts and theories, of new methods and routines, so far absorb the physician's attention and arouse his interest that the personal relations seem to have become less important, if not absolutely, at least relatively to the new and powerful technology of medical practice." (Henderson, 1935, p.819)

Henderson (1935) proceeds to state that in his experience of the doctor-patient relationship appealing to the sentiments of the patient are more important than divulging and explaining the diagnosis. Henderson (1935, p. 821) says "it is meaningless to speak of telling the truth, the whole truth, and nothing but the truth, to a patient. It is meaningless because it is impossible; - a sheer impossibility." The meaning of appealing to the sentiments of patients is best articulated in Henderson's (1935, p.821) own words:

"There should be no argument about the prejudices of the patient, for, at any stage, when you are endeavouring to evoke the subjective aspect of the patient's experience or to modify his sentiments, logic will not avail. In order to modify the sentiments of the patient, your logical analysis must somehow be transformed into the appropriate change of the patient's sentiments. But sentiments are resistant to change. For this reason, you must as far as possible utilize some part of the sentiments that the patient has in order to modify his subjective attitude."

It is clear in terms of this research that in divulging their diagnoses, the medical practitioners fail to elicit and therefore understand, and appeal to the participants' sentiments regarding the stigmatisation of psychological illness.

In a different context and manner, Kawanishi (1992) makes similar claims to Henderson. He demonstrates how a patient presenting with “somatic talk” and afraid of the possible social reaction to mental illness comes to accept the diagnosis of depression by treating the patient at the level of the somatic appeal. Kawanishi (1992, p.22) says that it is important to address a patient at the level of the somatic appeal, regardless of whether or not the illness is physiological in origin, “to focus on it for a while because it provides the only route to communication at that moment.” It appears that in this research the participants medical practitioners did not address them at the level of the somatic appeal.

Kawanishi (1992) cites Kirmayer’s (in Kawanishi, 1992) research which distinguishes between three groups of patients. “Psychologisers”, who present at least one psychological problem. “Facultative somatisers”, who present at least one somatic symptom but when prompted accept psychosocial reasons as causes of symptoms. “True somatisers” who present at least one somatic symptom and reject psychosocial reasons. Kawanishi (1992) expands the definition of “facultative somatisers” to those who present somatic distress in some situations, but not in others.

In terms of this research, in the process of adopting self-management practises the participants refer to the ‘stress’ that they experience in situations where they show a tendency to be submissive in relation to significant others, and its link with having subsequent relapses of symptoms if managed submissively. In addition, once the

participants become aware of responding to the needs of others before acknowledging their own thoughts about these, the participants make a conscious effort to consider their own thoughts first, and subsequently to respond to the needs of others accordingly. This appears to suggest that the participants in this research may be “facultative somatisers”. Had the medical practitioners treated the participants at the level of the somatic appeal, and appealed to their sentiments in relation to the stigmatisation of psychological diagnoses, the participants may have accepted their diagnoses and found meaning in their illnesses. Instead, the participants react defensively and the quest for meaning in their illnesses continues. They network the medical profession for a personally and socially legitimate diagnosis. In other words, the participants proceed to consult medical practitioners until a meaningful diagnosis is found.

In terms of the above discussion regarding the communication between facultative somatisers and medical professionals, in general ‘facultative somatisers’ are misdiagnosed as true somatisers. This may be understood to stem from the complication inherent in the application of the biomedical model to patients’ symptoms, mentioned earlier. The doctor’s main concern in relation to understanding and interpreting the patient’s language of distress is with the ultimate aim of diagnosing and treating physical dysfunction and less with understanding the subjective meaning of the illness to the patient.

In the process of networking the medical profession for a meaningful diagnosis, the participants become diagnosed as having CFS. Here, the medical professionals who diagnose CFS do not ascertain and appeal to their feelings of stigmatisation in relation to psychological illness. In addition, in terms of the above discussion of 'facultative somatisers', CFS may be a misdiagnosis. In relation to the medical profession, the opportunity to have psychological problems addressed is lost. The participants perceive the diagnosis of CFS as one that attests to the physiological origins of their illnesses. As such, it is personally and socially acceptable as it is perceived as a legitimate diagnosis, a 'real' illness worthy of the sick role. The tension within the contradiction between their own attributions of being ill and the attributions of others to the contrary, is resolved. The participants are relieved. However, the diagnosis of CFS, perceived as a physiological condition, does not close the discourse about the assumption that psychological illness is not 'real'. This discourse remains dormant and has a bearing on subsequent experience of having CFS, as will be shown.

4.2.5 The ill person in relation to the complementary sector

The complementary, or folk, sector is a heterogenous group of healers. It consists of the sacred and secular specialisations, not part of the official medical system, such as herbalists, homeopaths, reflexologists and spiritual healers (Helman, 1990). The complementary sector differs from the professional sector in advantageous ways even though it is largely considered with suspicion by the professional sector (Helman,

1990). Social, psychological and moral dimensions of illness are taken into account. Some complementary practitioners view their approach to illness as holistic.

Once diagnosed as having CFS by medical practitioners in their search for a legitimate and meaningful diagnosis, the participants cope by using external treatment resources. Helman (1990) maintains that when treatment from one health system practitioner fails to relieve physical and/or emotional distress, the patient moves to the next practitioner. Thus networking between and across the sectors occurs. The participants network the health system for effective treatment. As a consequence of feeling alienated from the medical profession in the process of searching for a diagnosis, one of the participants networks the lay and complementary sectors of the health system, excluding the medical profession. The more these treatments are found to be ineffective in terms of suffering from CFS, the more desperate they become for help, and the more they network the health system. In this process, the participants once again experience social and professional scepticism. In this instance it is scepticism about the legitimacy of CFS as a 'real' illness. The discourse about the assumption of mind-body dualism is in operation once again. The participants feel stigmatised in relation to the popular and professional assumption that medically unexplainable somatic symptoms can be ascribed to psychological causes (Ware, 1993) and the assumption that this does not constitute a 'real' illness.

As a consequence of feeling stigmatised about being ill with CFS, and the ineffectiveness of numerous treatments used, the participants feel alienated from the health system, i.e. the medical profession, others in their lay networks, and the complementary sector. The participants become uncertain about the meaning of CFS. Their illnesses are no longer understood in terms of the condition of CFS. For two of the participants this culminates in the experience of depression. All the participants stop networking the health system for effective treatment.

In terms of the discussion so far, CFS may be a misdiagnosis for psychological problems. Becoming diagnosed as having CFS arises as a consequence of the search for meaning in relation to social processes where the assumption that psychological illness does not constitute 'real' illness, operates at both the levels of popular society and the doctor-patient relationship.

By no longer networking the health system for treatment the participants are removed from the discursive contexts in which the current discourse that psychological illness does not constitute 'real' illness operate. The participants are no longer drawn into the discursive operation of the discourse. Being diagnosed as having CFS leaves them in the same position they were in initially when implicitly attempting to be understood as being ill. They feel stigmatised in the initial process of attempting to be understood as ill and in the subsequent process of being chronically ill with CFS. They become trapped in a closed process. Feeling alienated from the health system

and consequently, no longer networking the health system for treatment, creates a clearing for new possibilities. This will be discussed below.

4.3 LEVIN'S (1987) POSTMODERN PERSPECTIVE OF DISEASE

In terms of the assumption of mind-body dualism where it is conceptualised that the mind is experienced as separate from the body, it is considered that people ought to express their psychosocial distress in psychological terms and their physical afflictions in bodily terms (Kawanishi, 1992). However, presenting emotional distress through body language dates back several centuries and is a universal form of expression (Kawanishi, 1992; Kleinman, 1986; Scheper-Hughes & Locke, 1987). Kleinman (1986) and Scheper-Hughes & Locke (1987) point out that the lived experience of the body is mindful, and the mind, in the same way, is embodied. In accordance with a postmodern perspective of disease, Levin (1987) shows how disease constellates as embodied expressions of the meaning of experience. Levin (1987) develops Gendlin's (in Levin, 1987) conceptualisation of experience and the creation of meaning to explain this perspective of disease. This is described and discussed below.

Abstract conceptual "experience" is distinguished from felt "experience". Abstract conceptual experience consists of conceptual contents with which the self learns to identify, and which should ideally express felt experiencing. The influence of cultural

and social processes comes in at this point. Initially, the participants think that they are suffering from a physical condition, and subsequently they understand themselves to be suffering from the condition of CFS. The role of cultural and social processes in the process in which the participants come to identify with the diagnosis of CFS to understand their experience of being ill with a physical condition has been discussed above.

Felt experiencing is preconceptually implicit in the sense that the body bears experience regardless of what one may think one is experiencing. The mind and the body are interrelated because experiencing meaning comes from the situational context in which it occurs. Out of the awareness of the preconceptual whole sense of the subtle body¹ in implicit experiencing, numerous possibilities of symbolising abstract experience exist (Levin, 1987). The embodiment of experiencing psychosocial distress prior to the onset of symptoms is symbolised in abstract conceptual terms of being ill with a physical condition, and subsequently the understanding of having CFS.

