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# CHRONIC ILLNESS AND THE PERSONAL CONSTRUCTION OF SELF: THE CASE OF MYALGIC ENCEPHALOMYELITIS

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For Grandpa

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# ABSTRACT

Myalgic Encephalomyelitis (ME) has attracted a great deal of media attention in recent years, resulting in a fallacious term, 'Yuppie Flu', being publicly identified with the syndrome. In addition, many studies have identified ME as psychological in origin. Thus, despite increasing evidence that ME has a viral, immunological or neurological aetiology, such negative publicity has led to people with ME experiencing negative reactions from medical doctors and lay-people who have regarded them as depressed at best, and malingerers at worst. Hence, a number of questions arise; including: What is the effect of such negative reaction on the self-concepts of sufferers? Did diagnosis improve self-concept? What effect does a negative public view of ME have on the self-concepts of sufferers? To test these questions, a rating-style repertory grid was drawn up after semi-structured interviews with a sample of fifteen diagnosed ME sufferers and was administered to a larger sample of fifty people with ME. The results of this retrospective study indicate that a change in self-concept had indeed occurred since contracting ME, but diagnosis has no effect on this change in self-concept and ME sufferers actually identify themselves in the same terms as they perceive their public stereotype. Reasons for these findings are discussed with reference to both Personal Construct Theory and, as a post hoc explanatory tool, Social Identity Theory.

# CHAPTER 1

## INTRODUCTION

### 1.1 Introduction

Over the past twenty years, while greater control has been exerted over infectious disease, there has been a rise in the incidence of chronic illness (Herzlich & Pierret, 1987). Thus, it is surprising that there is a paucity of work conducted by social scientists into the experience of people living with chronic illness (Anderson & Bury, 1988).

Myalgic Encephalomyelitis (henceforth ME), a chronic illness of elusive aetiology, is currently arousing a great deal of interest in both scientific and lay-circles. However, despite the attention being paid this malady (mostly concerning its legitimacy or illegitimacy as an illness), very little work has focused on the experience of ME. Therefore, with reference to the dearth of studies into both chronic illness as a whole, and ME specifically, the present study switches the focus from the controversial aspects of ME to the person with ME.

The work which follows takes the following form: Chapter 1 defines ME, highlights the medical and psychological debate surrounding the illness and examines the nature of lay-perceptions concerning ME. Essentially it is attempted to demonstrate that ME is a stigmatised illness.

Chapter 2 outlines and contextualises Personal Construct Theory and the repertory grid. The utility of the repertory grid for this research is discussed and issues of reliability and validity are delineated.

Chapter 3 provides a detailed description of the method employed in executing this research.

Chapter 4 highlights the constructions of ME sufferers. That is, whereas detailed statistical data concerning constructions are provided later, it is also desirable to transcend the data in order to 'listen' to the people with ME who were interviewed for this study.

Chapter 5 details the results of the experimental condition.

Chapter 6 constitutes a discussion chapter where the results outlined in Chapter 5 are discussed and interpreted in the light of Personal Construct Theory and, as a post hoc explanatory device, Social Identity Theory. In addition, suggestions are made for further research and possible limitations of the current research design are discussed. Finally, concluding comments are made.

## 1.2 <u>Myalgic Encephalomyelitis</u>

The aim of this chapter is to outline the nature, diagnosis and psycho-social implications of ME. In so doing, it is hoped to establish the rationale for this study by demonstrating the extraordinary status of people with ME as suffering from a unique chronic illness about which no consensus as to aetiology exists and which attracts a measure of scepticism from both professional and lay-quarters. As the present research is mainly concerned with the self-image of sufferers, this chapter attempts to demonstrate that many sufferers are forced to adjust to both the disabling effects of their illness and the 'stigma' of being labelled psychologically ill or 'malingerers'. In other words, factors which could possibly prove hazardous to the self-image of sufferers are highlighted.

Myalgic Encephalomyelitis is a chronic syndrome which afflicts between 2000 and 3000 people in South Africa (Spracklen, 1988). The disease seems to occur more commonly in <u>younger</u> women than in men, possibly due to this population's increased exposure to children (Ibid). However, Ho-Yen (1990) has noted that the disparity in affliction across gender may be a function of chronically ill men being less inclined to partake in research studies.

ME may occur epidemically or sporadically (David, Wessely & Pelosi, 1988; Wallace, 1991). Perhaps the best known epidemic outbreak occurred at London's Royal Free teaching hospital in 1955. Due to this, the illness is sometimes known as 'Royal Free Disease' (Ramsay, 1986)[1]. Other names which have been attached to this condition include: Epidemic Neuromyasthenia, Icelandic Disease, Chronic Epstein Barr Syndrome and Post-viral Fatigue Syndrome (Dwyer, 1988). In 1988, researchers working from the Center for Disease Control (CDC) in the United States proposed that the term Chronic Fatigue Syndrome replace the term Chronic Epstein Barr Syndrome (up to then favoured in the United States)[2]. This was due to their assertion that no causal link had been established between the Epstein Barr Virus and the syndrome (Holmes *et al*, 1988). However, for the purposes of this study, the term ME will be used as this seems to command both lay and professional understanding in South Africa. A case in point would be the name of the national sufferers' association; that is, Myalgic Encephalomyelitis Association of South Africa. In addition, Dowsett (1988, in Spracklen 1988: 449) has argued that:

> (T)he use of the term CFS (Chronic Fatigue Syndrome) as opposed to ME is to be deplored ... (T)o adopt the phrase `chronic fatigue syndrome' does nothing to indicate the unique epidemiological, geographical, clinical and laboratory findings of ME.

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[1] An epidemic outbreak also occurred at Durban's Addington Hospital in the same year where the illness was termed "Addington disease" (Spracklen, 1988).

[2] It is worth noting that the term currently favoured in the United States seems to be CFIDS (Chronic Fatigue and Immune Dysfunction Disorder). (see The CFIDS Chronicle, Volume 1, Issue 1 March 1991).

### 1.2.1 Symptoms

ME symptoms include low grade fever, tender lymph glands, persistent sore throat, physical and mental exhaustion, muscle weakness (worsened by exercise), and insomnia or hypersomnia (Macintyre, 1989a). The central nervous system is also affected by the disease; with memory loss, difficulties in concentration, irritability and emotional lability being common occurrences (Yousef, 1990).

Because epidemiological and other research is hampered by the diversity of the syndrome, Holmes *et al* (1988) have established baseline criteria for research purposes which stipulate debilitating fatigue (not resolved with bedrest) lasting for a period of six months, in persons with no previous experience of such a condition. Other conditions (physical and psychological) which might give rise to similar symptoms must be excluded before diagnosis can be made.

## 1.3 Aetiological Controversy

The aetiological status of ME is a matter of intense debate in the medical, psychiatric and psychological literature. As this debate has relevance in terms of the self-image of ME sufferers, it shall be outlined in detail below.

### 1.3.1 The Medical Debate

ME is a controversial illness. Even when the illness is recognised as an entity, there is debate as to which term best describes it (see above), or as to whether misdiagnosis has been occurring (Rosen, King, Wilkinson & Nixon, 1990; *see also* Holmes *et al*, 1988). Additionally the aetiological status of the illness is a great source of dispute, with explanations being supplied in accordance with the medical speciality of the researcher. Thus Macintyre (1989b: 29) notes:

> Virologists find ME is usually caused by a virus. Immunologists find ME is a disordered immune system. Clinical ecologists say ME is a condition of multiple food and chemical allergies. Psychiatrists decided long ago that ME is a psychiatric illness. Neurologists think ME is a disorder of the nervous system.

In short ME is, at time of writing, a medical enigma. What follows is a brief review of the medical literature. It should be reiterated that many in the medical profession remain sceptical of the very existence of ME. The following exposition of the medical aetiological debate serves to emphasise that ME sufferers are confronted with controversy, even from within the ranks of those who accept the legitimacy of their illness. In addition, a perusal of the medical literature serves to emphasise that, while <u>consensus</u> is lacking, there is indisputably an organic basis to ME.

Many researchers have linked ME to viral infection. Indeed, as mentioned above, one of the names associated with this syndrome is Postviral Fatigue Syndrome, implying that ME proceeds an acute viral infection.

There are national divisions in terms of which viruses are presumed to be the principle cause of the illness. In Britain, researchers favour the Echo and Coxsackie A and B enteroviruses, while in the United States, the Epstein Barr Virus (henceforth EBV) is preferred (Spracklen, 1988; David *et al*, 1988. *See also* Straus, Tosato, Armstrong *et al*, 1985).

Evidence for enteroviral infection (particularly by Coxsackie B), has been provided by Dowsett, Ramsay, McCartney & Bell (1990 in Kennedy, 1991). Another study by Gow & Behan (1991) found that 53% of ME patients, as opposed to 15% of a control group showed evidence of enteroviral infection. Cunningham, Bowles & Archard (1991) found enteroviral RNA in 24% of muscle biopsy samples taken from ME sufferers. They conclude that persistent viral infection of the muscles as well as, specifically, enteroviral infection of the central nervous system may account for the myalgic and neuropsychological dysfunction which occurs in cases of ME.

The evidence for a causal link between ME and the EBV has been rigorously questioned. Holmes *et al* (1988) in outlining their diagnostic model for ME, argued against the (American) term for the illness - Chronic Epstein-Barr

Syndrome - by asserting that the association between ME and viruses such as cytomegalovirus, herpes simplex virus types 1 and 2 and the measles virus are as strong as those between ME and the EBV. In addition, Gold, Bowden, Sixbey *et al* (1990) followed up 26 patients with elevated EBV titres. They found that 50% of these patients improved during the course of their study, but that this improvement did not correlate with change in EBV titre. In other words, there was no evidence for EBV as an aetiological agent. Additionally, Cunningham *et al* (1991) found that only 9% of biopsy samples from an ME group evidenced EBV RNA.

Recent, as yet unpublished research, has focussed attention away from the EBV and enteroviruses. Two researchers claim to have isolated a specific virus, but differ as to whether this virus constitutes a 'spuma' or 'foamy' virus or whether it belongs to the reterovirus family (the family of viruses to which the Human Immunodeficiency Virus belongs) as possible aetiological agents (Cowley, 1991). At time of writing, the identity of this virus remains a source of dispute (Ibid).

Another suggested cause of ME has been immune dysfunction and, indeed, immunological abnormalities have been noted in patients with ME. Behan, Behan & Bell (1985) examined 50 patients with ME and found that 35 had altered lymphocyte function in vitro. Some positive results have also been found when using gammaglobulin, a preparation made from the

T-cells (IgG) of healthy people (Dwyer, 1988). Though researchers are not sure why this occurs, it has been hypothesised that damage to the regulatory T-cell system is reversed as a result of this treatment (Ibid).

Interesting in connection with the proposed immune-dysfunction associated with ME, is evidence of the link between stress and impaired immune response. Friedman *et al* (1965 in David *et al*, 1988) demonstrated that infection with the Coxsackie B Virus occurred in mice only after exposure to environmental stress. Kasl (undated in Martin, 1987), established a link between stress levels and Epstein-Barr Virus infection in students at the West Point Military Academy in the United States. With specific reference to ME, Stricklin, Sewell & Austad (1990) found that stress levels were higher than average in a sample of ME patients 12 months prior to the onset of their illness. However, as Struckmann (1991a) has pointed out, this evidence is problematic as it is based on retrospective data.

There is evidence to suggest that neurological damage may cause (or be caused by) ME. Tests for multiple sclerosis diathesis have indicated nervous system damage in ME patients. In addition, magnetic resonance scans have revealed 'white spot' brain lesions in ME patients (Macintyre, 1989). These abnormalities may, or may not be caused by viral infections (Ibid). Prasher, Smith & Findley (1990) studied a group of 37 ME patients with and without enterovirus infection. They found significant deficiencies in attention and speed of information processing amongst these patients suggestive of neurological damage.

### 1.3.2 The Psychiatric and Psychological Debate

While previous research had established the presence of psychological disorder in people with ME (Kendell, 1967), the first major assertion that ME was psychological in origin was made by McEvedy and Beard (1970) who examined case-records from the 1955 ME outbreak at Royal Free Hospital and concluded that the illness was a manifestation of mass hysteria. This claim was, unfortunately, taken up by the press with the result that the 'hysterical hypothesis' remains prevalent today (Macintyre, 1989b).

In 1973, McEvedy and Beard published a further report on a follow-up study comparing nurses, affected with ME during the epidemic, with a control group of unaffected nurses. This report is worth examining in depth to illustrate the nature of the McEvedy and Beard studies which, for many years, have proved influential in determining attitudes towards ME. The general conclusions reached in this report are that a certain number of those affected by the illness were in fact *pathological* hysterics, whereas the vast majority of patients were "normal representatives of their age-group" with a "tendency to behave hysterically under stress" (Ibid, 149). The authors support this argument (some 20 years after the epidemic) by showing that the 'N' ('neurotic' scores on the Eysenck Personality Inventory) of the affected population were higher than those obtained by the control group. Those most severely affected by the epidemic seem to have obtained <u>even higher</u> 'N' scores than the others. Further factors advanced as proof of the hysterical hypothesis are:

(1) The affected population had married an average of one year later than the controls and had a lower rate of fertility;

(2) Two members of the affected group had at one time attended a child guidance clinic and

(3) Two respondents admitted to faking symptoms.

The above study is problematic for the following reasons:

(1) Male victims of the epidemic were not followed up. Indeed, the study is inherently sexist. Surely male cases would also have provided useful information? This omission appears to relate to the sexist views of the authors combined with their enthusiasm to justify the 'hysterical hypothesis'. That is, they believe that only females can be 'hysterical', therefore, they

ignore the male population in order to justify their hypothesis[3].

(2) The study ignores evidence that most patients had symptoms such as lymphadenopathy, high fever, ocular palsy and other clinical features which are not accounted for by hysteria (Ramsay, 1973; Dwyer, 1988).

(3) Four extreme cases (two women who committed suicide a few years after the epidemic and two women who had never recovered from ME) are outlined in great detail. The two suicide-cases, it is argued, had histories of 'severe' personality disorder, but the evidence for this is based on posthumous biographies supplied by friends and relatives, rather than on direct examination of clinical records. The two women who became chronically ill are labelled with 'hypochondriacal' personality disorder, though the duration of their illness is not unusual, baring in mind that chronicity is an outstanding feature of ME (Holmes *et al*, 1989) with 50% of cases lasting up to two years and some 25% of cases persisting for over ten

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[3] As evidence for the authors' dubious views on women, consider the following statements: "Biological maturity in the female is reasonably assessed by reproductive behaviour. The difference of a year in age of marriage (and the lower rate of fertility) is consistent with the hypothesis that hysterical traits correlate with immaturity"; "... (T)here is a much greater threshold for the perception of ill health in female to female communication than in male to female communication. This is of some interest in relation to the greater liability of exclusively female populations to attacks of mass hysteria" (McEvedy & Beard, 1973: 148).

and even 20 years (Macintyre, 1989a; 1989b; Ramsay, 1989; Garrett, 1990). In any event, it is scientifically unsound to bias the reader by highlighting the cases of 4 'unusual' members of the affected group. Perhaps more thorough investigation would have revealed 'personality disorders' in the control group as well. It is clear that, as the latter group was not of interest, it was not thoroughly investigated.

(4) The study does not take into consideration epidemiological evidence that most people with ME contracted their illness sporadically rather than as a result of an epidemic. (Stricklin *et al*, 1990; Wessely, 1990).

(5) A danger in accepting the 'hysterical hypothesis' is that any search for other possible causes is forestalled. For example, Parish (1973) sites the example of a Japanese epidemic of benign myalgic encephalomyelitis where investigators eventually established that the disorder resulted from a contra-reaction to a drug.

Further studies reported in the psychiatric and psychological literature have concentrated on prevalence rates of affective disorder (for example, Taerk, Toner, Salit, Garfinkel & Ozersky, 1987) and other psychological conditions, such as phobias (for example, Kreusi, Dale & Straus, 1989) and somatisation disorder (for example, Manu, Lane, Matthews & Escobar, 1989) in people with ME. Underlying many of these studies is a debate which has been succinctly summarised by Millon, Salvato, Blaney *et al* (1989: 139):

> The controversy can be pared down to a single question: Is the affective disturbance noted in these patients indicative of a reactive state, or does it reflect a predisposing pervasive trait? In other words, is this depression in some way responsible for the onset of symptomatology or, does it instead result from the experience of chronic ill health?