In order to live a healthy life, the experience of abstract conceptual contents should express as closely as possible, the bodily felt meaning of experiencing. The reason being, that the body can continue to operate within a certain threshold of

The subtle body of energies refers to an invisible aspect of the body not taken into account in scientific explanations of the body. Jung, cited in Schwartz-Salant (1987) refers to it as the “somatic unconscious”, the avenue through which the unconscious experiences the body.

physiologically held tension. When abstract experience does not express implicitly felt bodily experiencing, tension is created and held in the subtle body. If this continues to occur beyond the threshold of physiologically held tension, the resulting tension expresses itself in the form of disease according to the way in which the subtle body is affected. (Levin, 1987)

When abstract experience expresses implicitly felt bodily experiencing, existing tension in the body is released and the breakdown of the body into disease can be avoided. It can therefore be seen how mind-body unity characterises experience. They are inter-related, and when abstract experience (mind) does not express implicitly felt bodily experiencing (body), the mind is experienced as separate from the body. In health, the mind and body need to be experienced as united (Levin, 1987).

The participants understand that they are suffering from CFS and cope by networking the health system for external treatment resources. In the process the participants remain chronically ill with CFS. Abstract conceptual experience does not adequately express implicitly felt bodily experiencing. At the same time, and not in the awareness of the participants at this time, existing self-management practises such as tendencies toward self-effacement, being submissive in relation to significant others, and avoiding negative feelings precipitate relapses into symptoms of CFS. In terms of the idea that abstract conceptual experience should express felt experiencing as

closely as possible, the participants' felt experiencing of the above-mentioned self-management practises, is not conceptualised at all. The participants are unaware of their self-management practises. As such, tension is created and held in the subtle body. This tension expresses itself in the form of relapses into symptoms of CFS.

With the shift in perception from perceiving their illnesses as "something" they have which is external and separate from their self-identity to a perception of being responsible for their illnesses, the coping styles of the participants change accordingly. Coping by using external social and external treatment resources shifts to using internal resources. The participants use their own resources by adopting self-management practises to cope with having CFS.

By no longer networking the health system for treatment the participants are no longer drawn to identify with the abstract conceptual experience of CFS. They no longer have to identify with CFS as a way of coping with being confronted with the stigma associated with being perceived as suffering from psychological illness at a social level. In the process of having to carry on living by finding out how to manage themselves, in order to avoid relapses, identification with CFS as an expression of felt experiencing begins to shift. The participants find themselves in the position of having to carry on living by finding out how to manage themselves in order to prevent relapses. This induces the participants to initiate experiencing which is closer "to an organismic wholeness directly felt in the body" (Levin, 1987, p.182). In this process

the participants become aware of the link between existing self-management practises (mind) and the experience of relapses (body). In order to prevent relapses the participants accommodate self-management to the physical limitations of having CFS. In this process, existing self-management practises shift toward self-acknowledgement, assertion in relation to significant others, and self-soothing in the face of negative feelings. These self-management practises prevent relapses and maintaining these contribute to the participants' perception of having recovered from CFS. In other words, the participants learn to express the bodily felt meaning of experience more adequately in terms of abstract conceptual experience. The participants' understanding that they are recovering or recovered from CFS is an embodied one. This understanding adequately expresses the embodied feeling of managing themselves effectively in order to avoid relapses.

An interpretation of the above discussion of the participants' experience of recovering from CFS in terms of Levin's (1987) perspective of disease may be that CFS does not adequately express the participants' illnesses conceptually. Rather, problems with self-management more adequately explain the participants' illnesses. Viewed in the light of the interpretation that becoming diagnosed as having CFS arises as a consequence of the discourse about the assumptions of mind-body dualism operating at the discursive levels of popular society and the doctor-patient relationship, CFS is indeed a social construction. While CFS may be a misdiagnosis of psychological problems, or problems with self-management, the social process of becoming diagnosed as having CFS is a way of coping with the stigma associated with being

perceived as suffering from psychological illness. Coping with this stigma compels the participants into a social process of being diagnosed with CFS and away from addressing problems in self-management. That the participants do not address problems in self-management at the time of the onset of the illness is not due to an alexithymic inability to do so, but a way of finding meaning in the social process of being ill.

4.4 CONCLUSION

In most of the research into CFS concepts are used and findings are obtained that describe states that are static as opposed to those describing processes and the dynamics of change. A phenomenon is described from the observation of its regular occurrence at a particular point in time as opposed to the process in which it comes to be over the course of time. In the research on conceptualising CFS from a dualistic perspective, the attempt is to view CFS as an objectified 'thing' or state. Is it a physical disease, or a psychiatric disease (depression, somatisation), that a person gets, or does it involve psychological attributes (perfectionism and over-achievement) or behaviours (abnormal illness behaviour) which the person has regardless of social or cultural context? Referring to the subject of psychology, Miller (cited in Gilbert, 1989, p. 93) says:

“There appears to be a fundamental cleavage between theories concerned with states and theories concerned with change, between being and becoming. This distinction is fundamental because it cuts deep and finds expression in the very nature of the units we either explicitly or implicitly adopt to support our theoretical constructions.”

Concepts as identified static states give “some evidence concerning what the phenomena are, but very little knowledge about how things [get] to be that way” (Berry, cited in Gilbert, 1989 p. 93).

A model is a limited and limiting construction of reality in the sense that the basic propositions of a model, and the methods employed to test the validity of a model can in no way contain the whole of reality (Heather, 1976). The cognitive-behavioural model of CFS is an attempt to contain more of the reality of CFS than the biomedical model of CFS. The psychological and social dimensions of illness not taken into account in the biomedical model of CFS are taken into account in the cognitive-behavioural model. In the cognitive-behavioural model CFS is described as a process and not as an objectified ‘thing’ or state. However, in both of these models with the various concepts used to understand CFS, the social processes involved in their construction and the social processes involved in their perpetuation, as these models and concepts are applied in practice, are obscured. Understanding CFS in terms of these models and researching the experience of persons suffering from CFS in terms of the concepts in these models represent a closed system of thought.

Szasz and Conrad (in Kawanishi, 1992) point out that new illnesses are not created because they are newly discovered disorders. Rather, illnesses are partially constructed through the negotiation of meaning from and between those who define categories of illness, and those who exhibit and experience the symptoms (Mishler, in Kawanishi, 1992). On the one hand, life problems previously managed as moral,

religious and criminal become 'medicalised' and 'psychologised' as new disorders (Kleinman, 1988). Conditions such as hysteria, hypochondriasis, obsessive-compulsive neurosis, depression (Kawanishi, 1992) and in the case of this research, chronic fatigue, were part of human experience before they were defined as disease categories. Conrad, cited in Kawanishi (1992, p.28) says:

Illnesses are human judgements on conditions that exist in the natural world. They are essentially social constructions – hypothetical constructs of our own creation. The fact that there is high agreement on what constitutes an illness does not change this: The high degree of consensus on what 'objectively' is disease is not independent from the social consensus that constructs these "facts".

On the other hand, the new 'illnesses' arise as frameworks for attribution of different types of distress. The attempt to view CFS as an objectified 'thing' or state creates the illusion that it is a newly discovered disorder.

The present research investigates the process of coping and self-management in the experience of recovering from CFS. The finding that the participants use external social and external treatment resources to cope with the onset of symptoms and being chronically ill with CFS are interpreted in terms of a function of discourse (Shotter, 1992), concurrent with a perspective of the social relations of sickness (Helman, 1990). Here, the obscure social processes that govern CFS to which Wessely (1990), among others, refer, as cited in the literature review, are highlighted. Becoming diagnosed with CFS arises as a consequence of the search for meaning in relation to the discourse about the assumptions of mind-body dualism operating at the discursive levels of popular society and the doctor-patient relationship. The participants feel

stigmatised in relation to the assumption in the discourse that psychological illness does not constitute 'real' illness, at both the levels of popular society and the doctor-patient relationship. However, in the process of being chronically ill with CFS where the participants network the health system for effective external treatment resources, they encounter the assumption again. In relation to the popular and professional assumption that medically unexplainable somatic symptoms can be ascribed to psychological causes and the assumption that this does not constitute a 'real' illness, the participants once again feel stigmatised. They become trapped in a closed process.

The finding that coping by using external resources shifts to using internal resources in the experience of recovering from CFS is interpreted in terms of Levin's (1987) postmodern perspective of disease. Here, it is found that CFS does not adequately express the participants' illnesses conceptually. Rather, problems with self-management more adequately explain the participants' illnesses. Viewed in the light of the interpretation that becoming diagnosed as having CFS arises as a consequence of the operation of the discourse about the assumptions of mind-body dualism at the discursive levels of popular society and the doctor-patient relationship, CFS is indeed a social construction. While problems in self-management may be a more adequate explanation of the participants' illnesses than the diagnosis of CFS, becoming diagnosed as having CFS is a way of coping socially, with the stigma associated with being perceived as suffering from psychological illness. This conclusion confirms what Wessely (1993, p.338) says about CFS:

“What lies behind CFS is neither a virus, nor psychiatry, but our idea of what constitutes a real illness, what doesn’t, and what we do to make something real.”

The above conclusion of this research shows how CFS is not a newly discovered ‘objective’ disorder. While the participants may have psychological problems, or in the case of this research, problems with self-management, becoming diagnosed as having CFS arises as a constituent of social processes. Understandings of CFS as a form of illness behaviour, as a form of somatisation, or in terms of the construct alexithymia, are cut away from being a pathology within the person and placed within the process of social interchange.

With regard to research into CFS as a form of abnormal illness behaviour, described in chapter 2, Shorter (1992), Coetzer et al. (2000) understand, and Howlett & Lindegger’s (1996) research finds, that the high levels of disease conviction of CFS patients are a distinctive feature of CFS patients. However, this research finds that it is a way of coping with the stigma associated with being perceived as suffering from psychological illness.

CFS as a form of somatisation is described in chapter 2. The argument is presented in chapter 5 that presenting emotional distress through body language is a universal form of expression. It does not necessarily mean that the person is somatising in the pathological sense. Kawanishi (1992) shows how this and the failure of doctors to treat Asian patients at the level of the somatic appeal can lead to the erroneous assumption that Asian patients tend to somatise their emotional distress. In this

research, medical practitioners fail to treat the participants at the level of Kawanishi's (1992) somatic appeal or to appeal to their sentiments (Henderson, 1934) regarding the stigmatisation of psychological illness. The research indicates the role that this plays in becoming diagnosed with CFS. Hence, the understanding of CFS as a form of somatisation may not be an intrinsic pathology in the patient, but a constituent of social processes.

4.5 SHORTCOMINGS OF THE RESEARCH

One of the shortcomings of this research may be that the researcher did not explicitly explore self-management prior to and during the experience of having CFS. A more extensive exploration of this may have given more impetus to the conclusion that problems in self-management more adequately explain the participants' illnesses than the diagnosis of CFS. However, in view of the stigmatisation of psychological illness it may be anticipated that explicitly exploring self-management may be complicated. Asking research participants with CFS questions directly related to self-management may alienate the participants from the research process.

4.6 SUGGESTIONS FOR FURTHER RESEARCH

In terms of a shortcoming of the present research presented above, a suggestion for further research is to research self-management throughout the course of the illness. This will have a bearing on the conclusion of the present research.

As this research is an exploratory study, in the sense that it is representative of a hermeneutical model of doing research, most of the findings in this research may be researched in greater depth, in relation to more people with CFS and those who are recovering or recovered from CFS. The social processes in each of the key features of the experience of having and recovering from CFS, may serve as suggestions for further research.

A further suggestion is an investigation into self-management of persons who remain chronically ill with CFS. Is it problems in self-management and/or other reasons that persons remain chronically ill with CFS?

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APPENDIX 1**BACKGROUND INFORMATION AND THE PSYCHOSOCIAL CONTEX OF
ONSET OF CFS****PARTICIPANT 1 (P1)****Background information:**

P1, aged 33, is a divorced single mother, and currently works part-time. She reports that she was diagnosed as having CFS on the basis of laboratory tests. Consequently she became medically boarded from her “high-profile” work in the corporate arena. She had CFS for 5 years. She reports that she considers herself as recovered from CFS.

Psychosocial context of onset of CFS:

Central to P1’s life situation at this time are her ways of attempting to cope with her divorce two years previously. She describes the divorce she did not want as the most stressful time in her life. Her demanding work, raising her daughter, and particularly her busy social life, suffice to keep her busy enough to avoid having to directly deal with it.

P1 and her daughter moved house three times in the previous two years. They moved to live with her first boyfriend since her divorce. Shortly after moving in with him she realises that she has made a mistake. She finds “this demonstrative, dreadful man” to be “abusive, jealous, and possessive”. It is at this time she develops flu and moves back to live with her parents.

The nature of her work is such that its pace is fast and the requirements unpredictable. She finds her boss to be more demanding than supportive.

Her social life consists of drinking alcohol with friends, mainly at pubs, at least three times a week.

PARTICIPANT 2 (P2)

Background information:

P2, aged 38, has been married for 11 years, has an academic degree and currently helps her husband in his business. Five years previously she resigned from her managerial position in a corporate business. She had worked there for 11 years. Her husband had moved from the city over a year before she joined him. They were separated and contemplating a divorce.

P2 was diagnosed with CFS a year after she had joined her husband. She had been for her second unsuccessful in vitro fertilisation attempt to fall pregnant. P2 considers herself as recovering from CFS after having the condition for 4 years.

Psychosocial context of onset of CFS:

Central to P2's life situation at this time is living by her re-commitment to her marriage, her unsuccessful attempts at in vitro fertilisation to become pregnant, and adjusting to a different environment and lifestyle. This is after a lengthy period of instability in her marriage, and an emotionally painful separation.

P2's relationship with her husband is difficult in that they are trying to live together in the context of attempting to resolve past problems. She finds it difficult to adjust to a rural lifestyle and misses her job and her life in the city.

PARTICIPANT 3 (P3)

Background information:

P3, aged 24, has diplomas in two fields of complementary medicine. She wanted to study medicine upon leaving school. However, firstly she had been suffering from CFS since the end of her standard 9 year, and secondly, her matriculation results were below those required to apply for the degree in medicine. She was diagnosed with CFS in the second year of having the condition. She had CFS for four years. She considers herself as recovered from CFS.

Psychosocial context of onset of CFS:

P3 describes herself as an over-achiever, enjoying competition, with high goals in all spheres of her life. She likes to be in ideal terms with friends and family, particularly her father. She feels that achieving all her goals is stressful for her.

Her relationship with her father is, for the first time in her life, unsatisfactory, since his discovery that she dropped a particular school subject the previous year without discussing it with him. He is angry and disappointed in her, which upsets P3 greatly. The central issue in P3's life becomes to repair her relationship with him by doing well academically in school and consequently being accepted into Medical School.

However, she is anxious when she observes that she is failing in her attempts to reach these goals.

APPENDIX 2**INTERVIEW QUESTIONS****Interview questions for second interview regarding the onset of symptoms:**

1. Describe your experience of when you first got symptoms.
2. How did you understand your experience of these symptoms?
3. What did you do about your experience of the onset of symptoms?
4. How did people that you know respond to your being ill?
5. Describe how you became diagnosed as having CFS.
6. How did you cope with having CFS?

Interview questions for third interview regarding recovering from CFS:

The direction of the third interview was to be determined by what the participant said in response to the first and second questions below. The aim of the researcher in this interview was to find out about the participant's self-management. Transcripts of the third interview for each participant are provided in the next appendix, appendix 3.

1. How did you move from being at your lowest point with this illness to the point where you have been able to say that you have recovered from CFS?
2. Describe how you recovered from CFS.
3. Describe what you did?
4. Give examples of what you did.

APPENDIX 3**TRANSCRIPTS OF THIRD INTERVIEW****THIRD INTERVIEW WITH P1**

How did you move from being at your lowest point with this illness to the point where you have been able to say that you have recovered from CFS?

Living through the worst of it all somehow gave me a lot of strength. I mean before I got CFS if circumstances had led to me being down and out I don't know if I would have coped.

What do you mean?

Okay, you see it's like the person I was then; I wouldn't have allowed myself to be depressed. I was just too busy with things to actually stop and face myself. I mean now I just physically can't go drinking and partying, and burying myself in my work and other peoples demands. Now, if I'm depressed, well, it's not pleasant, but I cope, I'll get over it, look at what the problems are and try my best to solve them. Otherwise, I will feel consumed and get CFS again.

What you are saying is quite significant, that you have changed as a person through having CFS and somehow you are linking this to recovering from CFS. There are a few things about this that I'd like to ask you, firstly in what ways have you changed and secondly how do you think this has happened?

Well, it is quite complicated. I think a big thing is that it wasn't like usual illnesses where okay you are sick and everyone knows that and you're allowed to take time out and then your life is there for you when you get better. But with CFS it was so different. The fact that sometimes you're fine and then you relapse, and the fact that people don't know where you stand with your looking fine but not being fine, all the time, and it just goes on and on. At first all the usual demands, you can say "no" I'm too ill. Most people just gave up on me, and I can understand that now. But eventually, you've actually got to engineer your life to suit you. So what happened was that in the process of doing this my old life slowly disappeared and a new one took shape.

Can you be more specific here by trying to go into more detail?

Take work for example, I just physically couldn't do my job, I got boarded which means that a big part of my life had changed. I knew that I had to eventually find work, which could fit in with my illness lifestyle. So now, many years later, I do part-time work for two businesses and I adjust my life around that. The type of work is different – it had to be – there are no weekly sales targets and rewards for doing everything and for doing it all now. This work is just work, providing services to people. You don't have to go and create sales and rush around. And then, if I've got

to be there from 5 to 10 then I'll make sure that I don't tax my body in the day, just taking it easy and make sure that I don't have too many commitments that day and have time to rest or sleep. If I don't do this, if I push myself then I know that there will be a relapse.

So how do you manage to make sure that you don't tax your body and have too many commitments in the day?

I just say "no". That's one thing I've learned to do. In the past I could never do that. If someone wanted to play squash during lunch hour, I wouldn't even ask myself if I want to or not. I just felt I had to. The same with a lot of things, my bosses at work, my folks, fetching and carrying my daughter wherever. Most of the time I was feeling obliged to doing things. I mean I know I allowed this to happen, people always knew that they could call on me. I have to stop myself and ask do you want to do such and such. I'm more aware of how I feel. And, I include this in making decisions about what to do. So now it's not only a question of can I do it in terms of watching my limits, its do I want to do it? Now, being this way doesn't constantly put myself in positions where I don't want to be. People know that they can't just call on me. My life was hectically out of control before. Now it's at a much slower, peaceful pace and I feel like I'm largely in control of it.

How did this change do you think?

It was having to adjust to this illness. I had no choice but to learn to live within my physical limits. I mean I still in my mind have a tendency to want to rear ahead, I miss the rush of doing so many things and all the success with everything. But, it is much better for me now. I've had to set new goals. Living with this illness has led to having different values.

Like what for instance?