What follows in an outline of <u>key</u> psychological and psychiatric research into ME. For further information, the interested reader is referred to an excellent, in-depth review provided by David (1991).

Taerk *et al* (1987) compared 24 ME patients with 24 controls for prevalence of psychological (especially depressive) symptoms. They found that the ME group had a higher rate of affective disorder than the control group, while frequencies of anxiety disorder did not differ significantly between the two groups. The overall conclusion reached by these authors is that:

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

> debilitation which triggers a depressive syndrome (Ibid: 54).

In other words, Taerk *et al* (Ibid) choose the middle-ground, arguing that both organic factors and psychological predisposition are relevant in the aetiology of ME.

Millon *et al* (1989) tested 24 sufferers in a bid to establish the psychological profile of ME. For this purpose, they utilised a battery of psychometric tools including the Profile of Mood State (POMS) and the Hamilton Rating Scale of Depression (HAM-D). Their findings suggest the presence of severe personality pathology and affective disorder in this population. However, the study, as the authors themselves comment, is flawed because of the failure to identify an appropriate control group. In addition, as they acknowledge, their tests may have been tapping somatic concerns.

Kreusi *et al* (1989) found a high rate of psychiatric disorder (especially depression and phobic disorder) amongst a sample of 28 ME sufferers. In addition, they concluded that these disorders predated the onset of ME symptoms.

Stricklin *et al* (1990) conducted a study amongst 25 <u>women</u> with ME and 25 non-ill subjects. Their aims were, among other factors, to document measurable psychological symptoms in people with ME and to determine the severity of these symptoms. They used the Minnesota Multiphasic Personality Inventory (MMPI), the Social Readjustment Rating Scale and the Mehrabian Achieving Tendency Scale for Females. Subjects were also asked to note the "subjective rating of anxiety" on a four-point scale. Their results seem to indicate that psychopathology was more prevalent in the ME-group than it was in the "non-ill" group[4]. Yet another study (Hickie, Lloyd, Wakefield & Parker, 1990) compared 48 ME sufferers with 48 subjects suffering from non-endogenous depression to determine rate of psychological disturbance. Their results indicate that people who have ME are:

(1) Not excessively hypochondriacal.

(2) People with ME are not more depressed (premorbidly) than members of the general population. In fact, they found the incidence of psychological disorder amongst people with ME to be 24,5% which, they note, is equivalent to general community estimates.

(3) ME is not a specific somatic expression of a depressive illness.

(4) Depression (and other psychological symptoms) are provoked by ME rather than the other way around.

(5) Psychiatric morbidity in the ME sample was less severe than that of the control group.

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[4] These authors also noted the following result: "(W)e found that 86% of the patient group were either the eldest child, the youngest child, or the only child in their families. No middle children appeared in the patient group". (Ibid: 33). Such information is doubtlessly of great importance in the investigation into ME.

The strength of the above study lies in the size of its sample (48 subjects were assigned to each group). In addition, careful inclusion criteria were exercised (similar to those suggested by Holmes *et al*, 1988), although, for obvious reasons, concurrent psychiatric morbidity was not regarded as an exclusion factor as required by the latter authors.

At present, the question of the causal or reactive nature of the affective and other psychological disorders found in ME remains unresolved and will be the subject of ongoing controversy. Nevertheless, it appears that most of the evidence points to depression being caused by ME, rather than depression causing ME.

To end this section, it would perhaps be useful to take note of David, Wessely & Pelosi's (1988) suggestion that the dichotomy between organic and functional aetiology is spurious. These authors suggest that a multifactorial approach is necessary for understanding and treating ME. David (1991) has further commented that, even if patients <u>are</u> 'neurotic', they should not be labelled 'neurotic', but should receive proper care and attention[5].

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[5] David (1991) also notes that the tendency to contrast ME patients with psychiatric controls in order to prove the legitimacy of ME, tends to perpetuate the view that psychiatric illness lacks acceptability.

## 1.4 ME in the Public Arena

While research into ME continues, there remain sections of both the medical and lay-public who regard the illness as exclusively an illness of the mind (Shepherd, 1990). It is indeed unfortunate that designations such as 'Yuppie Flu' (Spracklen, 1988), nurtured by the media, have tended to relegate the illness to a level of travesty in the popular mind[6].

### 1.4.1 The Media

Unfortunately the mass media has tended to foster the 'all-in-the-mind' view of ME (Macintyre, 1989b). For example, Beechey (1989: 18) mentions an article in the London *Sunday Times*, headlined: "*Yuppie Flu is all in the mind say doctors*". Beechey notes that "(T)he article which followed managed both to convey the idea that ME is a just dessert for overachieving people and the illness is primarily psychological in origin".

Such 'disinformation' can be found in popular South African periodicals. For example, a recent issue of a 'gossip' magazine contains an article headlined: "*Yuppie Flu victim*

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[6] With regard to public perceptions of ME, it would be useful here to mention a phenomenon which the author has observed. Many people, when they hear he is interested in ME, will tell him: "You can interview me! I think I have Yuppie Flu." It seems that people, firstly, misunderstand the full implications of ME and therefore do not regard it seriously, (It is doubtful that the same response would be elicited if, say, the author was interested in cancer or tuberculosis!). Secondly, this reaction seems to indicate a tacit belief that ME is hypochondriacal.

*Cher axes shows*". The opening paragraph states: "Superstar Cher has had to scrap all her live shows after being struck down by *a depressive illness which hits workaholics*" (*People*, 1991, 5: 31) (emphasis added).

### 1.4.2 Medical Scepticism and the Importance of Diagnosis

Many members of the medical profession are sceptical as to the organic validity of ME. This leads to many sufferers being 'labelled' with a psychological diagnosis, or they are dismissed as malingerers. There can be no doubt that such diagnoses influence lay-perceptions of ME.

Cases of ME sufferers who have been treated with scepticism by doctors are well documented. Macintyre (1989b) describes the case of a British schoolgirl who became mysteriously ill: After she collapsed during her physical education class, her mother took her to various paediatricians, who were unable to find anything wrong. One doctor even suggested that the child should partake in more exercise (not good advice as exercise can exacerbate the symptoms of ME). Eventually the mother read about ME in the newspaper and was able to locate a general practitioner knowledgeable enough to diagnose the child.

A South African ME sufferer indicates that she feels 'nothing but bitterness' towards doctors and points out that she was examined by over 200 doctors and physiotherapists before being diagnosed with ME (Holland, 1991). Another ME sufferer (Scher, 1990: 71) who was initially referred to a psychiatrist by her doctor tells this story:

> Without even giving me a medical examination one psychiatrist hospitalised me and large doses of antidepressants and sleeping pills were prescribed. Eventually a pathologist in Pretoria discovered I had Bornholm's Syndrome which is due to a Coxsackie virus. From there I was extremely lucky to find a GP who knew about ME and could treat me.

In a letter to the author, an ME sufferer tells of the hurt, frustration and humiliation she felt when she fell pregnant and doctors and colleagues did not accept that she was ill:

> By the time I became pregnant with my second baby, the tiredness became over-whelming and I was given 3 weeks sick leave, which resulted in a lot of snide remarks from my fellow workers. I nearly miscarried at 10 weeks, but then went on to full term. During the birth, I was too tired to push and the doctor used forceps. His words to me were: "This is unnecessary, this is totally unnecessary." He was very angry and thought I was too lazy to push. One of the nurses actually told me afterwards I was lazy. Remarks which really stung.

Medical diagnoses perform an important legitimising function in Western society. Herzlich & Graham (1973) outline the functionalist view of illness which holds that the proper *functioning* of society depends on the *health* of members. Therefore, illness is seen as *deviance* and it is the duty of doctors to 'control' illness by bestowing legitimation;

which itself depends on categorisation (diagnosis) of the illness[7].

The latter point goes a long way towards explaining the importance of diagnosis for ME sufferers. For example, diagnosis is essential if a patient is to be granted sick leave. Cowley (1990: 38) quotes a mother who, together with her son, suffers from ME as saying: "We get less sympathy than AIDS patients". Her son has had to tolerate the disbelief of school officials and was initially refused special consideration in terms of school attendance. His mother says of the school officials: "They still believe (ME) is an attitude, not an illness".

In addition, there is the simple desire to avoid being disbelieved by family and friends. Robinson (1988: 49) quotes a Multiple Sclerosis sufferer on the importance of diagnosis from this perspective (MS is also something of a medical mystery at present):

> I felt great relief at knowing at last that my symptoms were no longer a mystery ... I felt if only I had known earlier I wouldn't have had to struggle as I had done at times, because people - including my family - would have understood and been able to help and make allowances. As it was,

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[7] Kleinman, Eisenberg & Good (1978) have suggested a distinction between the terms 'illness' and 'disease'. They believe that 'disease' should be defined as organic dysfunction whereas 'illness' can be the reaction to the latter, as well as general discomfort. These authors also indicate that doctors tend to treat *disease* at the expense of *illness* (which does not necessarily have to have an organic basis), thereby perpetrating the alienation of patients from biomedical practice.

> even my own family thought I was 'putting it on'. I felt hurt deep down inside me that no one had believed me when I told them I didn't feel well.

A major problem patients have, specifically after being diagnosed with a psychiatric disorder, is the stigma attached to such a diagnosis. Woods & Goldberg (1991: 911) have noted that:

> Even within the more liberal societal norms of today, the label of mental disorder still implies an element of malingering or faking, or that those with a functional condition are somehow culpable, and so it remains less acceptable. The frequent insistence of (ME) sufferers to put a name to their disorder which reflects a physical nature is notable.

With reference to the above point that ME sufferers insist that their doctors attach a physical diagnosis to their condition, Wessely (1990: 45) has noted that:

> One of the reasons for the rapid rise of ME (the ME Association is Britain's fastest growing charity, attracting 150 new members per week) lies in the nature of the principal alleged aetiological agent (viruses) ... The agent is external, and is beyond the subject's control. There is no `maleficium' nor guilt or self-blame. External attributions of illness to entirely organic causes distinguishes ME patients from matched psychiatric controls.

The need for diagnosis also extends beyond social factors. There are, of course, even more fundamental reasons for obtaining an accurate and appropriate diagnosis. Parish (1973) points out that patients suffering from an organic complaint, who are treated as psychologically ill, will be denied possible treatment. Peel (1988) notes that ME can be exacerbated by exercise and if a patient is not diagnosed correctly, there is a danger of exacerbating his or her condition.

While there is increasing recognition being shown towards ME by the medical profession (Beechey, 1989), it remains apparent that sufferers still encounter scepticism and their illness is often dismissed as psychological in origin. This is an unfortunate and dangerous state of affairs. Frank (1946, in Millon *et al*, 1989: 140) has shown that "ambiguity of medical status" can be a great cause of emotional distress for illness sufferers. Diagnosis is, therefore, personally, as well as socially legitimising.

## 1.5 Chronic Illness and Self-Esteem

Chronic Illness and disability[8] have been shown to decrease self-esteem (Fisher, 1985; Newman, Fitzpatrick, Lamb & Shipley, 1990). However, this is not explanatory. While dynamics which could engender a low self-esteem in, specifically, ME sufferers are outlined in the preceding section, and this process is viewed from the perspective of Personal Construct Theory in the following chapter, there remains a necessity to examine factors which could cause loss of self-esteem in chronically ill patients *generally*, with reference to ME specifically. It is therefore useful that Kleinman (1988) introduces the concept of *stigma* when

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[8] It should be noted that the term disability is relevant to the experience of ME sufferers as their illness is debilitating. In a sense, it is the disabling effect of ME which is of interest to the present research.

he points out that "(Chronically ill) patients feel shame in response to the (negative) reactions of family and especially health professionals". The question can now be asked as to what is *stigmatising* in the context of ME?

The issue of *stigma* occurs in the context of ME in two major forms. Firstly, there is the possibility of being laboured with a 'psychiatric' label (see above). Secondly, as is the case with AIDS, an illness can be stigmatising because it is perceived as having being contracted as a result of 'questionable' behaviour as well as it's equation with death (Herek & Glunt, 1988). Halleck (1988) has suggested that patient responsibility for an illness is judged according to the responsiveness of the behaviour to the environment. In other words, someone with, for example, measles cannot be held responsible for his or her illness. On the other hand, an alcoholic is more culpable. This is an interesting point as there is a tendency to blame ME patients for their illness. They are often held to be people who drive themselves too hard and who have, thereby, caused their illness (Beechey, 1988; Wessely, 1990).

## 1.6 Conclusions

This chapter has attempted to both introduce ME and demonstrate why it constitutes a unique illness which places sufferers in an unusual position. The following points must be reiterated.

(1) ME constitutes a medical mystery. While examination of the literature should convince anyone that ME is very real, many in the medical profession are sceptical as to whether the illness exists at all. Even where researchers do accept the existence of ME as an entity, there is no consensus as to its aetiological status.

(2) There is debate as to, firstly, whether ME is organic or psychological in origin; and, secondly, whether depressive symptoms observed as part of the syndrome are causal of or reactive to the ME syndrome.

(3) Sceptical and unsympathetic media reports function to portray ME sufferers as 'malingerers' and their illness in an inaccurate light. In addition, there is much scepticism from doctors. These two factors combine to provide a negative public image of ME sufferers.

(4) Diagnosis performs an important social process in that it legitimises illness. Psychiatric diagnoses are perceived by Western society as less legitimate than organic diagnoses.

(5) ME can be viewed as a stigmatising illness in that it is often viewed as psychiatric in origin. Because ME sufferers are perceived to be people who 'over-work' themselves, they are often regarded as being responsible for the onset of their illness.

In summary, the argument presented in this chapter has attempted to show that people with ME suffer from a debilitating and mysterious illness which is poorly understood. Recovery rates are varied. These factors alone have been shown to exacerbate chronic illness and to lead to a loss of self-esteem and hopelessness (Sharpe, 1991). This, combined with the specific factors listed above, is responsible for causing ME sufferers an abnormal degree of distress and loss of self-esteem.

# CHAPTER 2

## PERSONAL CONSTRUCT THEORY

### 2.1 Introduction

In this chapter an elementary description and contextualisation of George Kelly's Personal Construct Theory (henceforth PCT) is provided. It is considered important that the reader gain an understanding of this theory as it's tenets are symbiotic with the questions which guide this research.

Further to the above, an attempt is made to explain the specific relevance of PCT as a means of understanding the personal experience of chronic illness and disability, with specific reference to Myalgic Encephalomyelitis.

Thirdly, an explanation is provided of the utility and mechanisms of the repertory grid (the psychometric instrument arising from PCT). Again, the relative obscurity of this instrument necessitates more introduction than normally attributed a measuring device.

Lastly, the debate concerning the validity of the repertory grid for disabled/chronically ill populations is outlined.

## 2.2 An Outline of the Theory

Kelly first outlined Personal Construct Theory in *'A Theory of Personality'*, published in 1955. As shall be shown below, he saw his theory as divergent from the main psychological paradigms in the United States. Indeed, several authors have commented that PCT was radical to the extent that it was divorced from the influence of existing theories, partly as a result of Kelly's initial isolation from the rest of the psychological community[9]. (Hergenhahn, 1980; Zelhart and Jackson, 1983; Fransella, 1988).

The theory itself is expressed in the form of the cardinal, or *'Fundamental'*, postulate, qualified by eleven corollaries. The Fundamental Postulate states that:

> A person's processes are psychologically channelized by the ways in which he anticipates events (Kelly, 1963: 46).

It is evident from the above statement that Kelly sees psychological processes as orientated towards the future (Bannister & Fransella, 1986). In addition, the use of the word 'anticipates' implies an image of people as active

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[9] Kelly had no formal clinical training. This, combined with his academic detachment from his fellow staff members in the psychology department at Fort Hays Kansas State College and his geographical isolation from other psychologists in the United States, meant that Kelly was forced to 'play it by ear' in terms of the development of the clinical program at the university and later his Personal Construct Theory (Hergenhahn, 1980).

beings. That is, people are not driven by unconscious motives as suggested by Freud. Nor are they governed by Skinnerian reinforcement schedules, or Rogerian needs and drives. Rather Kelly suggested "that we look at ourselves as if we are alive and kicking and that a feature of living creatures is that they get up and do things" (Fransella, 1988: 28).

The Fundamental Postulate is immediately modified by the Construction Corollary which elucidates the mechanism by which people anticipate events. This corollary states that:

> A person anticipates events by construing their replications (Kelly, 1963: 50).