Before, it was, I needed to be involved in so many things. It made me feel good about myself. I was an achiever and the more I achieved the better I felt. The same with people. It was important to me that people wanted me to do things. I valued that a lot. Now, it is more a matter of having quality time, and less with doing, doing, and doing so much. It's like I've learned the art of being of living a quality life now. CFS makes you slow down and be more with yourself. Feng Shui has helped me a lot with this. In fact a lot of the changes I made in my life where because I could identify with many of the principles of Feng Shui. One of the main things was realising what was blocking me, why I was possibly stuck in this rut of this illness. On the practical level, they talk about getting rid of your clutter in your house, and also in your life. And that's where my biggest challenge came. Working it out was one thing, but then making these changes was difficult and where I've learned the most. I was still a child in many ways, living with my parents in their house, with their clutter, their rules and expectations. I didn't have any space. That's when I decided that I had to pack up, leave, and move far enough away from them, not maliciously. And I killed

many birds with this one stone. All the unfinished business with friends, I just didn't need that in my life anymore.

I guess the big jump came when I had to tell people what I was doing, and to do this within the limits of my illness, not to rush, panic, and worry. I was surprised, I felt more confident as I watched how I progressed with this whole thing. I mean it took a lot of courage for me – not to ask my parents and to get into debates and possible problems, that whole trip. I just refused to go there. It was a matter of telling them I was leaving, no fussing. Just demonstrating that I'm the boss of my life. I think that the way I did it made it easier for them actually. This was a good move. It has done our relationships a lot of good. We get on much better now. I let them parent my daughter, at that time, I needed them to. But now, I wanted to be her mother, not her sister, for goodness sake! That was taking responsibility and it's been a challenge and growth experience. We are much closer now. She's had to learn to accommodate me, that my needs are just as important as hers are. And engineering this was a big learning curve.

Making this big change in your life, you relate it to asking yourself why you were stuck in the rut of this illness, what did moving away from your parents have to do with your having CFS?

It had a lot to do with realising where most of the stress was coming from. I'd be fine and then there'd be a lot of fuss about who was going to take my daughter somewhere a simple thing like that. Ontop of it, what we are going to have for supper, that type of thing. Often, I could feel myself losing it, something wasn't right and it was so complicated to fathom how to get out of these kinds of situations. Ten to one I'd have a relapse. I was stuck in this illness rut. I had to get out, to save my sanity and my health.

Let's just reflect on all the changes you've mentioned so far, you've spoken about your change in work and how the needs of your body dictated this, also, you've learned to identify your needs and be more assertive in relation to them, about changes in lifestyle you've made. Is there anything else that may stand out as having been a significant change?

Yes, in general, it's like CFS forced me to grow up. I couldn't rely on anyone or anything to kind of fix me. I learned to take responsibility for my illness. And I think it is in this process that I've become more independent. One thing I do want to stress is how now I look after myself, and particularly I have to look after my body. Okay fine if I don't look after myself then it will come up in my body, I'll get sick. But also, I'm more aware of my body and I spend a lot of time working on it. I don't do such hectic sport, squash is hectic and I played competitively. Now, I do things like calanetics, I'm getting into serious yoga now. So it's a completely different physical experience and I like to treat my body with regular visits to the reflexologist and aromatherapist. And now I do this without expecting anything, just to enjoy it, which is great.

THIRD INTERVIEW WITH P2

One of the things you mentioned the other day, stands out, you mentioned where you are today as a person and where you are as a person with CFS. This was in relation to psychotherapy. Am I right in saying that it seems that your experience of recovering from CFS is related to your personal growth over this time?

Oh definitely! I can come out and clearly state that if I hadn't worked on myself as a person, I will not have recovered from CFS. That was the crux of my recovery.

What do you mean?

Taking responsibility for my illness meant taking responsibility for my life. Going that route, working on insight into myself, and what I got from that had a direct impact on how I handled having CFS.

Can you be a bit more specific, give some examples of what you mean by this?

Ha! Let's see I'll try. For one thing, it was staring me in the face, but I never put two and two together. All my life really, whenever there was change of some sort, times of stress. You see, I function well in a structure or system that is familiar, I have to know what I can and cannot do, what I have to do and so on. My success all those years in my career, can be put to that. When things are vague, or unknown, then I stress, and when I stress I get sick. I only had to look. I've always suffered from headaches, bad migraines, and that is usually when times are difficult. When I left for boarding school as a teenager, I developed an eating disorder. Come exams, I'd get nausea. I got glandular fever when I started university. And then now, making this recent big change, leaving my job and my familiar and cherished lifestyle to come to the farm, where I have to make a life, it was too much, and the stress of it all, I get CFS.

So, you're saying that you realise now that your unintentional way of managing stress is getting sick?

Yes, it's because I can't deal with the stress emotionally. It was also tough for me to come to terms with this. Now, I'm learning to deal with it a bit better. Even small things, like if my mother-in-law comes to visit, she thinks that getting on with me is about telling me all about her complaints. She tries to get me to do things in this twisted, round-about way. There I am, having to listen to all her and getting more and more uptight as I realise how she is trying to manipulate me. Then I feel symptoms coming, headache, that's the first sign, and then I know something's not right. I'm not handling this correctly. And this is where the challenge is, not feeling obliged to do things, and that's a huge pressure in my husband's colonial-like family. And I've

got to the point where I can say to myself that I cannot and do not have to listen to this. Then I rather actively orchestrate, steer the conversation in a different way.

What do you mean?

Instead of just sitting through situations like this, and there were many, having to do things that I didn't want to, and getting sick over it. I had to take responsibility for how I felt by learning to impose myself on the situation and at the same time, not being rude or angry and then alienating them. I mean I live with my in-laws, they are always a stone's throw away.

To get back to how taking responsibility for your life has impacted on taking responsibility for your illness; can you say more about that?

Right, I think that before I could even look at my illness, I had to deal with why I was depressed and why it happened when it did. It took months and I was very sick, so absolutely exhausted. I was actually grieving many things without knowing what it was at first. It was serious having to live through it and learn to feel that it's okay to be depressed. I mean when I grew up, you just weren't allowed to be depressed, everything had to be a big fat joke. That is how we knew how to relate to each other. Being depressed was like being a failure. I see now why I was so angry when I was diagnosed with depression. You see, I just couldn't get it then. I couldn't be depressed, so I got sick instead. And then finally, when I had taken it as far as I could to avoid it, you know, like I kept running away when I was searching and trying all those treatments, it was like the big axe came. It was inevitable and it hit me hard. I was at a total loss, what now? I had nowhere else to run. For me, learning how to cope with this illness has been a lot about how to cope with my feelings. Watching when I get relapses and instead of avoiding it, rather, looking at what's going on in my life at the time. And I've learned to read it so well now, I was telling you earlier.

You have clearly now adapted to your farm life and you feel that you have recovered from CFS, how did this take place do you think?

Having understood my having CFS in this way helped me in many ways to accept it, I felt I had a handle on it, in my mind. Accepting that I chose now to come to the farm, and to work on my marriage, and accepting that I had CFS went hand in hand, and it was about choice. I could choose to leave and I could choose to not work with this illness. I had to take responsibility for recovering. No one else was going to do this. It took me long enough and a lot less money in my bank account to realise this. Eeking out a life on the farm was the same as working out how to live with this illness.

What has this meant?

It has meant a long process of experimenting and finding out what is best for me. What is important for me and the best way of getting that.

You have spoken a lot about the psychological aspects of recovering, what are some of the more concrete things that you've done to recover from CFS?

Yes, I have done a lot to recover from CFS, but I have to say that it's the most important, being able to keep myself balanced, my body, my mind, and what I do about them both. It's all interconnected.

I know it must be hard to try and describe it. Maybe if you could give me some examples of what you are saying about this?

First and foremost I had to start with what was needing the most attention. My body was a wreck and so was my mind. But to physically being able to move around and get to the psychologist I had to try and get myself there. At first I had to focus on those two appointments a week. Everything was geared around that. If I stayed in bed too much then I'd be too weak and my eyes would hurt, have that sick feeling. I had to moderate what I did and rest and so on. Diet has always been important for me, and I'd learned a great deal from seeing a dietician and a naturopath and feeling on top of my diet and vitamin in-take is important to me. And after much trial-and-error I've got it all worked out now and included in this is an exercise programme, which I had, done with help from Walk for Life. Everyday I have certain fixed appointments with myself where I know this and this has to be done in that time and the other time I'm free to play around with what I've got to do. I have to have this to keep myself in a balance, which I constantly keep fine-tuning.

How does this tie in with feeling that your mind, body and behaviour are interconnected?

Usually, if something's not right, like if there's something that I'm upset about, like if I bottle up my feelings about how my husband is being false with his mother and he is seething about being manipulated, and it starts affecting our relationship, my body just can't hold the tension. I start getting sick. Then I have to confront it, as hard as it is for me, but I do. I feel much better and then the downward spiral is avoided. I've realised it's all about nipping things in the bud.

If one thing goes out, like if I don't stick to my routines, then I become unsettled. Anxious, and then that affects how on top of things I feel. It has taken me a long time and hard work to find out what works for me, they may not for someone else with CFS, like my diet, it's important for me to stick to it. It keeps me well. Now, I'm onto growing my own organic vegetables and my herb garden is coming on. This is how my new lifestyle, working out a life for me on the farm is tied up with getting over CFS.

THIRD INTERVIEW WITH P3

Describe how you began to recover from CFS?

The are a quite a few things. The fact that without really being aware of it, I was less and less seeing myself as a person who has CFS. I was getting caught up in, how can I describe it, the magic of getting better, and learning to do it myself, relying on myself, and doing it myself.

At one time, having the diagnosis of CFS was very important to you. How do you think this has changed to the point where you can say that you hardly identified yourself as a person with CFS?