In other words, Kelly is positing the concept of 'man[10]-the-scientist'. That is, just as the scientist attempts to predict and control events by forming hypotheses and subjecting these to observation, so Kelly sees people as anticipating (or *constructing)* future events through reliance on a series of perceptions formed as a result of current and past interactions with the world.

Other corollaries are:

(2) Individuality Corollary: This states that "*Persons differ from each other in their constructions of events*".

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[10] sic.

In other words, people are unique in their anticipation of the world. Button (1985) points out that this corollary may appear fairly obvious, but it should be remembered that, in the 1950's, this represented a departure from behavioural theory which negated the existence of personal interpretation of events in favour of the stimulus-response model.

(3) <u>Organisation Corollary</u>: "*Each person characteristically evolves, for their convenience in anticipating events, a construction system embracing ordinal relationships between constructs*". What this means is that people perceive relationships between constructs[11] and that these are, for purposes of simplification, organised in a hierarchical fashion. Thus, for a behavioural psychologist, as schematically represented in Figure 1, the construct Good Psychology/Bad Psychology may be superordinate[12] to the construct Skinner/Jung, which may in turn be superordinate to the construct empirical/non-empirical.

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[11] Bannister & Fransella (1986) have defined *constructs* as "the discriminations we make (between replications of events) not the labels we attach to them". In other words, people anticipate the world in terms of contrasting factors, for example, mean/generous; hard/soft; young/old, etcetera. It is important to note that constructs should not themselves be seen as <u>verbal</u> labels, though many constructs do acquire such labels (Bannister & Mair, 1968). Kelly referred to constructs without labels as "nonverbal and preverbal bases of discrimination" (Ibid: 29).

[12] A superordinate (or subordinate) relationship between constructs implies similarity between them in a person's construct-system; albeit inferred rather than stated.

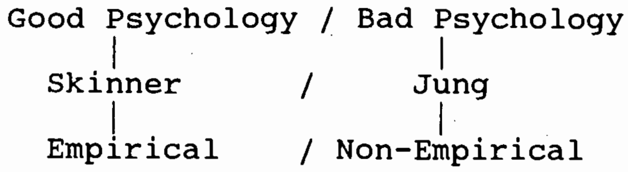

Figure 1. Schematic representation of hypothetical construct hierarchy.

(4) Dichotomy Corollary: "*A person's construction system is composed of a finite number of dichotomous constructs*". This is an important corollary in that constructs are identified as being dichotomous, or *bipolar*, in nature. This means that constructs are defined in terms of their contrasts. Thus, when someone states that s/he is *happy*, s/he is in fact saying that s/he is *not sad*. Constructs, therefore, should be seen as composed of an *emergent* and *implicit* pole. It should be noted that Kelly is not implying that people see the world simply in 'black and white' terms, but rather that people tend to revert from 'scalar modes' of construing to dichotomous modes. For example, a researcher might spend a long time weighing up the pros and cons of attempting a piece of research, but ultimately s/he will have to decide whether it is feasible or non-feasible.

(5) Choice Corollary: "*Persons choose for themselves that alternative in a dichotomised construct through which they anticipate the greater possibility for the elaboration of their system*". This corollary is important as it emphasises that people are active in selecting the direction which best

elaborates their construct system[13]. This, of course, does not imply that people necessarily choose the 'best' or 'correct' direction (Ryle, 1975; Bannister & Fransella, 1986).

(6) Range Corollary: "*A construct is convenient for the anticipation of a finite range of events only*". This refers to what is known as the "*range of convenience*" of constructs. Simply put, constructs are only valid for certain elements[14].

(7) Experience Corollary: "*A person's construction system varies as they successively construe the replication of events*". This implies that people have a capacity for change and that the accuracy of constructs are either validated or refuted through experience. This is an important construct in terms of the present research for reasons which are discussed below.

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[13] This is quite a controversial corollary in terms of the free will versus 'determined' debate. Bannister & Fransella (1986: 7) have argued that Personal Construct Theory manages to cut through the middle of this debate by positing that: "You are not the victim of your autobiography though you may enslave yourself by adhering to an unalterable view of what your biography means". Of course, the cynical re-wording of this so-called 'middle-ground' approach, is that Kelly is suggesting that many people choose to be determined!

[14] Ryle (1985) has defined *elements* as anything that can be compared or contrasted. Thus constructs are the discriminations or comparisons we make between elements. Therefore, if we wish to choose between three *mattresses* (elements), we might regard one as being *firm* while the other two were *soft* (the construct being *firm/soft*.)

(8) <u>Modulation Corollary</u>: "*The variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie*". Once again, an important corollary in terms of the present research as shall be discussed below. Following from the 'Experience' corollary, this implies that the ability to make sense of, or accommodate, new events varies from person to person.

(9) <u>Fragmentation Corollary</u>: "*A person may successively employ a variety of construction systems which are inferentially incompatible with each other*". This simply takes account of, for example, contradictory opinions, beliefs and attitudes held by people.

(10) <u>Commonality Corollary</u>: "*To the extent that one person employs a construction of experience which is similar to that employed by another, their processes are psychologically similar to those of the other person*". This corollary introduces the social dimension to Kelly's theory (Button, 1985). That is, the focus moves from the individual to the level of social interactions. It is important to note that Kelly is emphasising that people share constructions, but not necessarily experience. As Bannister & Mair (1968: 23) explain: "In common language, the point here is that having bumped into different sets of circumstances, and worked out what their ideas about what these circumstances were all about (two people) have come to

similar conclusions". Thus, two members of a political party may come from completely different background and sets of experiences, nevertheless, they have placed a similar interpretation on experience.

(11) Sociality Corollary: "*To the extent that one person construes the construction processes of another, they may play a role in a social process involving the other person*". This corollary posits that people interact on the basis of interpretation of each others' construct systems. This does not imply that people have to be in perfect understanding to interact, merely that they have to *construe* the construction system of others. Fransella & Bannister (1986) provide the example of an adult interacting with a child. This interaction does not occur on the basis of similarity between construct systems, but rather because the adult construes the child's construct system to the extent that s/he can derive meaning from it.

## 2.3 Kelly and Psychological Theory

George Kelly's attitude towards the scientific establishment was generally ambivalent. Holland (1970: 111) comments that:

> (Kelly's) writings are so full of the most personal invitations to join in the good life of inventing and exploring different ways of seeing the world, and each other that he seems to celebrate and exemplify the scientific quest. At the same time his engaging modesty, his constant deflation of his own pretensions by the use of colloquialisms, promises a completely humane, fun-

> loving irreverence towards the established systems, structures and orthodoxies of that dehumanized *Science* which he obviously despises and frequently attacks.

While Kelly initially based his clinical program at Fort Hays Kansas State College on the works of Freud (Ibid), he soon became disillusioned with psychodynamic theory. With regard to this change in conviction, Holland (Ibid: 114) has noted:

> Kelly ... decided to cast Freud in the role of the old-fashioned bad scientist - the accumulative fragmentalist - against whom Kelly brings his sharpest criticisms.

In addition to his rejection of psychodynamic theory, Kelly saw himself as cutting a path between behaviourism and psychological humanism. In outlining his own philosophical departure point, Kelly states that:

> This theory of personality actually started with the combination of two simple notions; first, that man might be better understood if he were viewed in the perspective of the centuries rather than in the flicker of passing moments; and second, that each man contemplates in his own personal way the stream of events upon which he finds himself so swiftly borne. Perhaps within this interplay of the durable and the ephemeral we may discover ever more hopeful ways in which the individual man can restructure his life ... Let us then, instead of occupying ourselves with *man-the-biological-organism* (behaviourism) or *man-the-lucky-guy* (humanistic psychology) have a look at *man-the-scientist* (Kelly, 1963: 3 & 4).

However, there are inescapable similarities between PCT and humanistic psychology. Buhler (1977 in Davisson, 1977) has pointed out that Kelly's view that people evolve construction systems to allow themselves optimal interaction with the world is similar to humanistic concepts such as Maslow's self-actualisation and Rogers' concept of growth processes.

On the other hand, Kelly's theory also retains the essential element of behavioural psychology (that is, the 'science model'). Kelly, firstly, understands the person as a 'scientist'. Secondly, his development of the repertory grid, demonstrates a scientific, statistical emphasis which is, again, reminiscent of behaviourism (Ibid). However, it should be noted that Kelly rejected the 'Newtonian' concept of science as a model for psychology. Rather than attempting to find behaviours and characteristics common to collectivities of people, he preferred individuals as the focus of psychological enquiry (Fransella, 1988).

## 2.4 Personal Construct Theory and Chronic Illness/Disability

Very little has been written about disability from the point of view of Personal Construct Theory (Beail, 1985). Therefore, it is necessary to explicate how PCT can act as a vehicle for obtaining a perspective on the *personal experience* of the disabling effects of a chronic illness such as ME.

The first aspect of PCT which has a bearing on any piece of psychological research is the corollary of 'sociality'. In other words, the research enterprise itself fits within the paradigm of PCT in that it attempts to *construe* the construct systems of other people. With regard to the 'sociality' corollary and with specific reference to disability, Bannister (1981) has pointed out that the task of the researcher is not merely to *know* about the disability, or to sympathise with the disabled, but rather to understand the disability to the extent that meaningful interaction is possible with people who are disabled.

The focus of the present study is on reaction to change. In other words, broadly speaking, the research concerns itself with the question of what happens to the construct systems of previously healthy, generally successful people who find themselves debilitated by a controversial illness such as ME. The 'experience' corollary ("*A person's construct system varies as he successively construes the replication of events*") is therefore pertinent as it provides a conception of construct variability. That is, humans can adapt to change. However, our ability to absorb change is not infallible. As Button (1985: 10) notes:

> Each day ... we are confronted with new, sometimes unwelcome experience. Although these surprises are usually fairly trivial, occasionally they may challenge us to alter radically our expectations and goals ... This variation or change in our

> construct system ... can be potentially very threatening[15].

At this point, it is useful to consider the 'modularity' corollary ("*The variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie*"). Kelly (1963) has indicated that a construct can be regarded as permeable if it is able to admit new elements to its range of convenience. For example, if someone applies the construct *beautiful/ugly* to a mountain range, then s/he should also be able to attribute the same construct to valleys, beaches, paintings, and so on. Therefore if a person becomes ill with ME, experiences the consequent drastic change in lifestyle and easily incorporates the new elements into his/her construct system, s/he will not experience the change as *threatening*. However, there are people whose construct systems are impermeable to the extent that they are unable to adapt to any change. What is most desirable is that a person's construct system maintain a certain degree of stability. As Button (Ibid: 11) notes, a person "... with too permeable a (construct) system ... will be in danger of being disturbed by virtually every occurrence".

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[15] In Kellyan terms, change becomes *threatening* when a person becomes aware of potential change to his/her *core* structure. In other words when fundamental change to those constructs central to a person's sense of self is imminent (Bannister & Mair, 1968).

Bannister (1981: 233) has pointed out that reactions to acquisition of a disability will vary according to a person's construction of themselves. That is:

> A person who sees life as about nothing but achievement and success in competitive, practical spheres, may find that their disability has, in a major sense, invalidated their life and significantly reduced their value as persons. A person with the same disability, who sees life as also and importantly about personal relationships, about reflective experience, about what you are, rather than what you do, might find the same disability truly less disabling.

## 2.5 <u>The 'Self' in Personal Construct Theory</u>

As the notion of 'self' is fairly central to the present research, a brief outline of the 'self' in the context of Personal Construct Theory must be provided.

Kelly (1963: 131) defined the 'self' as:

> ... a group of events which are alike in a certain way and, in that way, necessarily different from other events. The way in which the events are alike is the self. That also makes the self an individual, differentiated from other individuals.

In other words, Kelly saw the 'self' as a pole of the construct 'Self/Non-self'. Thus, Kelly believed one could infer something about a person from what s/he said about others (see the 'Dichotomy' Corollary). Therefore, if someone calls another person, say, a liar, we can infer that the person construes him/herself *in relation* to the <u>dimension</u> of *liar*. This does not, of course, mean that the person sees him/herself as a liar - it could mean the opposite is true. Self Concept, then, in Kellyan terms refers to someone's *construction* of him/herself in relation to others.

Norris & Makhlouf-Norris (1976) have proposed that the 'self' be looked at in terms of the concept of a 'self-identity system' which they see as being integral to a person's behaviour in that it serves to validate (that is, perpetuate or refute) a person's self-conception. It is also worth noting that Adams-Webber (1979) has pointed out that the category of 'self' constitutes an extremely reliable and stable repertory grid indices. In other words, the 'self' constitutes an important variable in terms of subjects' construction systems.

A word is due regarding the use of the repertory grid (see below) to measure self concept. Ryle (1975) has argued that the repertory grid diminishes potential bias in self-rating. For example, it is easier to define oneself *in relation* to someone else in terms of, say, intelligence, then it is to attribute a simple inferior or superior numerical rating to oneself.

## 2.6 Repertory Grid Technique

The repertory grid constitutes a psychometric device of Personal Construct Theory[16]. Essentially, the repertory

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[16] For an outline of other 'grids' in use refer to Fransella & Bannister (1977).

grid should be seen as the means by which a person's personal construct system attains mathematical definition (Bannister & Fransella, 1986). The repertory grid constitutes a means of dissecting the construct hierarchy and to establish a picture of the inter-relationship between constructs in proportion to the elements. As a simple example, when someone ascribes the construct pole 'good' to his/her maths and science teachers and 'bad' to his/her English teacher and then proceeds to ascribe the construct pole 'speaks clearly' to the maths and science teacher and 'mumbles' to the English teacher, then we have an idea of:

(1) The relationship between elements (favoured teachers)
(2) The relationship between elements and constructs (which construct-pole applies to which teacher)
(3) The ordinal structure of the construct system (correlation between good/bad and speaks clearly/ mumbles).

An illustration of the unpredictable nature of the ordinal relationship between constructs is provided by Fransella & Bannister (1977) who report on a experiment they conducted to test the validity of the repertory grid as a predictor of voting behaviour. They found that <u>both</u> Conservative and Labour voters indicated a positive relationship between the constructs *conservative* and *patriotic*. This surprising finding is understandable when it is taken into account that, for Labour voters, there was a further positive relationship between *patriotic* and *prejudiced*, whereas, for Conservative voters, there was a negative relationship between these constructs.

### 2.6.1 Reliability of the Grid Method

Kelly is supposed to have said that: "Reliability is that characteristic of a test which makes it insensitive to change" (Fransella & Bannister, 1977: 82). Indeed, the very notion of reliability is a contradiction in terms of Personal Construct Theory, which sees people as subject to constant flux (Bannister & Fransella, 1986).

Nevertheless, some studies have been conducted to measure the reliability of repertory grids. Unfortunately these are rare and Ryle (1975) has commented that the simplest experimental method of reliability-testing (short-term test/re-testing) has seldom been employed. A series of notable experiments were conducted by Bannister (1960; 1962 in Bannister and Mair, 1968) and Bannister & Fransella (1966; 1967 in Bannister & Fransella, 1986) to gauge consistency of construct rating across differing elements by comparing a schizophrenic and a 'normal' sample. Their findings indicate a degree of construct stability, however

Mair & Boyd (1967 in Bannister & Mair, 1968) failed to replicate these findings[17].

Fransella & Bannister (1977) have noted that there is no standardised grid, a factor which, in addition to the issue of theoretical contradiction, renders debate concerning reliability somewhat futile. Indeed, the grid does not purport to be a 'test' in the accepted, clinical sense of the word. Perhaps Bannister & Mair's (1968) conclusion is worth observing. That is, if knowledge of the reliability of a grid is absolutely necessary, then it would be best if individual experimenters were to determine the reliability of the grid they have utilised.

### 2.6.2 Validity of the Grid Method

Kelly is known to have said that: "Validity is the capacity of a test to tell us what we already know" (Bannister & Mair, 1968: 177). This comment refers to the tendency to evaluate the validity of a test against pre-existing measures or concepts.

There have been a number of studies concerned with the validity of repertory grids (see Bannister & Fransella, 1986; Fransella & Bannister, 1977; Bannister & Mair, 1968).

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[17] A detailed outline of all these studies is beyond the scope of this section. The reader is referred to Bannister & Mair (1968) and Fransella & Bannister (1977) for such information.

These have mostly validated the grid as a methodology. However, Bannister & Mair (Ibid: 200) have commented that:

> In psychology, the validation of measures commonly involves ... subjects not (being) credited with the ability to create and construe situations, or to predict and evaluate outcomes in their own terms ... So far, the grid has been largely validated in studies which accept these restrictive conventions. In terms of construct theory, these modes of validation seem incomplete. Construct theory envisages each individual as developing and operating an elaborate ... construct system, designed to deal with many situations. Measures of such a system can only be minimally validated in artificial and restricting contexts.

Perhaps then, the emphasis should be on the subjects themselves playing the central role in ensuring the validity of repertory grids. For example, the *content validity* - that is, the degree to which the content of a 'test' is representative of the concepts/variables it aims to measure (Kerlinger, 1986) - of grids used in large studies could be monitored by involving subjects in construction (see Chapter 3) or in approving or suggesting alteration to supplied constructs (and elements) at the pre-test stage (see for example, Dawes & Donald, 1987).

A crucial problem of validity is that of whether constructs should be supplied or elicited when using the repertory grid as an instrument in research. Indeed, the very notion of using constructs with more than one person ostensibly contradicts the 'individuality' corollary which states that *"people differ from each other in their construction of events"*. Adams-Webber (1970) has provided an extensive review of this problem. He begins by outlining studies which have shown that "... subjects generally regard their own personal constructs as more useful than provided constructs for describing persons (themselves and others)" (Ibid: 350). However, Adams-Webber further notes that people, to a certain degree, employ common constructs in communication with each other and he concludes that "... the results of several studies suggest that normal subjects, at least, exhibit approximately the same degree of differentiation in using carefully selected supplied lists of adjectives as when they employ their own elicited personal constructs" (Ibid: 352). Essentially, this conclusion is supported by the contention that it is the <u>structure</u> of construct systems, rather than verbal labels which are of interest when use is made of repertory grids.

Nevertheless, Bannister & Mair (1968: 202) warn that experimenters should avoid supplying constructs which are "a naive equivalent of the psychological dimensions in terms of which he is framing the experiment". In other words, assuming that the theoretical constructs necessarily tally with those of the subjects. These authors suggest pre-test interviews as a simple means to counteract this and other problems encountered in supplying constructs.

To conclude this section, Fransella & Bannister (1977: 3-4) have noted that:

> The results of the grid have often been looked on as a map of the construct system of an individual, a sort of idiographic cartography ... To the extent that a grid gives us a map of an individual's construct system, it is probably about as accurate and informative as the maps which Columbus provided of the American coastline. At that, it may be a good deal more sensitive to the nature of the person than the kinds of psychological instrument we have tended to use to date.

## 2.7 The Repertory Grid and Disability: Difficulties and Debate

Debate exists as to the usefulness of the Repertory Grid technique in applications with disabled people. Cunningham (1977 in Beail, 1985) attempted to utilise grids with Multiple Sclerosis sufferers, but was forced to abandon her research at the pilot stage as her subjects (who, like ME sufferers suffer from fatigue) found the procedure too time consuming. However, Beail (1985) argues that there are ways to circumvent this problem which were not attempted by Cunningham. For example, the construction of grids over a period of time, the use of large print, the use of rating, rather than time-consuming rank-order scales, and the careful consideration of questions being asked which leads to concise choice of elements and constructs.

Beail (Ibid) further notes that very little has been done in terms of using repertory grids to study the meaning of disability[18]. This may be as a result of Cunningham's experiences. Nevertheless, the grid technique has been used

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[18] It should be emphasised that the term disability is relevant to the experience of ME sufferers as their illness is debilitating.

successfully with disabled people since Cunningham's attempt. Beail (1985) used repertory grids to investigate the relationship between the self and the public stereotype of severely disabled people. Taking note of Cunningham's experience, he used the rating method of element allotment and presented each construct scale in large, black print. His results indicate that, firstly, the repertory grid is useful for measuring the meaning systems of disabled people and, secondly (testing Fransella's [1977] contention that people will reject negative stereotypes of themselves), that the disabled do indeed reject what they perceive to be the public stereotype of themselves. Beail (Ibid: 132) seems unable to resist a parting shot at those who reject the possibility of using repertory grids with the disabled when he notes that:

> (T)he fact that this group of disabled people reject society's stereotype of them does not mean that they are unaffected by it. The stereotype is imposed on a group by others and limits are set on their behaviour and alternatives open to individuals within the group ... The idea that you cannot use grids with disabled people is held by professionals and imposed on disabled people, this being a minor example of a major problem.

Other studies which utilised the repertory grid to measure the personal experience of disability and chronic illness include Brumfitt (1985) who used grids to study aphasic people and Fisher (1985) who used a grid to determine self-image changes in people who have had a limb amputated. Viney (1983) and Bull (1984) have used grids in their research into coping styles amongst cancer patients.

Gardner & Gibson (1989) used a Semantic Differential Grid (similar in structure and purpose to the repertory grid) to study perceptions of health amongst twenty ME sufferers. They found no problem with the technique and note that it constitutes a useful method of gathering quantifiable data for the purpose of monitoring health perceptions. In addition, Struckmann (1991b) used the repertory grid to investigate coping styles amongst people with ME, as compared to people who identified themselves as having recovered from ME. She reported no problems with using the method with either of these groups.

As no problem with using the grids was reported by any of the subjects in the present study, it can reasonably be concluded that the repertory grid represents a sound method of data collection and analysis for disabled and chronically ill people.

## 2.8 <u>Conclusions</u>

Personal Construct Theory and the repertory grid method of psychometric inquiry have been outlined above. The theory offers a means of understanding human beings as constructing interpretations of, and acting upon, the world. In this way, the theory is divergent from other major psychological theories which see people as acted upon. Most important for the purposes of the present research, Personal Construct Theory offers a means of understanding the person as a being in a state of change. It is, after all, the reactions to, and perceptions of, the extreme change experienced by a group of people struck down with a debilitating illness, which are of interest in this research.

Which leads to the utility of repertory grid technology, which, though flawed (Fransella & Bannister, 1977), offers a 'window' into the web of constructions held by ME sufferers about who they were and who they have become. Though the reliability and validity of repertory grid technology are far from established, measures such as subject involvement in construction as well as approval of element and construct content may alleviate this type of problem. Any questions which may exist as to the usability of the repertory grid with disabled/chronically ill people, such as ME sufferers, has been dispelled by previous research, and was not found to be a problem in the present research.

## 2.9 Aim of Research

Finally, an overview of the aims of the present research is necessary. Essentially, this study was guided by the following research questions:

(1) Has the self-image of ME sufferers changed since contracting the illness? What effect did diagnosis have on this change?

(2) What is the relationship between the 'self' and the public stereotype of ME sufferers and ME as a syndrome?

In other words, to what degree do ME sufferers internalise the public view of ME?

### 2.9.1 General Expectations of Research

(1) It was expected that the self-image of ME sufferers would have deteriorated subsequent to contracting the illness. However, diagnosis, because it serves a legitimating function, would function to bring about an improvement in self-image.

(2) As with Beail's (1985) finding that disabled people reject society's stereotype of themselves, it was also expected that people with ME would reject their stereotype and not identify themselves with it.

# CHAPTER 3

## METHOD

### 3.1 General Procedure

The research was divided into two phases; the first being a pre-test phase, the aim of which was to determine, by means of interviews, those constructs most salient for the population under investigation. Following the elicitation of constructs, some subjects were re-approached so that the meaningfulness of the resulting repertory grid could be assessed.

During the second, experimental, phase, repertory grids were posted to 100 respondents together with a short biographical questionnaire. Returned grids were subjected to analysis using the Ingrid computer program (Slater, 1976). These results were then subjected to further statistical analysis using *t- tests*. A further, more detailed description of the study is provided below.

### 3.2 [I] Pre-Test

The aim of this phase was to construct a repertory grid which would have a sufficient degree of validity with the target population. Therefore it was necessary to elicit constructs from subjects and assess the usefulness of these constructs, as well as the supplied elements, before utilising them in the repertory grid to be employed in the experimental condition.

### 3.2.1 <u>Sample</u>

All subjects used in this research were recruited via an appeal placed in various newspapers and periodicals throughout South Africa. (See Appendix A for the text of this appeal.) For the pre-test condition, subjects were randomly selected from a pool of respondents who met the inclusion criterion of living in the Western Cape and having been diagnosed as suffering from ME by <u>any</u> medical practitioner[19]. Potential subjects were contacted telephonically by the author. They were informed of the broad aims of the study and additional autobiographical details were checked (for example, which doctor had diagnosed them). Subjects meeting inclusion criteria, were then asked if they would consent to being interviewed. It was emphasised that the interview would be taped and that it would last for about thirty minutes. A sample of fifteen ME sufferers (which included a married couple and two sisters) were selected in this way. Subjects' ages ranged from 17 - 58 years, with a mean age of 36,5. In terms of gender

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[19] Although all medical practitioners do not abide by stringent diagnostic criteria (such as those provided by the CDC and outlined in chapter 1), it was felt that the present study is specifically interested in <u>personal</u> construction. Therefore, as long as a respondent <u>believes</u> that s/he has the illness, and has had this belief engendered or confirmed by any medical practitioner, this is sufficient for the purposes of this study. Respondents diagnosed by 'alternative' practitioners were excluded to provide at least a degree of control.

distribution, 13 women and 2 men were included. Ultimately, ten subjects were interviewed by the author, and five by a research assistant recruited from a third-year research methodology class. Interviews were audio-taped and notes were taken as a 'backup' measure.

### 3.2.2 Procedure

Constructs were elicited via a loosely structured interview. Subjects were asked to:

(1) Describe the differences between someone with ME and someone without ME.

(2) Describe the differences between themselves before contracting ME and themselves with ME.

(3) In addition, subjects were always asked to list possible stereotypes attributed by the public to people with ME. This was done to ascertain whether sufferers indeed perceived themselves to be negatively stereotyped by the public.

Subjects were always asked if they objected to the interview being recorded. None objected. For the most part, the interviewer would listen with minimal interruption to what the subject was saying, thereby allowing the subject a 'free-flow' of conversation. However, the interviewer would interrupt when issues needed to be clarified, or when it was felt that the subject was straying too far from the subject. For financial reasons, the interviews were only taped for thirty minutes. However, most interviews continued after this time had elapsed and handwritten notes were kept.

All tapes were transcribed and transcriptions were merged with the handwritten notes. Following this, the transcripts were 'content-analysed', with all the most common descriptions/adjectives (constructs) being listed. As part of this process, it was necessary to combine constructs with similar meanings. Ultimately the 12 most prevalent constructs were selected[20].

Following this, the author returned to eight of the initial subjects (all pre-test participants were not approached due to time constraints) in order to assess the validity of the elicited constructs as well as the supplied elements. Although elements were selected by the author on the basis of the focus of the present study, it was felt that subjects should preview the elements to assess factors such as ambiguity of meaning. Most importantly, the subjects were asked the following questions about the constructs:

(1) Were the constructs applicable to the elements? In other words, did the elements fall within the range of convenience of all the constructs?

(2) Were the constructs understandable? In other words, were they ambiguous? Did they make sense?

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[20] See Chapter 4 for an outline of these constructs in terms of their original context of presentation.

(3) Were these descriptions adequate for describing the elements?

Only two subjects indicated problems with the constructs and elements. The first questioned the 'Strong/Weak' construct. She asked whether this referred to physical or psychological factors. As none of the other subjects questioned this construct, it was decided not to discard or modify it[21]. The second subject complained that she would find it difficult to think of a disliked and admired person. Once again, this problem was not raised by other subjects.

As mentioned in Chapter 2, there exists some doubt as to the utility of the repertory grid methodology amongst physically disabled people. Unfortunately, as the grids were not yet completed in their final form at pre-test stage, subjects were not given the opportunity to test the length of time it would take to complete the grids. In addition, the instructions for completing the grid were not pre-tested on subjects. This would have been useful as the grid can seem daunting to a subject who has never completed one before. To counteract this problem, several non-subjects were asked to read the instructions and explain the procedure for

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[21] It should be mentioned that this construct could mean whatever is salient for the person construing it. The reader is reminded that constructs need not have identical meaning for all subjects in order to assess cognitive structure. Kelly (1969 in Adams-Webber, 1970: 351) has stated that "regardless of the words he uses each person does his own construing".

completion of the grid. The non-subjects found the instructions to be adequate.

## 3.3 [II] Experimental Condition

The aim of this phase of the research was to obtain repertory grid measures from subjects and subject the resulting data to statistical analysis.

### 3.3.1 Sample

A sample of fifty subjects, all current ME sufferers and, once again, all diagnosed by medical practitioners, was randomly selected from replies to letters placed in newspapers and periodicals nationally (subjects included those utilised in the pre-test condition).

In terms of gender distribution, exactly 80% of the sample were female and 20% male. This correlates well with figures provided by the ME Association of South Africa (MESA News, September, 1991) which reports that 78,6% of medically diagnosed people with ME in South Africa are female, and 21,4% male.

Subjects' ages ranged from 17 to 64 years, with a mean age of 37,5 and a mode of 39,5. Expressed in more detail, 24% of subjects were aged 25 or less; 46% were aged 26 to 45 and 30% were 46 years and above.

### 3.3.2 The Repertory Grid

A rating grid (Fransella & Bannister, 1977) was utilised. It consisted of nine supplied elements and twelve elicited constructs. The elements were:

(1) Self Now

(2) Ideal Self [22]

(3) Healthy Person

(4) Future Self

(5) Public Stereotype of ME Sufferers

(6) Admired Person

(7) Disliked Person

(8) Self Before ME Diagnosis

(9) Self Before ME

The above elements were chosen on the basis of their potential to provide information regarding the context of interest. A nine-point scale was utilised, where 1 was representative of the extreme of the left pole, 5 was neutral and 9 was representative of the extreme of the right pole. (See Appendix D).

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[22] That is, the "representation of (a person's) aim or direction of desired movement" (Norris & Makhlouf-Norris, 1976: 80).

The following elicited constructs were included:

| | Emergent Pole | | Implicit Pole |
|---|---|---|---|
| 1. | Strong | - | Weak |
| 2. | In Control | - | Lacks Control |
| 3. | Decisive | - | Indecisive |
| 4. | Busy | - | Inactive |
| 5. | Hard Working | - | Malingerer |
| 6. | Selfish | - | Appreciative |
| 7. | Efficient | - | Inefficient |
| 8. | Secure | - | Insecure |
| 9. | Attractive | - | Unattractive |
| 10. | Abuses Self | - | Cares for Self |
| 11. | Achiever | - | Loser |
| 12. | Independent | - | Dependent |

### 3.3.3 Procedure

Approximately 300 replies were received to the appeal in the press for people with ME to contact the author. Of this total, the name of 100 medically diagnosed, current ME sufferers were randomly selected[23] and the following package was sent to them:

(1) A general biographical questionnaire, including questions checking the diagnostic status of the respondent and whether s/he was currently suffering from ME;

(2) A set of instructions for completing the repertory grid;

(3) The repertory grid[24]; and

(4) A post-paid self-addressed envelope.

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[23] It would have proved too expensive to send questionnaires to all respondents meeting the inclusion criteria.

[24] Items 1 - 3 are included in Appendices B, C and D.

In order to prevent completion of the grid proving too time-consuming, and hence tiring for subjects, it was recommended that subjects complete the grid over a series of days.

The first 50 completed questionnaires received after a period of one month were included in the study. This was necessitated by time constraints and a desire to streamline numbers.

## 3.4 Method of Data Analysis

The data was analysed using the SERIES and INGRID computer programs (Slater, 1976). The SERIES program facilitates the computation of an averaged, or 'consensus' grid from a number of grids. The consensus grid was then analysed on the INGRID program. This program provides a Principle Components Analysis which indicates element-construct distances. In addition, this analysis provides data on inter-element, inter-construct and construct-element correlations. Correlations are expressed as cosines (see Chapter 5).

Slater (1976) warns that the application of probability theory to grids is problematic. Tests of significance are particularly problematic for use with cosines. In order to surmount this complication, Dawes & Donald (1987) utilised cosine values of greater or less than +0.50 and -0.50 as 'meaningful' interactions. However, for the purposes of this study, the *t*-test for significance of correlations is used to provide additional 'insurance' as all values exceed +0.50 or fall below -0.50 and the assignment of more stringent values could become somewhat arbitrary. To test significance of variation between elements, protected *t*-tests were utilised.

## 3.5 Afterword

It is perhaps necessary to explain the absence of a control group in the research design. It should be emphasised that this study is interested in the person's construction of events. Although the aim of the research is to gather generalisable data, the inclusion of a control group, would, for reasons which are outlined below, be to negate the theory underlying the repertory grid. Essentially, the issue is not so much whether change actually occurred, as whether subjects construe change as having occurred and the manner in which they construe this change. Thus, it is primarily the perceptions of people with ME which are of interest to this study.