After a while, a lot of people with CFS, certainly myself, because of all I went through, having to cope with what many people think, you know, that it's not a real illness, and that there is nothing to help you, nothing ever changes. Having CFS to explain my situation was just getting me nowhere. It came to mean something else. I can't really express myself clearly, but it got to the point where it meant very little. Which is why when I realised what Keta [physiotherapist] was doing, not ever referring to CFS, it made sense. Also, trying to get a normal life again presented so many more immediate challenges, I was beginning to do what I needed to do, and it did not involve having to think CFS, CFS."

What did you need to do, or rather, what did you do?

The first phase of my treatment with Keta was working on gradual tasks toward achieving the level of functioning of the average healthy person. I learned here how important nutrition and exercise where. It was amazing for me to see how what Keta said about if I get my balance with nutrition and exercise, how my sleeping would come right by itself. Keta's whole method of working, how she worked with me towards goals and how to set these. This is what was invaluable. How to pay attention to myself, in ways that I never specifically thought about before.

So, in this process you learned what you needed to eat, how to become and stay fit, that type of thing? What else did you learn?

Throughout, maintaining physically was always there, it continued in the treatment. The treatment began to include other aspects. I had to complete quite a detailed worksheet on where I was at, basically, with career, work and finances, family concerns, social activities, spirituality, that type of thing. And each week I left there with specific tasks to complete regarding each aspect that I've just mentioned. The next consultation would involve discussing what I did, and the consequences and what I was going to do next.

It's now about a year since you completed this treatment and you say that during this treatment you began recovering from CFS. Can you describe how you have managed to continue to be free from CFS since then?

For me, recovering from CFS has had a lot do with perspective and coping with it in that way. I'm not as healthy as I used to be in the sense that I've got physical weaknesses. I'm forced to be aware of it. Before, I could go on full steam ahead without having to be aware of my body and its reactions. As soon as I start running away with myself, or I forget myself, like if I'm doing too much and getting worked up over things, warning bells start wringing. I start getting flu symptoms and then I've got to make emergency plans and center myself again. I have to prioritise, question myself, and keep focused.

To get back to what you started saying about your perspective on recovering from CFS, what do you mean?

Ja, what I'm trying to say is that to me, it's like CFS is under the surface, and under certain conditions it will flourish. If I still saw myself as someone with CFS I'd be that person. It's the way I've chosen to see it and what I've learned to do to keep it at bay.

You have spoken about how you have learned to detect a relapse and a way of preventing relapse. Can you think of other things that you do to maintain your status of recovery?

The lifestyle I have made now – it's a different me. I'm no longer trying to be a hero out to please her father. I was too busy trying to be someone I was not. Looking back and it's only now that I can say this, afterwards, that CFS, I mean I was asking for it. All that missioning and pressure to get A's and be involved in everything. It wasn't really me. CFS is probably one of the best things that could have happened to me. CFS forced me to make a new life for myself and it made me do things I would not ordinarily have done.

Like what for instance?

Living at home, being with my father all the time, it wasn't good for me. I, on purpose, chose to keep him, my parents at bay. And I just haven't allowed him to get to me. He has got a way; he knows how to get to me, to make me feel bad, like I'm doing the wrong thing. Just from what he says about my new career, Herbalism and Aromatherapy. He thinks it's a lot of nonsense. I mean he really wanted me to be a doctor, and his disappointment still rings loud. When I was at school, I could not tell him that I had dropped Latin. I suffered in the face of the inevitable. Obviously the time came for him to find out. And what he thinks of my boyfriend, they are so different. Before, it would have freaked me out if he didn't like one of my boyfriends. Now, I still have him as my boyfriend. But before CFS, I probably wouldn't. And I don't try to explain myself, why I like him to my father. That's the way it is it's a pity, but what can I do. I just don't let it get to me any more. I think that what I went through, it makes you stronger. I've learned also not to alienate people, to be more constructive. One side of me just wants to freak out, but the stress it is just not good for me, and the guilt afterwards. Keeping focused on what's good for me, and I know now, instinctively, what is and what isn't.

Is there anything else you think is important to say about this?

Ja, uhm, there is more. And I think it's an important thing. Talking to you like this, thinking about how I was before I got CFS, and looking at myself now, there is something that's really different. I feel more free, not bound as I was before. I'm not so hard on myself. There was something chasing me before, and I was always on the go, have to do this, then go there. If things don't work out as planned, I don't panic and keep at it, sort of desperately. And I feel free to change my mind, ja, it's living with a sense of not having to answer to anybody else.

APPENDIX 4**PARTICIPANT 1 (P1)****Reading guide question 1:**

How does the participant cope with the experience of the onset of symptoms of CFS?

P1 describes her experience of the onset of symptoms in physical terms.

“For me, it was like my body could not overcome the flu that I had. Normally, when I had flu in the past, my body would deal with it in a way that it made me forget that I had flu. I would just recover. But this time, I’d just be getting back into things and wham! I’d be stopped dead in my tracks. I’d feel so sick, be so tired and feverish that I’d just collapse into bed. I couldn’t continue with normal living. Like I’d be back at work rearing to go and I’d have to end up going home. It was on and off like that the whole time.”

The participant responds by defining herself as ill and attempts to understand what her symptoms might mean. She believes she is ill with a physical condition.

“Well, I thought that there must be something wrong with me that I just couldn’t get over this flu. There must be something major going on. I began to panic. I had been on antibiotics for this flu. So, when it felt like I hadn’t got over it, it was scary. Perhaps I had glandular fever I thought. The thought of Aids crossed my mind, but I knew I couldn’t have that. But I was very worried because it felt like I was being taken over by something.”

“The point is that I didn’t want to be sick. Okay, everything was hectic and chaotic, but that was me, nothing unusual ... I was desperately trying to carry on with everything and I just couldn’t understand why I had these symptoms. It was like my body wouldn’t cooperate.”

However, the participant gets the impression that others believe she is somatising stress. With regard to her parents the participant says the following:

“My folks for instance, they have always been concerned about me being over-stressed. Like with my sleeping problem that I had since being pregnant with my daughter. They believed it was psychosomatic. The whole thing about me not being married at the time of being pregnant, and then getting married in the wrong way... Then of course, the stress in my marriage and my divorce. It was like it was my fault. It was the same with me having ME. My hectic socialising since the divorce and moving in with my new boyfriend which ended in disaster and being so busy at work.

They believed that my symptoms were as a result of all this stress. They said that if I just moved back with them, cut down on my work life and stop socialising so much that I'd be better."

With regard to her friends and colleagues at work the participants says:

"It was kind of the same thing. They all felt sorry for me with my divorce, you see. He left me. I didn't want the divorce, everybody knew that. Anyway, it was my friends who got me into all the socialising and partying. I suppose it was a way of trying to help me get over the divorce. So when I became ill, after my relationship with my new boyfriend ended in disaster, they also believed it was stress."

The participant experiences conflict over the difference between her own illness attribution and that of others. She experiences the somatisation illness attribution of others as an implication that she is "pretending" and that therefore her illness does not justify occupation of the sick role. The participant says:

"I was very angry, upset by this suspicion that I wasn't really ill. I wasn't pretending. They were not allowing me to be sick."

She copes with the demand of this conflict by seeking professional validation for her illness, in the form of a medical diagnosis. The participant consults her doctor, with her problem regarding others not believing in the reality of her illness, in mind. She says:

"I was sure that by this time [the doctor] must be getting quite tired of me and I went to see him with this in mind."

"I had the impression that he thought I was just not coping with life, you know, from the previous times I had seen him about being off work. Then, when I suggested to him that I had ME he was hesitant and sceptical."

The participant's illness was diagnosed as psychological in origin. She defensively resists this and feels alienated from others in her social network and the medical profession. The participant describes this experience as follows:

“Now, I had been to a psychologist already after my divorce and it didn’t work. I didn’t want to go through that again. I mean the evidence was there that I had a physical disturbance. I felt blatantly insulted and in no uncertain terms did I let him know it. I wanted a second opinion and had to find a doctor who knew about ME.”
“It was incredibly frustrating being misunderstood like that by everyone, even my own parents.”

The participant had heard and read about CFS in the media and obtained a referral from the ME Association of South Africa to a doctor in her area who believes in CFS. This time laboratory tests are positive for EBV. She becomes diagnosed with CFS. The tension created by the contradiction from others that she is not legitimately ill is resolved. The diagnosis of CFS is experienced as confirmation that she is legitimately an occupant of the sick role. As the participant says:

“Eventually, many months into it all, when I got diagnosed with ME, it was a hell of a relief. There was something else going on and I wasn’t pretending and now I could be ill without having to worry about the possibility that they were right. It felt great to be able to tell people now that I had ME, you know, like when people would ask me what was wrong with me.”
“And then, I could stay at home in peace. My folks came round and were really concerned and helpful.”

Reading guide question 2:

How does the participant cope in terms of her experience of being chronically ill with CFS?

The participant expects that medical treatment will relieve her symptoms over time and that a medical cure is imminent. However, each successive treatment is found to be ineffective. The participant becomes desperate for something to end her pain, discomfort and suffering. In her own words:

“I was prepared to try anything, just to feel a little better even. In the end I didn’t even worry about finding some complete cure from this.”
“At first I relied very much on anything any doctor would recommend. Anti-inflammatories, I even went on an over-seas based, I think it was connected to Belgian research, anti-biotic programme which stressed me out and made me worse,

with all the sampling. I even accepted referrals to psychiatrists, took anti-depressants. There were many alternative treatments that I tried and they helped in little ways.”

Over time the participant's relationship with the professional and complementary sectors of the health system leads to a fragmentary illness experience.

“The whole long effort to find treatment was like clutching at straws.”