The inclusion of a control group, besides providing a gauge of change - a standard against which the significance of the change could be measured - would also provide a means by which retrospective constructions, for example, regarding 'Self before ME Diagnosis' could be checked. Fortunately, this is unnecessary in Personal Construct Theory. As noted by Bannister & Mair (1968), psychologists point to distortions and omissions which occur in memory over periods of time as a factor which makes retrospective data questionable. Actually, the distortions are explained in Construct theory as changes in interpretation and understanding of an event. Therefore, one could have interpreted an event one way as a child, but changes in the construct system lead one to understand an event in a different way as an adult. In addition, certain aspects lose their salience and disappear from the system. As Bannister & Mair (Ibid) point out, remembering and understanding are perceived as the same phenomenon in Personal Construct Theory. In other words, memory is tied up with perception - the way we construe events according to our current construct systems is how we remember them.

Therefore, it would be pointless to use repertory grid technology and Personal Construct Theory if there is concern about retrospective data having dubious validity. To reiterate, both Personal Construct Theory and methodology are about change. A central assumption is that people are constantly changing in the way they construe events.

# CHAPTER 4

## RESULTS I: CONSTRUCTIONS

### 4.1 Introduction

In the previous chapter, it was indicated that constructs included in the repertory grid constructed for this research, were elicited via informally structured interviews. However, the constructs themselves constitute abbreviations of the constructions of pre-test subjects (and in this way are by necessity the constructions of the author). In other words, the 'story', as it were, of each subject remains hidden behind the shortened constructs presented in the final grid form and, ultimately, behind statistical observations.

Therefore, it is necessary to provide an insight into the actual discourse of the subjects. That is, to provide a fuller, qualitative, picture of their constructions in accordance with the construct dimensions which ultimately appeared on the finished grid. It should be remembered that most constructs are interlinked in hierarchical fashion, with some being superordinate to others. This aspect shall be discussed in a later chapter. For now, the main interest is in allowing the subjects to 'be heard' by examining their verbal labels, rather than their cognitive structure.

## 4.2 Constructs

### 4.2.1 Strong/Weak

Many pre-test subjects felt that people with ME were weaker than people without ME. It should be emphasised that this did not necessarily mean that all subjects identified with a particular pole, but rather that they defined themselves along this dimension.

Two 'categories' of identification with the 'Strong/Weak' construct can be identified. The first is exemplified by Bernice[25], who says:

> I used to be quite a strong sort of person before. I mean, I could handle my boss shouting and screaming at me before. I would just say: 'Stop shouting at me!' Now I just actually burst into tears, whereas I would have just handled it before.

This could be termed the 'Descent to Vulnerability', where the person with ME finds him/herself no longer able to cope with the rigors s/he faced before contracting the illness.

The second 'category' could be called the 'Struggle Against Encroaching Weakness', where the ME sufferer is actually forced to lower his/her standards as s/he attempts to fight the illness. Here, people believing in the utmost importance of being 'strong', battle the tides of a mysterious illness they construe as symptomatic of 'weakness'. To this end, they exacerbate their condition

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[25] All names supplied in this section are pseudonyms.

through trying harder. As Vivienne, a student at the University of Cape Town, puts it:

> You were capable of working hard (before ME), so you managed to achieve what you wanted. Now even when your sights are set low, you can't achieve and that - that breaks you. Because already its a concession to pull down your goals. Then when you're still not achieving *that*, you get upset. People like myself don't want to believe we're ill. Therefore if a doctor says there's nothing wrong with you[26], you say: Wow good! Your second reaction is to say, well I'm at fault, I'm being weak. The only answer I have to weakness is to overcome it, to fight it. To work harder to overcome it. Then you get yourself into a cycle (*where hard-work makes her feel worse, and where feeling worse is regarded as a sign of weakness*).

### 4.2.2 In Control/Lacks Control

It was common for people with ME to express themselves in relation to this construct. At the simplest level, people feel they have literally lost control of their lives to the illness. This is illustrated by Julie, a physiotherapist who was forced to retire as a result of her illness:

> The biggest thing is that you feel totally out of control. As a person, I'm normally very dynamic, very positive, very ebullient. On the bad days you think, I can't make a cup of coffee. I get out of bed and say to my husband: I feel so old, so old. I can't even pick up a book. Now this isn't me! I'm normally on the go. You feel a different person. You hit the wall.

For James, a financial manager, life has become unpredictable since he contracted ME. Ironically the

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[26] This refers to the experience many ME sufferers have, where doctors have initially been unable to find anything medically wrong with their patients.

attempts he makes to plan his life are indicative of the control he has lost.

> We're (*his wife and he both suffer from ME*) like a motor car which suddenly runs out of petrol in a matter of minutes. It means we have to plan ahead of time. We tend not to do things which may be physically demanding. I've lost the urge. I find I can't stick to my commitments - which is extremely frustrating for me.

Andrew, an engineer, speaks of the frustration of losing control over his life and social interactions, but especially his emotions. He speaks of the way in which he attempts, artificially, to control his moods so as to make himself more amiable when he is with his friends[27]:

> I'm not able to live my life as I would like to, or interact normally with my friends. I become depressed. I'll finish a bottle of red wine before a party and think f-- it, I'm not prepared to be a damper for this party! I'll do anything to improve my mood - but I'll pay for it the next day.

It is notable that Andrew's attempt at gaining control through using alcohol backfires. That is, the illness

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[27] The need not to be seen as a 'bore' by friends was wide-spread amongst the people interviewed. ME puts special strains on friendships in that the illness is not really apparent (sufferers look physically well) and perhaps due to the 'bad press' and medical scepticism discussed in an earlier chapter. Bernice tells of the trouble she initially faced with her friends:

> People were getting very impatient with me. Friends of mine say, well why don't you want to come out with us. And I say, can't, I'm tired. They don't understand it! A friend of mine phoned to ask me how I was. I said I was fine. Then she asked me to go out and I said I can't. She said, you just won't face reality!

exacts a heavy toll from him the following day. In other words, ME retains ultimate control.

Finally, Vivienne in emphasising the importance of control, notes that the loss of control brought about by ME can be potentially devastating. At the same time, she acknowledges a greater understanding of people's weaknesses than she had before falling ill.

> Before I couldn't understand people who were, say, depressed. I always thought you were in control of your destiny, in control of your emotions. CONTROL was the big word. ME just says thank-you, takes the control and walks away. I think I miss being able to control my life. I have to believe that I'm going to get better, otherwise I don't see much point in going on.

### 4.2.3 Decisive/Indecisive

This construct could probably be attributed to the neurological impairment characteristic of the ME-syndrome. In this sense, the psychological aspect is dominated by physical origins and this construct is therefore perhaps more 'observable' than others. Mary, sums up the sentiments of many ME sufferers in the following statement:

> The thing was that I had been known for was my incredible memory. I lost my memory almost completely. I've also always been very decisive. I became very incapable of making decisions - simple one's like what to have for supper.

On the other hand, some subjects indicated that the fatigue symptomatic of ME had led to a need to be more 'focussed'. As Andrew notes:

> The world becomes fairly black and white. You feel you don't have time. You don't have patience for these things - you like people to be decisive, to get to the point quickly. You haven't got time for crap. I have to battle against my own indecisiveness sometimes.

### 4.2.4 <u>Busy/Inactive</u>

Most subjects construed ME sufferers as having been busy, overactive people prior to contracting ME. Gladys provides the following description of herself before ME:

> I was a typical subject for it - I was very active, I was always in the fastest lane and I wasn't happy unless I was filling every minute with mind things or body things. That was the way I liked it. I like working. I like to be busy. So I was on the run, I had a very demanding job. So I was really on the hop. I think that, mentally and emotionally, I worked on the same sort of fast track. I didn't like wasting time. It was almost like running past myself.

Similar sentiments are expressed by Mandy, a department head for a giant insurance company.

> For the two years before I was ill, I had a very exciting, demanding job profile. I came to see myself as absolutely essential and was referred to constantly as essential to the functioning of my division. I was extremely busy. I enjoyed the pressure. I understood myself to be very efficient and infallible. I worked for the comment - if you asked Mandy to do it, it would get done, if you asked someone else, it won't. I was riding a wave. I was ambitious. I was working long hours, I would come home exhausted and often worked weekends and was still trying to be as available a parent as I had been before. I like being on the move and I like being busy and one of the big problems I realised after I was ill and inactive was how often I solved problems by activity.

What is particularly interesting about these two accounts is the emphasis placed on 'overactivity' as a causal factor.

There is a tacit acceptance amongst these sufferers that they were in this way responsible for the onset of their illness. Indeed, this is a popular notion which could be termed the 'S/he Asked For It' attitude. So prevalent is this attitude, that Cathy feels able to go so far as to draw a comparison between having ME and the experience of many rape victims.

> Friends told me I was pushing myself too hard. What a woman goes through when she's been raped - I don't know, there have to be parallels. I say now that I'll never push myself again. Like a rape victim who's been told that her mini or low-cut dress caused her to be raped won't expose herself to men again in that way. No one asks for any illness - or to be raped.

Some subjects specifically rejected the view that ME is an illness of overactive people. As Jean put it:

> I read in a magazine that ME sufferers are noted to be go-getters who are very active and highly intelligent. I don't know if that's an accurate description of ME sufferers. I think they're generalising a lot. I'm not a very active person.

### 4.2.5 Hard Working/Malingerer

Kelly (1962) in his 'Fragmentation corollary' indicated that people may employ incompatible construction systems. This corollary is well illustrated in that ME sufferers are often construed as both malingerers and over-working/overactive people.

Though ME sufferers, on the whole, seem to perceive themselves in terms of the 'Hard Working' pole of this construct (see the preceding discussion on the 'Busy/Inactive' construct), many believe others construe them as 'malingerers' who are faking their illness. Edna, a teenager with ME, speaks of the need to appear ill in order for others to accept the reality of her illness.

> I look too good. I sometimes don't want to look good - I have to justify myself. People tell me I look great when I'm feeling terrible. I even don't put on make-up so I don't look so healthy.

Edna also highlights the predicament of experiencing the scepticism of family members. This proves frustrating and hurtful to her.

> My brother doesn't understand. He's doing medicine and always tries to explain away what I feel. Last night I was feeling ill, but I didn't want to tell him.

The experience of being regarded with scepticism is also faced by ME sufferers in the workplace, where 'legitimacy' is especially important for reasons such as 'sick leave'. Debbie, a pharmacist employed by a large hospital, tells of the initial disbelief shown towards her by colleagues:

> People told me at work, that they didn't believe me. They thought I was just being lazy and that. They didn't tell me straight away, but I could feel it all along.

Debbie did not regard scepticism from her colleagues (many of whom were members of the medical profession) as destructive. She was able to ignore it, and eventually even change the attitude of one of the doctors.

> It's no use getting angry with doctors who don't believe in ME. So what! They're dumb! They've had 6 years of training and if they really think I'm faking it! Well! From the beginning, they thought it was psychological. Dr X (*a doctor who has become prominent in the diagnosis of ME*) eventually came to believe in it through me.

Similar resilience to that displayed by Debbie is also evident in Shirley's attitude towards sceptics. However, this only became true following her diagnosis. As discussed in an earlier chapter, diagnosis serves an important social legitimating function. In addition, Shirley draws a distinction between the professional and lay-response to ME.

> After I'd obtained the diagnosis, I became almost relieved that I had a problem. If the guy down the road says I'm a walking hypochondriac, I wouldn't give a damn because I know there is something wrong with me. The medical people (generally) think it's hypochondria. It's funny, the lay-man, if I tell them now, they will say, gee, I believe in it, I can see it in you, you're an example. As with AIDS, cancer, they'll acknowledge it's there, as long as it doesn't touch them.

### 4.2.6 Selfish/Appreciative

Some subjects indicated that there is a positive side to ME. One example of this is where sufferers feel they have become more altruistic and appreciative of factors which gain salience after they become ill. As Debbie points out:

> I see much more into life now that I've had ME. People are very selfish. You don't appreciate what you've got until you lose it. I get frustrated when people get cross about silly little things. People don't notice the mountains or the flowers or things like that anymore. When you're an ME sufferer you begin to notice things like that because you can't go at your normal pace anymore. You have to take note of other things.

> You have to find everything good. If you can't do that, life would be the pits as an ME sufferer.

Because family and friends often doubt the validity of their illness, some subjects indicated feelings of selfishness. That is, that they are a burden to their family and that they are not 'carrying their weight' enough. Essentially this feeling is tinged with a sense that others do not perceive them as being genuinely ill. Gail puts it this way:

> I used to be able to do quite a lot. I could go to work, come home, clean the house, cook the supper and do all that. Now sometimes I feel so exhausted it's all I can do to get out of bed in the morning. You just want to scream. My family find it hard to understand what I'm going through. They don't say it, but I think they think I'm just taking advantage of them.

### 4.2.7 Efficient/Inefficient

Subjects generally indicated that, before contracting ME, they had tended to define themselves in terms of efficiency and saw this as their key to achieving success. Naturally, they had trouble construing themselves along the dimension of the inefficiency which resulted from ME. As Vivienne notes:

> When you're doing a thousand things every day - varsity, sport - you need to be efficient. Otherwise you're not going to make it. You need to make the most of all the time you have. With ME, well you struggle to come to terms with not being able to do everything at once - at all! You get really angry with yourself.

However, in Mandy's case, as with the Selfish/Appreciative construct above, she felt able to use the experience of ME to attempt an understanding of those holding what she regarded as the negative character trait of being inefficient.

> I achieved my goal of obtaining a promotion and then I collapsed about a week after that, so it's like a cautionary tale. I remember lying here crying, trying to define myself. I was asking: Who am I if I'm not that efficient focal person. Before I was ill, I was absolutely intolerant of inefficiency at work and very impatient with people who couldn't make decisions. When I was ill, I became inefficient myself and I used to think that I would like to hold on to that insight into what it was like to be inefficient and dithery and stupid and forgetful so that I would be more tolerant.

### 4.2.8 Secure/Insecure

For ME sufferers, the physical and mental deterioration which accompanies their illness becomes, quite understandably, a source of insecurity. Compounding this is the perception that their illness is not fully understood by society. What is particularly evident from what Gail says below is the sense of being alone in her suffering.

> I also feel insecure when I'm forgetting names. Very much so. I'm usually a very secure person and, you know, when you have those doubts, you are inclined to feel insecure. And it's the fact that I don't think this ME is accepted by this society. You know, when you say you're suffering from ME, people automatically think it's a cough, or a cold, or they're not aware of what it actually involves. You know, the pain you actually go through at times. When I'm feeling really ill, my daughter and husband say: 'Oh no, Mommy's got the yuppies again'.

### 4.2.9 Attractive/Unattractive

This construct is symptomatic of another aspect of the deterioration caused by ME. Here again, people find they have to come to terms with possessing characteristics they had previously disliked in others. As Mandy says:

> I have found it very difficult in that my physical image has changed completely. I mean, I had highlighted hair and I was always made-up and I was slim. I don't want to go out because I feel I don't want people to see a fat, ugly person. I look like the kind of person I used to despise, fat, ugly with dirty hair.

Deterioration in appearance has, for some ME sufferers, the effect of convincing others of the seriousness of their condition. Gladys describes the moment her sister realised something was really wrong with her. Indeed such was her sister's reaction that Gail became convinced that she was going to die.

> My sister came and she saw me and her face was a picture! She said no, I'm taking you back to Port Elizabeth. I looked dreadful, very grey and pale. This is it! I thought. I'm going to die ...

### 4.2.10 Abuses Self/Cares for Self

Through necessity, people with ME have been forced to accept their physical limitations. This is another respect in which their illness has become a positive force for change. That is, people often become more careful of themselves after contracting the illness. As Shirley says:

> One has to learn to respect and care for one's self. I decided I have to eradicate anything that stresses me. I resigned from the Southern Cross

> fund committee last month. I really have to get rid of everything that stresses me. If my husband gives me a hard time, I say: Hey I don't need stress, thank-you very much! I have become more self-caring.

### 4.2.11 Achiever/Loser

This is another theme which was salient amongst subjects. Once again this statement by Vivienne evidences the problem of having to adopt lower standards, which are those previously disliked in others.

> The biggest obstacle for me is that I've gone from being a winner to being a loser. You've gone from being an achiever, often an overachiever, to being someone you are actually repulsed by sometimes because you have been so incapable of doing things.