”Some doctors don't take the physical symptoms seriously, believing that it's just stress. Those that do take them seriously are unable to treat it. The psychiatrists don't take the physical symptoms seriously. It left me feeling rather out in the cold”

“For me, living with ME has had a lot to do with living with depression”

“But then, it would always come back to the feeling of actually having a physical disease, suffering physically which felt as if it had nothing to do with what was going on in my mind.”

The participant experiences a cycle of hope and disappointment at each treatment found to be ineffective.

In relation to the antibiotic programme P1 tried, she maintains that the doctor “was very optimistic about it, and this made me excited. It wouldn't be long and things would be back to normal.” Once the treatment was completed P1 says “It did nothing and no matter what I tried, if I think of all the things I tried and did, it began to wear me down, you know being disappointed all the time.”

“You're always onto something else, hopeful, searching for something which would cure you and then prove that you aren't just depressed.”

P1 becomes frustrated at not knowing how to cope with the illness.

“There was a lot of frustration and loneliness.”

“So, I was going crazy with how to try and control my symptoms.”

P1 becomes desperate for help.

P1:”I became desperate for anything to help me out of this.”

“I'd often go to the doctor in a desperate state and I'd just break down in his office. I accepted his referral to a psychiatrist with relief because I knew I was seriously depressed.”

P1 becomes depressed.

"I didn't want to carry on this way and many, many times I would just want to die rather than to live this life of illness."

"For me, living with ME has had a lot to do with living with depression and being completely different even from my usual self."

"Having to come to terms with, at the end of the day, that no matter what you tried, you weren't getting better. It all seemed so pointless really. And I gave up hope eventually that there was going to be anything that could help me."

"In the end I just lost hope in everything that I originally had hoped and automatically expected could help me conquer this illness."

The meaning of having CFS becomes confusing. This is fueled by the response of others in her social network to the observation that many treatments are being tried to no effect, over a long period of time, and P1 looks well yet she asserts that she is still ill. Others, and P1 herself, begin to doubt the validity of CFS.

"But it gets a bit much when people ask you again and again how such and such a treatment has worked, and you say that nothing changes, you are still very ill, but you don't look too bad."

"It's hard to live with this yourself let alone get others to understand it. People, myself included, began to doubt the reality of ME. What's the point of having a diagnosis when it gets you nowhere? So, in the end, the relief of having the diagnosis of CFS sort of went back to the confusion before I got diagnosed. And it was so hard trying to make sense out of it when all I came up against was doubt about the reality of ME."

"It seemed that now that I was also a psychiatric patient what my friends and family thought about my illness initially was right. Maybe ME is all in the mind."

"Maybe it is a form of depression. For a while I really felt it to be like this. And other people treated me like ME is in the mind."

"But then, it would always come back to the feeling of actually having a physical disease, suffering physically which felt as if it had nothing to do with what was going on in my mind."

P1 reaches the point where she feels abandoned by, and alienated from, the medical profession.

P1: "I found that less and less would I go to doctors and try all sorts of things like I used to. In the end I just lost hope in everything that I originally had hoped and automatically expected could help me conquer this illness."

"I didn't want to have anything to do with doctors anymore because no matter where you start when you speak to them, you end up reaching a point where you realise it's no use. They say you must get psychological support and then you know what they

think. At times I've just wanted to scream. I couldn't get them to understand that what I've got is a physical problem."

"It left me feeling rather out in the cold."

For P1 the feeling of abandonment from the medical profession and being alienated from it is accompanied by depression.

"The depression I felt once I realised I was out in the cold was something else. For months and months I struggled on with fighting this illness on my own, without recourse to any doctors, trying to live just basically without being an invalid. But in the end, I just succumbed to it. I gave up. And then my whole life, even before I was ill just seemed to be a disaster."

Reading guide question 3

How does the participant cope with her experience of being chronically ill with CFS such that she arrives at the point where she is able to view herself as recovered from CFS?

In the context of the chronicity of the illness, the inability to find help in the form of treatment to control the illness, the alienation from the medical profession and others in her social network, P1 goes through a phase of self-confrontation.

"Being sick, with there being nothing more to try, left me just being with myself. It was scary, to have no option but to live with yourself. I had become so isolated with this illness, I couldn't do anything. No more attempts at treatments, activities and people to escape into. It was hell. I was left with no option but to think ... and the questioning. What have I done wrong? Why have I got this illness? What must I do now to break through, so that next time round, the next life maybe, I don't have to go through this again?"

P1 emerges from the experience of self-confrontation with a perception of being responsible for the illness.

"Having CFS forced me to look in, to recognise my faults and losses, things that I did not like, and to deal with them. CFS was the catalyst. To come out of it accepting my faults and to work with them."

It appears that recovering from CFS is about a process of negotiating her life within the physical limitations imposed by having CFS. P1's self-management practises are challenged by these physical limitations. Life becomes a matter of finding out how to manage herself in order to prevent relapses of symptoms.

"I had no choice but to learn to live within my physical limits. I mean I still in my mind have a tendency to want to rear ahead, I miss the rush of doing so many things and all the success with everything. But, it is much better for me now. I've had to set new goals. Living with this illness has led to having different values".

"And then, if I've got to be there from 5 to 10 then I'll make sure that I don't tax my body in the day, just taking it easy and make sure that I don't have too many commitments that day and have time to rest and sleep. If I don't do this, if I push myself, then I know that there will be a relapse."

In the process of finding out how to manage herself in order to prevent relapses of symptoms, P1's self-management practises change. It appears that recovery from CFS is a matter of maintaining her changed self-management practises.

As illustrated below, it may be said that P1 learns to acknowledge herself, be more assertive, and to self-soothe in order to avoid precipitating relapses.

P1 exhibits a tendency toward self-effacement before having CFS. Now she acknowledges her own thoughts and wishes.

P1:"Most of the time I was feeling obliged to do things. I mean I know I allowed this to happen, people always knew that they could call on me. I have to stop myself and ask do you want to do such and such. I'm more aware of how I feel. And, I include this in making decisions about what to do."

P1 shows a tendency toward being submissive in relation to significant others prior to CFS. She finds it "too complicated" to assert herself, for example, in situations regarding her daughter to her parents. She refers to "the stress" that she experiences in these situations, and its link with having subsequent relapses if not managed

differently. To resolve the tension between the tendency to be submissive in these situations, and the probability of precipitating a relapse if she continues to be this way, P1 becomes assertive in these situations, as illustrated below.

P1 remembers one of the principles of Feng Shui, a complementary health treatment that she tries during her search for treatment. It prompts her to question why she is “stuck in the rut of this illness”? She believes that living with her parents and all that this entails is “blocking” her potential to recover from CFS. She makes the decision to move out of her parent’s house and to make a new life in another town.

“Working it out was one thing, but then making these changes was difficult and where I’ve learned the most.”

“I guess the big jump came when I had to tell people what I was doing, and to do this within the limits of my illness, not to rush, panic, and worry.”

“I mean it took a lot of courage for me – not to ask my parents and to get into debates and possible problems, that whole trip. I just refused to go there. It was a matter of telling them I was leaving, no fussing. Just demonstrating that I am the boss of my life.”

P1 shows a tendency to avoid negative feelings prior to CFS. In order to prevent a relapse that such behaviour will probably precipitate, P1 learns to soothe herself in the face of negative feelings. Instead of compulsively avoiding negative feelings “by burying myself in my work, and in other people’s demands of me” and destructively acting-out negative feelings by “going drinking and partying”, P1 learns to tolerate negative feelings.

P1: “Okay, you see, it’s like the person I was then, I wouldn’t have allowed myself to be depressed. I was just too busy with things to actually stop and face myself. I mean now I just physically can’t go drinking and partying, and burying myself in work and other people’s demands. Now, if I’m depressed, well, it’s not pleasant, but I cope, I’ll get over it, look at what the problems are and try my best to solve them. Otherwise, I will feel consumed and get CFS again.”

In the process of maintaining her changed self-management practises, P1's self-identity shifts and her lifestyle is positively transformed. Prior CFS P1's self-identity is one of being an "achiever" and someone who valued being needed by others. She describes a "doing" lifestyle prior to CFS and a change towards having a "quality life" while recovering from CFS. The nature of her work, her home and family situation are fundamentally transformed.

PARTICIPANT 2 (P2)

Reading guide question 1

How does the participant cope with the experience of the onset of symptoms of CFS?

P2 describes her experience of the onset of symptoms in physical terms.

"When I was having in vitro fertilisation, the incredible doses of hormones that I had to have made me incredibly moody and mad, but knowing where it came from helped. During the first few weeks of feeling this change, being very tired, I got bronchitis. I don't think I ever really got over it. I was in bed more than out, for weeks afterwards. Getting an incredibly sore throat has always been a big symptom for me. At night, mainly, I'd frequently get temperatures, feeling feverish. I felt very stiff, my whole body, and it ached, even after the bronchitis was over. For about three months after having bronchitis I'd keep on trying to be well when I wasn't. At the first moment of feeling any sign of feeling better, I was so happy, I'd just be getting into doing things, and I was ecstatic about catching up, when then I would be taken over by this terrible exhaustion. It would just immobilise me and I'd literally collapse in a heap."

In her attempt to understand the meaning of her symptoms, P2 defines herself as ill.

P2 describes her understanding of her symptoms as follows:

"I knew that I was sick, and that it had nothing to do with the in vitro that I had gone through. I had to find out what it was. I was afraid of what might happen if I didn't get it diagnosed and treated as soon as possible."