For some, this construct is seen in terms of a battle against their illness. Julie puts it this way:

> Often you feel you can't carry on anymore. Everything's such a bind! It's a real battle for life. You're either a winner or a loser ... At the moment I feel like a loser.

### 4.2.12 Independent/Dependent

ME is a debilitating illness. As with other chronic illness and disabilities, the fear of (and indeed the actual) loss of independence become salient factors in the lives of people with ME.

For Mandy, her sense of independence from other people had served as a 'defense-mechanism'. With the onset of ME, she was forced to ask others to do favours for her. Thus while

ME forced her to become bedridden and give up her job, the illness has also served to force her into the world.

> (B)eing independent had been very important to me, probably because if you're not independent, you are woundable. It's been a defense behaviour. When I was bed-ridden, I was determined that the children's lives wouldn't change because I was ill and that meant delegating every lift I found it terribly hard to actually phone people and ask them.

For Gladys, so important was her independence, that she hid the worst of her disabilities and even went to the extreme of purposely isolating herself from people to prevent herself from being seen as an invalid:

> I didn't want people to know that I'd lost use of my fingers because I wasn't accepting myself like that and I'm an independent person and I couldn't rely on people to help me - though I had to ask my son. It was fear of being seen as an invalid or relying on anybody and that's why I actually withdrew. I didn't answer the bell, I'd isolated myself. I was happy to do that and I'm not that sort of person. My fear then was to just keep this mind going.

Debbie also mentions her fear of becoming an invalid. Her condition has improved, but there was a time when she was forced to accept the help of others.

> I went through such a long stage when people had to do everything for me. Dependence on other people is a very important thing. Your independence is the last thing you want to lose. I still stayed here, but my Mom did my shopping and cleaned my flat. She did everything for me. But I still wanted to stay here on my own. I didn't want to be a complete invalid. I kept wondering: Am I ever going to get out of this? That independence is to at least do something; even if it's just to make breakfast, or sit in a chair. I think it's important.

What is particularly salient in Debbie's statement is the way in which factors, such as living on her own, making breakfast and even sitting "in a chair" become particularly important, symbolising a maintenance of self-identity. Again, there is a sense of realisation evident here; a new appreciation for 'everyday' circumstances which were taken for granted before the onset of ME.

## 4.3 Conclusions

This chapter has attempted to make the constructs which are included in the research more accessible and thereby provide an introduction into the construct systems of ME sufferers which transcends the simple presentation of bipolar constructs and statistical relationships.

What stands out from the above is that, while ME sufferers are forced to undergo major life-changes in terms of physical and psychological capabilities, many are able to come to terms with this change. In Personal Construct terminology, their construct systems demonstrate a remarkable level of permeability. Some, though, reject their 'post-ME selves' and retain a sense of resentment towards health professionals and lay-people who have treated them with scepticism.

# CHAPTER 5

## RESULTS II: EXPERIMENTAL CONDITION

### 5.1 Introduction

The results of the main study (experimental condition) are outlined in this chapter. Because results are presented in a format which is unique to statistical analysis within Personal Construct Theory, an ongoing explanation of the nature of the results shall be provided. It should be emphasised that more detailed analysis and discussion of the implications of results is provided in Chapter 6.

It would be useful before proceeding further, for reasons of clarity, to reiterate the research questions guiding this study:

(1) Has the self-image of ME sufferers changed since contracting the illness? What effect did diagnosis have on this change (if any has occurred)?

(2) What is the relationship between the 'self' and the public stereotype of ME sufferers and ME as a syndrome? In other words, to what degree do ME sufferers internalise the public view of ME?

The results are mostly presented in the context of these questions. However, additional observations shall be made where they are relevant.

### 5.1.1 Statistical Analysis

The SERIES computer program (Slater, 1976) was used to obtain a single, averaged ('consensus') grid. Following this, statistical analysis was performed on the 'consensus' grid using the INGRID program (Ibid). The latter package tests for the following:

Inter-element correlations (in 5.3);
Construct-Element interactions (in 5.4);
A Principle Components Analysis (in 5.5);
Construct salience (in 5.6);
Element salience (in 5.7) and
Inter-construct correlations (in 5.8).

The nature of each of these tests is explained below.

## 5.2 Constructs and Elements

Before proceeding further, it should be pointed out that, for purposes of simplification, tables detailing construct/element interactions portray elements and constructs as the letters A to I and the numbers 1 to 12 respectively. Therefore, Table 1 serves as a reference to the labels attributed to the various constructs and elements identified below.

Table 1

Key to constructs and elements

| Constructs | Elements |
|---|---|
| 1 - Strong/Weak | A - Self Now |
| 2 - In Control/Lacks Control | B - Ideal Self |
| 3 - Decisive/Indecisive | C - Healthy Person |
| 4 - Busy/Inactive | D - Future Self |
| 5 - Hard Working/Malingerer | E - Public Stereotype |
| 6 - Selfish/Appreciative | F - Admired Person |
| 7 - Efficient/Inefficient | G - Disliked Person |
| 8 - Secure/Insecure | H - Self before Diag. |
| 9 - Attractive/Unattractive | I - Self before ME |
| 10 - Abuses Self/Cares for Self | |
| 11 - Achiever/Loser | |
| 12 - Independent/Dependent | |

## 5.3 Inter-Element Correlations

The INGRID computer program (Slater, 1976) provides an analysis of inter-element correlations. Simply, this details relationships which exist between elements contained within a repertory grid. Such relationships are measured in terms of construct values attributed each element by subjects (Ryle, 1975). Essentially, then, such correlations allow an understanding of similarities (and dissimilarities) which exist between the elements, thereby providing insight into the nature of element interactions as perceived by subjects (Ibid).

In terms of this analysis, inter-element relationships are expressed in cosines[28] (Slater, 1976). These perform a similar function to correlation coefficients, with values ranging between +1 and -1. A cosine value of zero implies that no correlation exists (Ibid).

By way of example, Table 2 provides hypothetical cosine values for four elements; salt, sugar, butter and biltong.

Table 2

Hypothetical element correlations

| | Salt | Sugar | Butter | Biltong |
|---|---|---|---|---|
| Salt | 1 | -0.901 | 0.250 | 0.850 |
| Sugar | | 1 | -0.839 | -0.980 |
| Butter | | | 1 | 0.501 |
| Biltong | | | | 1 |

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[28] It should be emphasised that this is not confined to inter-element correlations. As shall become clear below, all correlational data obtained from the INGRID analysis is presented in the form of cosine values.

This table, though a crude example, allows an understanding of the use of cosine values to express relationships between elements. In this case, the interpretation of cosine values is no different to that of the product-moment correlation coefficient (Pearson *r*) where values also range between -1 and +1 (Miller, 1984). Thus, from the figures provided in the example table, it is apparent that there is a perfect relationship (1.0) between salt and salt, a strong negative relationship (-0.901) between salt and sugar, a very weak relationship between salt and butter (0.250), a strong positive relationship between salt and biltong (0.850), and so on. Basically, this indicates that the subject construes salt as almost entirely opposite to sugar, salt as only vaguely related to butter and salt as strongly similar to biltong. To reiterate, such data provides an idea of the nature of element relationships as <u>perceived</u> by subjects.

Thus, if subjects in the present study indicate a strong negative relationship between 'Self Now' and 'Ideal Self', (the 'Ideal Self' being the "representation of a person's aim or direction of desired movement" [Norris & Makhlouf-Norris, 1976: 80]) it is clear that they are dissatisfied with their present selves. Alternatively, if subjects are generally satisfied with their 'lot', a strong positive correlation between 'Self Now' and 'Ideal Self' can be expected.

The significance of the correlations between elements can be tested using a *t*-test. It should be reiterated that Slater (1976) counsels against the use of tests of significance for cosines. Indeed, he warns that the application of probability theory to grids is generally problematic. Therefore data concerning significance values should be read with Slater's objections in mind. In order to avoid this complication, Dawes & Donald (1987) utilised cosine values of greater or less than +0.50 and -0.50 to represent significant interactions. However, for the context of this study, the *t*-test is used to provide additional 'insurance' as all values exceed +0.50 or fall below -0.50 and the assignment of more stringent values could become somewhat arbitrary. In any event, Fransella & Bannister (1977: 9), themselves great authorities on the subject of repertory grid technology, contradict Slater when they note that the use of *t*-tests with the repertory grid is:

> ... technically feasible. (*The t-test is*) potentially rich in the light (*it*) may throw on the construing which underlies the person's grid responses.

Further to the *t*-test for correlations, the significance of <u>variations</u> between specific elements was tested using the protected *t*-test (Struckmann, 1991b). This test can be performed using construct values ascribed to the elements of interest. When the variation between elements is significant, it is demonstrated that subjects view those two elements as dissimilar, whereas an insignificant variation indicates a degree of similarity between two elements.

Table 3

Inter-element correlations

| | A | B | C | D | E | F | G | H | I |
|---|---|---|---|---|---|---|---|---|---|
| A | | -.774 | -.857 | -.723 | .801 | -.815 | .598 | .864 | -.882 |
| B | | | .979 | .995 | -.978 | .989 | -.953 | -.946 | .867 |
| C | | | | .961 | -.971 | .979 | -.885 | -.968 | .883 |
| D | | | | | -.975 | .982 | -.968 | -.923 | .849 |
| E | | | | | | -.985 | .943 | .903 | -.927 |
| F | | | | | | | -.936 | -.944 | .898 |
| G | | | | | | | | .812 | -.822 |
| H | | | | | | | | | -.824 |

Note. Refer to Table 1 for full element labels.

### 5.3.1 Self and Public Stereotype of ME Sufferers

An important question posed by this research was whether people with ME internalise their public stereotype. Such a question can be answered by examining the correlation coefficient between 'Self Now' (which basically refers to 'self with ME') and 'Public Stereotype of ME Sufferers'. A negative correlation would reveal that subjects construe themselves as divergent from what they perceive their public stereotype to be. In other words, this would mean that they do not identify with their public stereotype.

With reference to Table 3, it can be seen that there is a positive correlation (*cosine* = 0.801) between the elements 'Self Now' and 'Public Stereotype of ME Sufferers'. A *t*-test found this correlation to be significant ($t = 9.23$, $t\ crit = +/- 2.021$, $p < .05$, $df = 48$). In addition, a protected *t*-test was carried out to test for variation between the elements 'Self Now' and 'Public Stereotype of ME Sufferers'. This test revealed an insignificant variation of 2.043 between these two elements ($t\ crit = +/-2.201$, $p < .05$, $df = 11$). Thus, if the correlation between these two elements is significant and the variation is *insignificant*, it can be inferred that people with ME do identify with what they perceive as their public stereotype. This contradicts Fransella's (1977) proposition that people would be unlikely to identify with negative stereotypes. In addition, the result differs from Beail's (1985) findings which indicated significant variation between 'self' and 'stereotype' amongst a severely disabled population.

However, it may be necessary to examine the meaning attached to the 'stereotype' element. It should not be assumed that subjects necessarily construe their public stereotype as being negative. This can be checked by examining the correlation between 'stereotype' and an element with a more apparent negative connotation. Such an element is 'Disliked Person'. A strong positive relationship (*cosine* = 0.943) exists between 'Public Stereotype of ME Sufferers' and 'Disliked Person' (this correlation is actually even stronger than that between 'self' and 'stereotype'). On the basis of this relationship, it can be determined that subjects regard their public stereotype as being negative. Another indication that subjects perceive their stereotype in negative terms is the strong inverse correlation between 'Admired Person' and 'Public Stereotype' (*cosine* = -0.985).

In addition, further examination reveals that the correlation between the constructs, 'Disliked Person' and 'Self Now' is 0.598 which, though weaker than the relationship existing between the former two elements[29], is nevertheless a significant correlation ($p < .05$). This means that subjects attach a negative connotation to themselves with ME. Further adding to the impression that subjects construe themselves with ME in negative terms, is the extremely strong negative relationship between 'Self Now' and 'Admired Person' (*cosine* = -0.815). It could be argued that such a result suggests a <u>general</u> lack of admiration for the self amongst this population (in other words that <u>ME</u> has nothing to do with the lack of admiration for the present self). However, examination of the correlation between 'Admired Person' and 'Self before ME' is 0.898, which reveals a strong positive relationship between these two elements and suggests that admiration for the self has indeed declined since contracting ME.

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[29] This correlation, though significant, represents the weakest relationship between two elements.

### 5.3.2 Self and Diagnosis

Another major question of interest to this research was the effect of diagnosis upon the self-concept of ME sufferers. That is, would subjects construe their self-concept as having improved as a result of the legitimising action of diagnosis? Results indicate that this was not the case. In order to test for change in self-concept as a result of diagnosis, the correlation coefficients between the elements 'Self before ME' and 'Self before Diagnosis' were examined. This would indicate whether change in self-concept occurred after contracting ME, but before diagnosis. In other words: Did ME bring about a change in self-concept in the first place? After the establishment of this point, it is then possible to examine the correlation between 'Self Now' and 'Self before Diagnosis'; a negative correlation here would indicate that diagnosis had brought about a change in self-concept, whereas a positive correlation would indicate that no change had occurred.

While a strong negative correlation (*cosine* = -0.824) exists between 'Self before ME' and 'Self before Diagnosis', 'Self Now' is strongly correlated with 'Self before Diagnosis', (*cosine* = 0.864) suggesting that subjects perceive a similarity between themselves pre and post diagnosis. In other words, correlational data indicates that, while subjects regard themselves as having undergone a change since contracting ME, the strong correlation between 'Self Now' (which basically means, 'Self with ME') and 'Self before Diagnosis' suggests that little change occurred in self concept as a result of diagnosis.

In order to further test the conclusion suggested by the correlational data (that diagnosis does not improve self-concept), protected *t*-tests were carried out. These tests reveal a significant variation ($t$ = 4,2) between the elements 'Self Before ME' and 'Self Before ME Diagnosis' ($t$ *crit* = +/-2.201, $p < .05$, $df = 11$). In other words, once again, it is shown that subjects do perceive a change in themselves as a result of contracting ME. A further *t*-test showed a significant difference between 'Self Now' and 'Self before ME' ($t$ = 4,54, $t$ *crit* = +/-2.201, $p < .05$, $df$ = 11). This is useful in that a perceived change in self-concept between the self with ME and the self before the onset of ME is established. In addition, this variation can act as a 'yardstick' to determine whether the repertory grid is indeed measuring change. That is, if no change was indicated between the self <u>with</u> ME and the self <u>before</u> ME, then, to put it simply, something would be wrong. However *t*-tests carried out to determine significance of variation between 'Self Now' and 'Self before Diagnosis' reveal an insignificant variation ($t$ = 1.91, $t$ *crit* = +/-2.201, $p < .05$, $df = 11$). This, again, supports the correlational data in that subjects perceive no change in their self-concepts subsequent to their diagnosis.

### 5.3.3 Self and Ideal Self

In order to determine the discrepancy subjects perceive between themselves and their ideal selves, an additional *t*-test was carried out to determine the significance of the variation between 'Self Now' and 'Ideal Self' (*cosine* = -0.967, which constitutes an extremely strong inverse relationship). This revealed a significant variation ($t$ = 4.2, $p < .05$, *t crit* = +/-2.201). This is intriguing in so far as Ryle (1975) and Norris & Makhlouf-Norris (1976) have suggested that a large self/ideal self discrepancy is indicative of a high level of neurosis and affective disorder. However, as shall be discussed in Chapter 6 below, the attribution of neurosis to this population would be to make an erroneous generalisation. Simply put, people with ME have tangible reasons to be dissatisfied with their current selves.

### 5.4 Construct and Element Interactions

As outlined in Chapter 2 above, constructs consist of two poles. Because it is useful to determine which construct-pole applies to each element, an analysis of construct-element interactions is provided by the INGRID program. Such an analysis is necessary to determine the nature of the construction systems of subjects. In other words, the way in which subjects apply constructs to elements. Once again, results are presented in the form of cosines which constitute correlation coefficients, but this time the relationship is between a specific construct pole and each element. A negative cosine value simply indicates that subjects regard the left construct pole as most applicable to the element. Alternatively, a positive cosine value indicates that the right side of the construct pole is more applicable to the element (Slater, 1976).