However, others in her social network do not believe that she has an illness. They believe that she is suffering the repercussions of in vitro fertilisation, a medical procedure she had undergone recently.

The participant consults her doctor and he is unable to diagnose her condition. He refers her to a specialist physician. After various tests reveal no abnormalities she is told "there is nothing wrong with you." Subsequently, the participant is able to identify with the illness attribution of CFS that she receives from a friend. She networks the professional sector of the health system for a diagnosis. After several consultations with various medical professionals, some of which result in the diagnosis of depression, she is diagnosed with CFS. The participant vehemently denies the possibility of depression.

"It irritated me a lot, this talk about 'you are depressed'. I wasn't tearful and I wasn't complaining about anything. It was quite clear that I wasn't being listened to. I was rather insulted. It seems to me that no matter what is going on, if the doctors can't find anything, then it's depression. I was mad about this. The fact that my real complaints, feeling deathly tired, arthritic-like joints, struggling to focus from dizziness, and feeling feverish, were not taken at face value, was like a real slap in the face. These symptoms were just not addressed. It was bizarre. What was I supposed to do, say that I'm not feeling these things and that I'm depressed?"

The participant is relieved at being diagnosed with CFS. She perceives the diagnosis of CFS as being a legitimate illness worthy of sick role status, which in her perception refutes the diagnosis of depression. She believes depression is not a legitimate illness.

"The idea that I could have CFS made the most sense to me. When I got diagnosed it was good to know what I've got. That uncertainty was over,"

"It was most certainly better for me to tell people that I had CFS and not depression. CFS is a real illness whereas depression as an illness is rather frowned upon. I certainly would not have felt so comfortable retiring to bed. It was relieving to find that the other doctors who diagnosed me with depression were actually wrong."

Reading guide question 2:**How does the participant cope in terms of her experience of being chronically ill with CFS?**

The participant follows her doctor's prescription of staying in bed and remaining inactive. She takes medical symptomatic treatment for her symptoms. Over time, there is no improvement in her condition. The participant begins to network the professional and complementary sectors of the health system in search of effective treatment. The participant describes this as follows:

"I spent a great deal of time looking for something or someone to help me. I believed, or rather, I wanted to believe that there was something out there and if I looked hard enough I'd find it. I just couldn't accept that I must just go home and rest. That's not treatment. It's like, just put her in file 13, the waste-paper basket that's most of the medical profession. In hindsight, not accepting this cost me a fortune in all the various medical consultations and other therapies."

"I can't say that it was all a waste of money, no. None of them made a difference in terms of curing me, no. It was more what I was going through then, at the time of trying all sorts of treatments, I was quite bitter. I was still expecting someone else or something else to treat me, if I could just buy it, I would have paid anything. But later, when I'd got my mind right, then much of it came to use. I'd remember the raw food aspect of that diet, if I start on a tirade about something, then I'd remember Mike, he's from psychoneuroimmunology, I'd remember how influential negative thoughts are. They came in useful, but only much later."

What follows is a list which includes some of the treatments and/or resources the participant remembers she tried: six medical practitioners, some of which are specialists, the ME Association of South Africa, information and suggestions from various articles and magazines, herbalist, homeopath, naturopath, dietician, psychologist, psychiatrist. The participant describes this phase of her illness as follows:

"We've got a financial consultant who manages all our bits of money. What was missing really was a health consultant. Someone who knows the whole health field

who could have directed the whole thing, then I'd have felt a little bit more whole. It was a jigsaw puzzle of this one looking at your blood, and that one looking at your feelings, then your food. It was quite fragmented, yes it was."

The participant begins to lose hope about finding effective treatment. She begins to feel alienated from the health system. She begins to doubt the validity of CFS as a diagnosis for her condition, and becomes depressed.

"At first I was really hopeful and I could get it together even in the ups and downs of this illness to go looking for treatment. But, after all that time of getting optimistic and then being disappointed, it was like that, in cycles, in the end it became boring, pointless, and I got too tired of being frustrated."

"The time came when it all had to stop. There was no more. My husband had a hard time realising that all the money he was prepared to spend, there was just no point in spending another cent because there was nothing out there left for me to try."

"When I then withdrew into this shell and just couldn't get up anymore, I was dangerously depressed, most people, there was an awkwardness with me, and my husband told me that his family were saying that yes, it's actually depression after all. I didn't care about that anymore, I didn't know what to make of CFS anymore. For the first time in my life I found out what it was like to be depressed. This is when I needed psychiatric help. I went into psychotherapy for nearly three years.

Reading guide question 3:

How does the participant cope with her experience of being chronically ill with CFS such that she arrives at the point where she is able to view herself as recovered from CFS?

The participant goes through a gradual process of self-confrontation, supported by the experience of being in psychotherapy.

"I don't think I would have been able to get to where I am today as a person and as a person with CFS if it wasn't for psychotherapy."

"I can come out and clearly state that if I hadn't worked on myself as a person, I will not have recovered from CFS."

"I could choose to not work with this illness. I had to take responsibility for recovering. No one else was going to do this."

From the above illustration it may be said that P2 emerges from her experience of self-confrontation with a perception of being responsible for her illness.

It appears that recovering from CFS is about a process of negotiating her life within the physical limitations imposed by having CFS. P2's self-management practises are challenged by these physical limitations. Life includes finding out how to manage herself in order to prevent relapses of symptoms.

P2: "Even small things, like if my mother-in-law comes to visit, she thinks that getting on with me is about telling me all about her complaints. She tries to get me to do things in this twisted round-about way. There I am, having to listen to her and getting more and more uptight as I realise how she is trying to manipulate me. Then, I feel symptoms coming, headache, that's the first sign, and then I know something's not right. I'm not handling this correctly."

In the process of negotiating self-management in order to prevent relapses of symptoms, P2's self-management practises change. It appears that recovery from CFS is a matter of maintaining her changed self-management practises. As illustrated below, it may be said that P2 learns to acknowledge herself, be more assertive, and to self-soothe in order to prevent relapses.

P2 shows a tendency toward self-effacement before having CFS. Now she acknowledges her own thoughts and wishes.

P2: "And this is where the challenge is, not feeling that I have to do things, and that's a huge pressure in my husband's polite, colonial-type family. And I've got to the point where I can say to myself that I cannot and do not have to listen to this."

P2 shows a tendency toward being submissive in relation to significant others prior to CFS. She refers to the "stress" that she experiences in these situations, and its link with having subsequent relapses if managed in her usual way. To resolve the tension between the tendency to be submissive in these situations, and the probability of precipitating a relapse if she continues to be this way, P1 becomes more assertive in these situations, as illustrated below.

“Usually, if something’s not right, like there’s something that I’m upset about, like if I bottle up my feelings about how my husband is being false with his mother and he is seething about being manipulated, and it starts affecting our relationship, my body just can’t hold the tension. I start getting sick. Then I have to confront it, as hard as it is for me, but I do. I feel much better and then the downward spiral is avoided. I’ve realised it’s all about nipping things in the bud.”

P2 shows a tendency to avoid negative feelings prior to CFS. In order to prevent a relapse that such behaviour will probably precipitate, P2 learns to soothe herself in the face of negative feelings. Instead of avoiding depressive feelings by becoming “sick”, P2 learns to regulate her feelings by addressing her problems constructively. In relation to her experience of depression P2 says the following:

“It was serious having to live through it and learn to feel that it’s okay to be depressed. I mean when I grew up, you just weren’t allowed to be depressed,”

“Being depressed was like being a failure.”

“I see now why I was so angry when I was diagnosed with depression. You see, I just couldn’t get it then. I couldn’t be depressed, so I got sick instead.”

“For me, learning how to cope with CFS has been a lot about how to cope with my feelings. Watching when I get relapses and instead of avoiding it, rather, looking at what’s going on in my life at the time. And I’ve learned to read it so well now,”

In the process of maintaining her changed self-management practises, P2’s self-identity shifts and her lifestyle is positively transformed. This is illustrated below:

“I was a hard worker. I wanted to be recognised for that, as one who contributes to society. For me that meant not letting anything get me down. I couldn’t handle conflict, so I’d do what I could to avoid it. Now, I’m still a hard worker, but I have to put myself first. It is not so important for me to be successful out there in the market place. And conflict, well, I’m more confident in confronting things that upset me.”

PARTICIPANT 3 (P3)

Reading guide question 1:

How does the participant cope with the experience of the onset of symptoms of CFS?

P3 describes her experience of the onset of symptoms in physical terms.

“Being tired was never a problem for me before I got ME. I could always psyche myself out of everyday tiredness. But this time, it was after I had a bad case of flu in my September holidays, that was the end of standard 9, which hit me hard, it was quite frightening. I just didn’t get better. And I so badly wanted to, there was so much to be done. Every time when I’d feel, okay, this is finally going now and I’d muster my energy to rear ahead, I was getting behind in everything, no sooner than I’d be doing this, then I’d feel horribly sick again. Flu’ie, you know, my muscles and joints felt paralytically weak, sore, and stiff. And, quite striking was the absolute exhaustion, like I had been drained of my life blood. The worst was, before being diagnosed, fighting to ignore these symptoms and pushing painfully along despite feeling so sick.”

The participant responds by defining herself as ill and attempts to understand what her symptoms might mean.

“I didn’t understand it. I simply couldn’t handle it. It was frustrating, and I began to worry. “This is not normal”, kept niggling in the back of my mind until well, eventually, I had to admit that there was something seriously wrong with me. This is all I knew, yes, definitely I had something, and also, it had to do with the flu that I had initially.