The ensuing section highlights the nature of the interaction between key constructs and elements. The following elements will be accentuated as they are the most relevant to the research: 'Self Now', 'Ideal Self', 'Public Stereotype of ME Sufferers', 'Self Before ME' and 'Self Before ME Diagnosis'. Although a <u>full list</u> of interactions between elements and constructs is supplied in Table 4 below, for purposes of clarification, constructs/element interactions will be further highlighted for discussion by presenting each construct in relation to the accentuated elements in separate groups of four.

Table 4

Element/construct intercorrelations expressed as cosines

| Cons | Elements<br>A | B | C | D | E | F | G | H | I |
|---|---|---|---|---|---|---|---|---|---|
| 1 | .906 | -.967 | -.991 | -.944 | .968 | -.976 | .868 | .964 | -.927 |
| 2 | .790 | -.995 | -.977 | -.991 | .983 | -.991 | .951 | .947 | -.897 |
| 3 | .855 | -.985 | -.985 | -.973 | .978 | -.995 | .911 | .964 | -.913 |
| 4 | .917 | -.940 | -.969 | -.920 | .971 | -.963 | .849 | .925 | -.960 |
| 5 | .723 | -.935 | -.914 | -.940 | .982 | -.947 | .949 | .809 | -.919 |
| 6 | -.357 | .816 | .706 | .851 | -.821 | .793 | -.951 | -.594 | .683 |
| 7 | .786 | -.992 | -.970 | -.989 | .989 | -.986 | .958 | .927 | -.913 |
| 8 | .810 | -.992 | -.986 | -.983 | .964 | -.989 | .915 | .976 | -.858 |
| 9 | .758 | -.994 | -.971 | -.986 | .955 | -.984 | .942 | .950 | -.829 |
| 10 | -.396 | .830 | .782 | .848 | -.742 | -.780 | -.798 | -.774 | .451 |
| 11 | .767 | -.991 | -.965 | -.989 | .984 | -.988 | .968 | .922 | -.903 |
| 12 | .769 | -.987 | -.972 | -.986 | .996 | -.983 | .959 | .905 | -.901 |

Table 5

Highlighted element and construct intercorrelations (I)

| | Constructs | | | |
|---|---|---|---|---|
| Elements | 1 | 2 | 3 | 4 |
| A (Self Now) | 0.906 | 0.790 | 0.855 | 0.917 |
| B (Ideal Self) | -0.967 | -0.995 | -0.985 | -0.940 |
| E (Stereotype) | 0.968 | 0.983 | 0.978 | 0.971 |
| I (Self Before ME) | -0.927 | -0.897 | -0.913 | -0.960 |
| H (Self Before Diag) | 0.964 | 0.947 | 0.964 | 0.925 |

Table 5 indicates that the construct poles attributed by subjects to the various elements can be outlined as follows[30]:

**Self Now** = Weak; Lacks Control; Indecisive; Inactive

**Ideal Self** = Strong; In Control; Decisive; Busy

**Stereotype** = Weak; Lacks Control; Indecisive; Inactive

**Self Before ME** = Strong; In Control; Decisive; Busy

**Self Before Diagnosis** = Weak; Lacks Control; Indecisive; Inactive

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[30] As most values are relatively similar, a separate demonstration of proximity of elements along the dimension of the various constructs is unnecessary for this section. Such information can be obtained by examination of the composite diagram in Figure 2 below.

Thus, for example, in the case of the construct 'Weak/Strong', subjects felt that the pole 'Weak' was more applicable to the element 'Self Now', whereas 'Strong' was more applicable to 'Ideal Self'.

Notable from the above, is that there is once again an indication that subjects perceive a relationship between their current selves and the public stereotype of ME. That is, exactly the same combination of construct-poles are attributed to the elements 'Self Now' and 'Public Stereotype of ME Sufferers'. Additionally, the 'Ideal Self' is construed similarly to 'Self before ME' which, again, reflects a tendency on the part of subjects to construe their ideal selves in the same way they perceive themselves prior to contracting ME. In other words, they idealise the way they were before contracting ME. Subjects also construe their present selves as lacking control which seems to reflect that subjects feel they have lost control of their lives to ME. This impression is further strengthened by noting that subjects regard themselves as having been 'In Control' prior to contracting ME. That both 'Lacks Control' and 'Weak' are attributed to the same elements further demonstrates that subjects regard the state of no longer being 'In Control' (after contracting ME) as a weakness. In effect, subjects seem to imply that, if they had been stronger, they would not have succumbed to ME. Finally, as 'Self Now' and 'Self before Diagnosis' share exactly the same construct poles (this occurs throughout the

Element/Construct interaction analysis), it is, once again evident that subjects do not perceive change as having occurred since obtaining their ME diagnosis.

Table 6

Highlighted element/construct intercorrelations (II)

| | Constructs | | | |
|---|---|---|---|---|
| Elements | 5 | 6 | 7 | 8 |
| A (Self Now) | 0.723 | -0.357 | 0.786 | 0.810 |
| B (Ideal Self) | -0.935 | 0.816 | -0.992 | -0.992 |
| E (Stereotype) | 0.982 | -0.821 | 0.989 | 0.964 |
| I (Self Before ME) | -0.919 | 0.683 | -0.913 | -0.858 |
| H (Self Before Diag) | 0.809 | -0.594 | 0.927 | 0.976 |

**Self Now** = Malingerer; Selfish; Inefficient; Insecure

**Ideal Self** = Hard Working; Appreciative; Efficient; Secure

**Stereotype** = Malingerer; Selfish; Inefficient; Insecure

**Self Before ME** = Hard Working; Appreciative; Inefficient; Secure

**Self Before Diagnosis** = Hard Working; Selfish; Inefficient; Insecure

The relatively low correlation between 'Self Now' and the construct 'Selfish/Appreciative' (-0.357) is notable. While this indicates that subjects see themselves as *relatively* selfish, there seems to be a hesitancy on their part to completely commit themselves to this construct-pole. While there is a lower degree of identification with this construct-pole, subjects do define themselves along the *dimension* of 'Selfish/Appreciative'. This is established by the relatively strong cosine value (0.816) assigned to the 'appreciative' pole of the construct in relation to the element 'Ideal Self'. The relationship between the 'Public Stereotype of ME Sufferers' and this construct was strongly directed towards the 'selfish' pole (-0.821). This, again, implies that subjects perceive the public stereotype of themselves as a negative one.

Once again, the similarity between construct-poles attributed to the elements 'Self Now', 'Public Stereotype' and 'Self before Diagnosis' should be noted. Subjects perceive little change as having occurred as a result of their diagnosis, and similarity between themselves and what they perceive as the public stereotype of ME sufferers remains evident.

Table 7

Highlighted element/construct intercorrelations (III)

| | Constructs | | | |
|---|---|---|---|---|
| Elements | 9 | 10 | 11 | 12 |
| A (Self Now) | 0.758 | -0.396 | 0.767 | 0.769 |
| B (Ideal Self) | -0.994 | 0.830 | -0.991 | -0.987 |
| E (Stereotype) | 0.955 | -0.742 | 0.984 | 0.996 |
| I (Self Before ME) | -0.829 | 0.451 | -0.903 | -0.901 |
| H (Self Before Diag) | 0.950 | -0.775 | 0.922 | 0.905 |

**Self Now** = Unattractive, Abuses Self, Loser, Dependent

**Ideal Self** = Attractive, Cares for Self, Achiever, Independent

**Stereotype** = Unattractive, Abuses Self, Loser, Dependent

**Self Before ME** = Attractive, Cares for Self, Achiever, Independent

**Self Before Diagnosis** = Unattractive, Abuses Self, Loser, Dependent

From the above it is evident that, while there is a relationship between the element 'Self Now' and 'Abuses Self' (-0.396), this is minimal. A weak relationship also exits between the elements 'Self Before ME' and 'Cares for Self' (*cosine* = 0.451). Again, these minimal correlations do not necessarily indicate lower identification with this construct, as fairly strong relationships with other elements along the *dimensions* of this construct are evident; notably 'Ideal Self' where the correlation (0.830) is directed towards the 'Cares for Self' pole of the construct.

Apparent, also, is the change subjects perceive between themselves before diagnosis and themselves post-diagnosis. That is, the correlation with the 'Abuses Self/Cares for Self' construct increases from -0.775 to 0.396, indicating, perhaps, that subjects have taken more care of themselves since receiving diagnosis, but still not a level of self-care they would consider adequate. If the propensity of subjects towards valuing strength and self-control is taken into account (see section on 'Construct Salience' below), it could be ventured that subjects would view <u>any</u> care taken of themselves as inadequate. This is especially true when it is noted that, as shall be indicated in the section entitled 'Inter-construct Correlation' below, the construct-pole 'Cares for Self' is subordinate (that is related) to the construct-poles 'Weak' and 'Lacks Control'.

Again, there is a similarity between construct-poles attributed to the elements 'Self Now', 'Public Stereotype' and 'Self before Diagnosis'. That is, subjects perceive little change as having occurred as a result of their diagnosis. There is, once again, a similarity between their current constructions of themselves and what they perceive their public stereotype to be.

### 5.4.1 Cosine Values

Finally, it should be noted that the strength of the cosine values obtained in this study (whether positive or negative) are impressive. The closer the cosine value to -1 or +1, the greater subject identification with, and comprehension of, supplied verbal construct labels can be assumed to be (Adams-Webber, 1970). That only four element/construct correlations fell below +0.7 and above -0.7 establishes the validity of the constructs obtained from subjects in relation to the (non-elicited) elements. In other words, subjects perceived constructs as relevant to the elements. (The problem of validity of constructs and elements is discussed in the section entitled 'Validity of the Grid Method' in Chapter 2 above.)

### 5.5 Principal Component Analysis

The Principle Components Analysis (PCA), performed by the INGRID computer program, provides coordinates which plot a 'map' of element/construct distances (Slater, 1976). Ryle (1974: 34) has indicated that the psychological interest of the PCA is that:

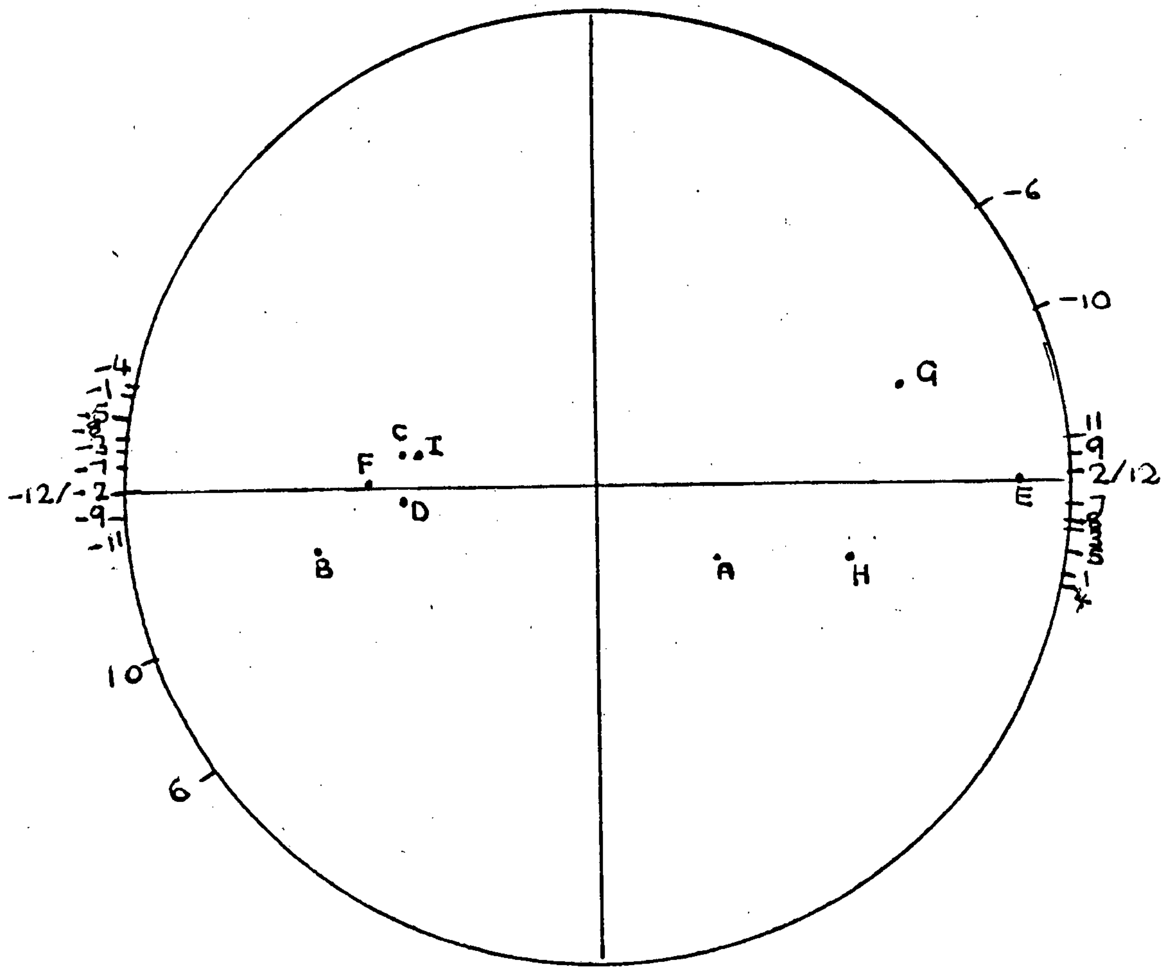
> (B)y identifying the systematic connections between elements and constructs in the grid, (the Principle Components Analysis) reveals how a large number of individual judgements made by the subjects in rating all the elements on all the

> constructs are manifestations of a relatively more simple underlying structure, and *it shows which elements in terms of which constructs are of major importance in the subject's system*" (Ryle, 1974). (emphasis added.)

The PCA, as its name suggests, identifies those components, or factors, which are responsible for the most amount of variation in a person's construct system. Only the two most prominent components are represented on the composite diagram (see Figure 2), as the third component usually comprises only minimal variation (Ibid; Slater, 1976).

<u>Key</u>

- = emergent pole
+ = implicit pole
Elements are portrayed as letters.
Construct loadings are located on the periphery of the diagram



<u>Figure 2</u>. Composite diagram for components 1 and 2.

As pointed out above, the composite diagram should be read as a map of subjects' construct systems in relation to the elements utilised in this study. To assist in reading this 'map', the following explanation is provided:

In the composite diagram, elements are presented as points marked by letters of the alphabet (A-I). The constructs are portrayed as axes projected on the surface of the diagram, while the construct loadings are listed at the periphery and are represented by the numbers 1-12. The constructs are placed on the periphery to reduce clutter within the diagram and to clearly distinguish constructs from elements (Slater, 1976). The peripheral positioning of each construct is obtained by means of a straight line which, if drawn from the centre of the diagram towards the periphery, would intersect at the construct co-ordinate loadings calculated by the INGRID program.

The horizontal axis should be viewed as representing Component 1, and the vertical axis as representing Component 2. In this case, Component 1 relates to all constructs except 'Selfish/Appreciative' and 'Abuses Self Cares for Self' (1 and 6). That the latter constructs do not relate to Component 1 can be determined by the relative isolation of these constructs from other constructs. Element E ('Public Stereotype of ME Sufferers') accounts for a great deal of Component 1 and, as can be seen, lies almost exactly on the component axis.

Component 1 accounts for a remarkable 93.84% of the variation in the PCA, while Component 2 only accounts for 3.67% of the variation. Such a contrast in variation levels is rare, with Component 1 usually accounting for between 30 and 50%, and the second component accounting for between 10 and 25% (Ryle, 1974). The high level of variability accounted for by Component 1 can, to a large degree, be attributed to the element 'Public Stereotype of ME Sufferers', which lies almost directly on the axis of Component 1. This shows that subjects are particularly concerned with their stereotype.

Element/construct distance can be determined by examining the proximity of the peripheral construct marking to the respective elements. A negative marking on the construct coordinate indicates the emergent (left) pole, whereas a positive marking indicates the implicit (right) pole. Thus, to determine which pole applies to which element, the pole closest to the specific element should be taken as applicable to that element. Simply, it is distance and proximity which determines relationship. Thus, when elements cluster together with elements, and constructs with constructs - the tighter the cluster, the more subjects regard these factors as similar, whereas the further apart, the more dissimilar subjects regard them to be.