The participant consults her doctor and various medical tests are negative for pathology. The doctor attributes her symptoms to stress. The participant denies her symptoms. However, she also accommodates to them by reducing her activities. Once the participant uncharacteristically fails to reach her goals in important areas of functioning, the participant accepts that she has been ill all along and believes that she is suffering from a post-viral condition. She obtains the attribution of CFS for her “confusing” illness from someone in her social network. The participant describes her search for confirmation from others that she is ill as follows:

“I knew I was ill and that it was possibly CFS. The reason why I couldn’t make it into Medical School was because I was actually ill. I had to get a diagnosis so that I could have a second chance. It just wasn’t fair. The worst was that a lot of people thought that I was just trying to get a second chance for failing myself. The most tragic thing for me was my parents, my father. I was just not in his good books, hadn’t been for years, and he was outright with that accusation, “bullshit” he said. That was devastating for me. And in that state I had to try and clear my name, get myself understood.”

“Ja, it could have led me to emphasise my symptoms to the doctors. I mean, can you imagine, if I told them the whole story about my father. Well, I just knew what the psychiatrists were making of this, it’s the kind of things they look for. They were suspicious, I could pick it up from the questions and in the general tone.

“It was the battle of my life to get a diagnosis. It kills me to think about that time. How frustrating it was not being heard. I mean I couldn’t believe it. How I felt, it was like being accused for a crime you didn’t commit. My father, other people, from their point of view, yes, I could understand why they could accuse me of pretending. But, it was the end of the world for me really, that the custodians of our health, that even they just couldn’t understand.”

The participant experiences conflict over the contradiction between her attribution of being ill with a physical condition, and the attribution of others that she is malingering. She is diagnosed with depression several times. She resists this diagnosis. Once the participant is medically diagnosed with CFS, she feels relieved. She describes her experience of being diagnosed with CFS as follows:

“I just burst into tears. Not only because I felt relieved, my integrity was returned, but because of the traumatic battle it was for me. All the suspicion it was terrible for me.”

Reading guide question 2:

How does the participant cope in terms of her experience of being chronically ill with CFS?

The participant’s negative experience of being ill in relation to others, specifically the medical profession, culminated in feeling alienated from it, to the extent that she did not utilise its resources for treatment.

“Once diagnosed, I got the distinct impression that I was not welcome to return to the medical arena. I didn’t want to go back and I haven’t been to see a doctor since. The doctor, who diagnosed me with CFS, she recommended that the best way to cope was to find a support group and take it from there. It turned out that the support group that I joined was my hugest coping mechanism.”

For two years, the participant relies on her support group not only for emotional support, but also for information regarding CFS and suggestions for treatment. The participant describes her experience of her support group as follows:

“The most important aspect was that being in this group helped me to find my feet. It helped me to find my feet with having CFS, and with the lifestyle changes. I had recently moved to [name of city], I had to cope with the rejection from my parents, and loss of old friends with the moving. It was a huge adjustment in all spheres of my life, and without the support from people in the support group, I wouldn’t have made it. I dread to think about what would have happened. It was comforting to know that there were other people in the world suffering from the same thing, I wasn’t alone, and they also had lifestyle complications.”

With regard to the information about CFS that the participant received from her support group the participant says the following:

“People in the group would talk about what was happening to them and advice was discussed. Books were passed around, books about various people’s experiences of CFS, self-help books, magazine articles and pamphlets from CFS organisations. In the beginning it was a huge support. I didn’t realise it at first, but they gave a rather one-sided picture of CFS. At times there was an almost cult-like following feel to it. Not surprisingly in my case, I got caught up with them in a hatred for the medical profession and the search for information that CFS was a real disease. I guess we felt redeemed by sticking to the notion that CFS was caused by an as yet unknown virus without an as yet known cure. At first this helped me to come to terms with having CFS.”

The participant, along with members in her support group, utilise various complementary therapies in search of relief from their symptoms. She tried acupuncture, meditation, physiotherapy, massage, reflexology, yoga, herbal supplements, various diets, and sleep management techniques.

With time, the participant finds that she no longer needs her support group and what they have to offer. Her illness was not improving. She was losing interest in complementary therapies as treatment.

“The terrible realisation that I’m not getting any better. Nothing worked. It was, I was still struggling with trying to get on with my life and the symptoms always getting in the way. Each time I’d decide that on my good days, I’d help my sister by working in her shop. I’d just be getting into it and then I’d start feeling the symptoms flaring-up and then it was back to bed for a while.”

Reading guide question 3

How does the participant cope with her experience of being chronically ill with CFS such that she arrives at the point where she is able to view herself as recovered from CFS?

P3 attributes the turning point in her experience of having CFS to holistic treatment she receives from a physiotherapist whom she consulted in a moment of desperation for the treatment of acute muscular pains. . It was during this treatment that the participant experiences an improvement in her illness. The physiotherapist was undergoing training as a Life Direction Therapist. The participant was in once weekly therapy with the physiotherapist for ten months.

The participant appears to emerge from the experience of holistic treatment with a perception of being responsible for her illness.

“The fact that without really being aware of it, I was less and less seeing myself as a person who has CFS. I was getting caught up in, how can I describe it, the magic of getting better, and learning to do it myself, relying on myself and doing it myself.”

“After a while, a lot people with CFS, certainly myself, because of all I went through, having to cope with what people think, you know, that it’s not a real illness, and that there is nothing to help you, nothing ever changes. Having CFS to explain my situation was just getting me nowhere. It came to mean something else. I can’t really express myself clearly, but it got to the point where it meant very little. Which is why when I realised what Keta [physiotherapist] was doing, not ever referring to CFS, it made sense. Also, trying to get a normal life again presented so many more

immediate challenges, I was beginning to do what I needed to do, and it did not involve having to think CFS, CFS.”

It appears that recovering from CFS is about a process of negotiating her life within the physical limitations imposed by having CFS. P3's self-management practises are challenged by these physical limitations. Life includes finding out how to manage herself in order to prevent relapses.

P3: "I'm not as healthy as I used to be in the sense that I've got physical weaknesses. I'm forced to be aware of it. Before, I could go on full steam ahead without having to be aware of my body and its reactions. As soon as I start running away with myself, or I forget myself, like if I'm doing too much and getting worked up over things, warning bells start ringing. I start getting flu symptoms and then I've got to make emergency plans and center myself again."

In the process of finding out how to manage herself in order to prevent relapses of symptoms, P3's self-management practises change. It appears that recovery from CFS is a matter of maintaining her changed self-management practises. As illustrated below, it may be said that P3 learns to acknowledge herself, be more assertive, and to self-soothe in order to avoid precipitating relapses.

P3 shows a tendency toward self-effacement before having CFS. Now she acknowledges her own thoughts and wishes.

"If I feel that I can't do something, something that my father expects me to do, I've learned to admit it to myself and to say that I can't without feeling it's the end of the world. Previously, it would be out of the question entertaining the possibility of not wanting to do it."

P3 shows a tendency toward being submissive in relation to significant others prior to having CFS. She refers to situations in relation to her father where she finds herself being submissive for fear of disappointing him if she asserts herself. She refers to

“the stress” that she experiences in these situations, and its link with having subsequent relapses if managed in the usual way. To resolve the tension between the tendency to be submissive in these situations, and the probability of precipitating a relapse if she continues to be this way, P3 becomes assertive in these situations, as illustrated below.

P3: “Living at home, being with my father all the time, it wasn’t good for me. I, on purpose, chose to keep him, my parents at bay. And I just haven’t allowed him to get to me. He has got a way; he knows how to get to me, to make me feel bad, like I’m doing the wrong thing. Just from what he says about my new career, Herbalism and Aromatherapy. He thinks it’s a lot of nonsense. I mean he really wanted me to be a doctor, and his disappointment still rings loud. When I was at school, I could not tell him that I had dropped Latin. I suffered in the face of the inevitable. Obviously the time came for him to find out. And what he thinks of my boyfriend, they are so different. Before, it would have freaked me out if he didn’t like one of my boyfriends. Now, I still have him as my boyfriend. But before CFS, I probably wouldn’t. And I don’t try to explain myself, why I like him to my father. That’s the way it is it’s a pity, but what can I do. I just don’t let it get to me any more. I think that what I went through, it makes you stronger. I’ve learned also not to alienate people, to be more constructive. One side of me just wants to freak out, but the stress it is just not good for me. Inevitably I’ll become symptomatic again. Keeping focused on what’s good for me, and I know now, instinctively, what is and what isn’t.”

In order to prevent a relapse if she is anxious in the face of her father’s disapproval, P3 learns to soothe her anxiety in the face of her father’s disapproval. In relation to her father, P3 says the following:

“Before it would have freaked me out if he didn’t like one of my boyfriends.”
 “And I don’t try to explain myself, why I don’t like him to my father. That’s the way it is it’s a pity, but what can I do? I just don’t let it get to me anymore.”
 “One side of me wants to freak out, but the stress, it is just not good for me. Inevitably I’ll become symptomatic again.”

In the process of maintaining her changed self-management practises, P1’s self-identity shifts and her lifestyle is positively transformed. With regard to her self-identity and her lifestyle P3 says:

“The lifestyle I have made now – it’s a different me. I’m no longer trying to be a hero out to please her father. I was too busy trying to be someone I was not. Looking back and it’s only now that I can say this, afterwards, that CFS, I mean I was asking for it. All that missioning and pressure to get A’s and be involved in everything. It wasn’t really me. CFS is probably one of the best things that could have happened to me. CFS forced me to make a new life for myself and it made me do things I would ordinarily not have done.”