As can be seen with reference to Figure 2, there is a remarkable lack of element dispersion (that is, elements tend to cluster together), especially amongst the elements 'Ideal Self', 'Healthy Person', 'Future Self', 'Admired Person' and 'Self before ME'. This is extraordinary in that a greater degree of dispersion is usually noted in a PCA (Ryle, 1974). This lack of dispersion could be ascribed to the strong interrelationship between constructs and elements which is described in the previous section above. What is particularly evident from the composite diagram is the clear dichotomy between 'Ideal Self', 'Healthy Person', 'Future Self', 'Admired Person' and 'Self before ME' on the one hand, and the elements 'Self Now', 'Public Stereotype of ME Sufferers', 'Disliked Person' and 'Self before ME Diagnosis' on the other. Quite simply, the former cluster could be referred to as the 'Ideal Self' cluster (that is, it refers to how subjects would prefer to be) while the latter cluster could be referred to as the 'Self with ME' cluster. The division between these two clusters is indicative of the *de facto* separation subjects perceive between their ideal selves and their selves with ME. In other words, they are dissatisfied with their 'lot'.

Element E (Public Stereotype of ME Sufferers) lies only fractionally above the axis of component 1 and also constitutes the most isolated element. This, besides illustrating the salience for sufferers of what they perceive as the public stereotype of people with ME, indicates the influence of the element in the huge amount of variation (93.84%) accounted for by this component (see discussion on element salience below).

As with the elements, the degree to which the <u>constructs</u> cluster together is distinctive. This is indicative of the strength of the relationship between constructs as perceived by subjects (see section on 'Inter-Construct Correlations' below). The <u>relative</u> isolation of the constructs 'Selfish/Appreciative' and 'Abuses Self/Cares for Self' is consistent with the lower element/construct interaction correlations commented upon above. Interesting, too, is the almost exact proximity shared by the constructs 'In Control/Lacks Control' and 'Independent/Dependent'. That subjects construe these constructs similarly is revealing. ME sufferers become dependent on others as a result of their illness and it is apparent that subjects regard dependence on others as equivalent to losing control of their lives. (Again, see the section on 'Inter-Element Correlations' below, where relationships between constructs shall be outlined).

From Figure 2 it can be ascertained that element/construct-pole interactions are similar to those described in the section on element-construct correlations above. Therefore, further discussion would be redundant. However, it should be reiterated that these interactions can be determined by examining the proximity of the construct-axis marking on the periphery of the diagram to the respective elements. In this case, this is fairly straightforward, with constructs being dichotomised in two dimensions which are clearly divergent in relation to the elements to which they are most applicable.

## 5.6 Construct Salience

Table 8 outlines variation attributed to specific constructs. The higher the percentage of variation recorded around a construct mean, the greater the degree of importance subjects attach to that construct.

Table 8

Variation about construct means

| Construct | Variation (as %) |
|---|---|
| 1 | 12.04% |
| 2 | 11.26% |
| 3 | 8.29% |
| 4 | 10.55% |
| 5 | 9.04% |
| 6 | 6.64% |
| 7 | 9.09% |
| 8 | 10.70% |
| 9 | 4.35% |
| 10 | 2.70% |
| 11 | 6.60% |
| 12 | 8.73% |

In this case, subjects attributed the greatest degree of salience to the construct 'Strong/Weak' (12.04%). Other constructs with a large percentage of variation are 'In Control/Lacks Control' (11.26%), 'Busy/Inactive' (10.55%) and 'Secure/Insecure' (10.70%). Constructs with minimal salience are 'Attractive/Unattractive' (4.35%) and 'Abuses Self/Cares for Self' (2.7%).

Thus, subjects prefer to define themselves along the dimensions of strength and weakness, control and lack of control, busyness and inactivity and security and insecurity. While it would be dangerous to ascribe these results to personality characteristics peculiar to ME, it is apparent that subjects attach a great deal of importance to the characteristics of strength and control. Although subjects do not attach much importance to being attractive or unattractive; or to whether they abuse or care for themselves, it should not be assumed that they view these constructs as <u>irrelevant</u>, but rather that other constructs are <u>more</u> important.

## 5.7 <u>Element Salience</u>

As with measures of construct salience, the greater the degree of variation caused by an element, the greater the salience attributed that element by subjects. From Table 9 it can be inferred that subjects attribute by far the greatest degree of salience to the construct 'Public Stereotype of ME Sufferers' (28.71%). This surprising finding, serves, once again, to demonstrate the centrality of their public stereotype for ME sufferers. To put it crudely, sufferers are very concerned about what others think of them.

Table 9

Element variations

| Element | As Percentage |
|---|---|
| A | 3.08% |
| B | 12.83% |
| C | 6.59% |
| D | 6.34% |
| E | 28.71% |
| F | 8.43% |
| G | 16.68% |
| H | 11.11% |
| I | 6.25% |

Interestingly, the second highest degree of salience was attributed to the element 'Disliked Person' (16.68%), followed by 'Ideal Self' (12.83%) and 'Self before ME Diagnosis' (11.11%). The least amount of salience is attributed to 'Self Now' (3.08%). The amount of salience which is attributed 'Disliked Person' could perhaps be explained as the *salience of the comparison* between the disliked person and themselves. That is, subjects do not necessarily regard the disliked person as important, but are concerned that they have come to share characteristics of the disliked person as a result of contracting ME.

Subjects attach little salience to themselves now, but a great deal to themselves before diagnosis, as well as their 'ideal' selves. Perhaps this suggests that subjects see themselves in a state of 'stagnation' - caught between the pre-diagnosis stage (when their illness was a mystery and they were concerned with obtaining a diagnosis) and recovery. Basically, subjects want little to do with their current 'illness selves'.

## 5.8 Inter-Construct Correlations

Correlations between constructs are indicative of what Kelly (1962) meant when he suggested that constructs are hierarchically structured. That is, through examination of inter-construct correlations, the interconnectedness of subjects' construct-systems is made explicit. A positive correlation indicates an exact relationship between constructs. Where there is a negative cosine value, the relationship is inverse. Thus, with reference to Table 10 below, an almost perfect relationship can be determined between constructs 7 and 2 ('In Control/Lacks Control' and Efficient/Inefficient'). This relationship (which is hierarchical) can be graphically represented with vertical bars linking related construct-poles. Thus, when a construct-pole appears beneath another construct-pole, it can be inferred that the latter construct-pole is subordinate to the former.

In Control    Lacks Control
|    |
Efficient    Inefficient

Here, subjects view the construct-pole 'In Control' as superordinate to the construct-pole 'Efficient', whereas they view 'Lacks Control' as synonymous with inefficiency.

As another example, the negative (inverse) relationship between constructs 5 and 6 (Hard Working/Malingerer and Selfish/Appreciative) can be represented as follows:

Hard Working    Malingerer
|    |
Appreciative    Selfish

Thus, subjects view a person who is 'Hard Working' as 'Appreciative', whereas a 'Malingerer' is seen as being selfish.

Table 10

Inter-Construct Correlations

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | | .97 | .99 | .99 | .91 | -.68 | .97 | .97 | .95 | -.70 | .96 | .96 |
| 2 | | | .99 | .95 | .94 | -.81 | .1 | .99 | .98 | -.79 | .1 | .99 |
| 3 | | | | .97 | .93 | -.75 | .98 | .99 | .98 | -.75 | .98 | .97 |
| 4 | | | | | .93 | -.68 | .95 | .95 | .91 | .63 | .94 | .95 |
| 5 | | | | | | -87 | .96 | .90 | .90 | -.68 | .96 | .98 |
| 6 | | | | | | | -.83 | -.75 | -.80 | .71 | -.85 | -.84 |
| 7 | | | | | | | | .98 | .97 | -.77 | .1 | .99 |
| 8 | | | | | | | | | .99 | -.83 | .98 | .97 |
| 9 | | | | | | | | | | -.85 | .98 | .97 |
| 10 | | | | | | | | | | | -.78 | -.78 |
| 11 | | | | | | | | | | | | .99 |

Note. Figures rounded off.

What is especially apparent from Table 10 is the strength of correlation scores between constructs, whether positive or negative. None of the scores fall above the -0.50 or below the +0.50 points (suggested by Dawes and Donald [1987] as cut-off points for the determination of those correlations which constitute meaningful interactions).

The following diagram (Figure 3) details the interaction between all constructs and 'Strong/Weak' (which was designated by subjects as the most salient). To reiterate, vertical bars indicate that there is a relationship between construct-poles. Relationships above +.90 or below -.90 are marked with a star (*).

| Strong | Weak |
|---|---|
| In Control | Lack Control* |
| Decisive | Indecisive* |
| Busy | Inactive* |
| Hard Working | Malingerer* |
| Appreciative | Selfish |
| Efficient | Inefficient* |
| Secure | Insecure* |
| Attractive | Unattractive* |
| Cares for Self | Abuses Self |
| Achiever | Loser |
| Independent | Dependent |

_Figure 3_. Construct interactions with the construct 'strong/weak'.

Figure 3 outlines the hierarchical structure of subjects' construction systems[31]. Thus, for subjects, the word 'strong' has the subordinate implications of, for example, achievement and independence. On the other hand, the label 'weak' could, for example, tacitly imply inactivity or insecurity. A definite pattern of 'good versus bad' is evident which suggests that subjects are fairly self-critical. It is noteworthy that 'In Control' is subordinate to the construct pole 'Strong'. As suggested above, subjects seem to regard themselves as having lost control of their lives to ME, and this is construed as a sign of weakness.

## 5.9 Chapter Summary

The following constitute the main findings of this study:

(1) Though Fransella (1977) and Beail (1985) have suggested that people will not internalise negative stereotypes of themselves, it appears that people with ME do indeed construe themselves similarly to what they perceive as the public stereotype of themselves. It was also established that subjects perceive their public stereotype as being negative.

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[31] Though the verbal labels attached to supplied constructs are not necessarily those of subjects, the high inter-construct correlation rate found in this study indicates an unusual and gratifying subject identification with supplied construct labels. See discussion on Validity of the repertory grid method in Chapter 2 above.

(2) It had been expected that ME sufferers would perceive an improvement in their self-concepts after being diagnosed with ME, as diagnosis can be said to perform an important social and personal legitimising function. However, this study indicates that, while subjects perceive a change as having occurred in their self-concepts <u>since</u> contracting ME, they perceive no significant change as having occurred to their self-concepts as a consequence of having being <u>diagnosed</u> with ME.

(3) Subjects attribute the greatest degree of salience to the element 'Public Stereotype of ME Sufferers'. Indeed this element contributes to the extraordinary amount of variation represented by Component 1 in the Principle Components Analysis. From the high salience attributed to this element, it can be understood that subjects are exceptionally concerned with the way they are perceived by other people.

(4) Subjects attribute the greatest degree of salience to the construct 'Strong/Weak'. In other words, for subjects, the dimension of strength and weakness is very meaningful in terms of their outlook on life. This could be linked to ME in the sense that subjects appear to view their illness as a weakness. This implies that subjects feel that, had they been stronger, they could have resisted ME.

(5) A finding, which acts to illustrate and further confirm the findings outlined in points 1 and 2 above, is the clear dichotomy subjects perceive between the elements 'Ideal Self', 'Healthy Person', 'Future Self', 'Admired Person' and 'Self Before ME' on the one hand, and 'Self Now', 'Public Stereotype of ME Sufferers', 'Disliked Person' and 'Self before ME Diagnosis' on the other. Such '<u>clear-cut</u>' dichotomy is rarely indicated by the Principle Components Analysis. Also unusual was the high level of variation accounted for by Component 1 (93.84%). Component 1 usually accounts for between 30 and 50% of the variation (Ryle, 1974). This high degree of variation can largely be attributed to subject concern with their 'public stereotype'.

These findings shall be discussed in more depth in Chapter 6 below.

# CHAPTER 6

## DISCUSSION

### 6.1 Introduction

In this chapter, the results outlined in Chapter 5 shall be discussed in terms of their implications for the questions guiding this research (see Chapter 2). Results shall be placed in the context of relevant theory as well as previous findings in the area of chronic illness, ME and repertory grid technology.

In addition, problems with the research method, as well as possible implications of the research are outlined and discussed. Finally, suggestions are made for future research.

### 6.2 Public Stereotype

It had been expected that ME sufferers would reject what they perceived to be society's stereotype of themselves. Instead, the results indicate that, paradoxically, they define themselves in the same terms as their stereotype (which they also regard as being a negative one). This surprising finding contradicts both Fransella's (1977) presumption that people will not identify with a stereotype if it is perceived as evaluatively bad and Beail's (1985) findings that disabled people reject what they perceive to be their stereotype.

It is difficult to explain the surprising finding that ME sufferers identify with their stereotype However, perhaps Henry Tajfel's Social Identity Theory (SIT) could be utilised as an explanatory tool.

Though ME sufferers would probably not identify themselves as a separate social group, they do retain important elements of group membership, notably their unavoidable differentiation into a specific social category (Tajfel & Turner, 1979) - namely that of sufferers of a specific chronic illness. According to SIT, people strive for positive self concepts, which, to a large extent, are determined by their comparative evaluation of the social category to which they perceive themselves as belonging (Ibid). Now, if subjects are identifying with the public stereotype of ME sufferers, and this stereotype <u>is</u> perceived to be a negative one, then what mechanism could be said to be operating?

According to SIT, when an 'ingroup' is perceived negatively in relation to a <u>relevant</u> 'outgroup', members may attempt to leave their existing group to join the group they perceive as being more positively 'distinct' from their own. (Tajfel & Turner, 1979). For people with ME, however, this option is unavailable. That is, until they recover, they are forced to remain within their 'group'. This is what could be reflected in sufferers' 'identification' with their stereotype - a negative self-concept engendered by a negative in and outgroup comparison, from which they are unable to escape. Sufferers <u>perceive</u> the negativity of their categorisation and tacitly accept the reasons for this[32], but are unable to escape the ME 'group'. It is intriguing, with regard to this point, that Tajfel & Turner (Ibid) have, in addition, suggested that, where people are unable to escape a negatively differentiated group, they attempt to imbue their group with more positive characteristics. Hence attempts by ME sufferers to make their 'group' attributes more positive; for example the formation of supportive, advocative ME associations and the emphasis placed by sufferers upon possible physiological (especially viral) aetiologies for the illness (Wessely, 1990).

## 6.3 Change

An important aim of this study was the measurement of change which had (or had not) occurred to sufferers' self-concepts as a function of contracting ME, and again, after being diagnosed as suffering from ME.

Results indicate that subjects <u>perceive</u> significant change as having occurred to their self-concepts since contracting

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[32] See, for example, Chapter 4 where it was pointed out that sufferers seem to accept that they caused their illness though pushing themselves too hard.

ME. That is, a significant variation was recorded between 'Self Now' and 'Self before ME'. However, subjects perceive no further, significant, change between contracting ME and obtaining their diagnosis, as is demonstrated by the insignificant variation, and inverse correlation, between 'Self Now' and 'Self before Diagnosis'.

The difficulty in asking subjects to provide measures of changes which have occurred within themselves is that such data is retrospective and therefore subject to bias (Kerlinger, 1986). However, as discussed in Chapter 3, Personal Construct Theory explains distortions in memory over time as caused by changes in interpretation and understanding of an event. In addition, certain aspects lose their salience and disappear from the system. Essentially, memory is interlinked with perception in the sense that the way we construe events according to our current construct systems is how we remember them (Bannister & Mair, 1968). In short, Personal Construct Theory not only accounts for retrospective data, but points out that, just as people are continually construing their world, so what they remember is also constructed. Thus, if the repertory grid is intended to measure people's constructions, then constructions of past events are as relevant as constructions of the present.

Personal Construct Theory further theorises personal change as coming about as a result of variation in experience. The theory explains, in the 'Modulation Corollary', that people's capacity for healthy change depends on the permeability of their constructs (Kelly, 1962). Simply put, in the course of change, people should be able to incorporate new elements into their construct systems. It should be added, on the other hand, that Button (1985) has warned that a construct system which is too subject to change is in danger of being easily disturbed.

While this research was not specifically interested in assessing the permeability of subjects' construction systems as such, an examination of the results reveals that change occurred in terms of construct-poles specified to the various elements, specifically, in this case, in the constructions accorded the elements 'Self Now' and 'Self before ME'. For example, while the self before ME was construed as strong, in control, decisive and busy, the current self was perceived as weak, lacking in control, indecisive and inactive (See Tables 4 - 7). While this change could be regarded as 'negative' and does not necessarily reveal anything about underlying psychological processes such as the degree to which 'Threat' and

'Anxiety'[33] are experienced by subjects, it can be observed that radical change has occurred in terms of the way subjects construe events. In addition, such change serves to illustrate what Bannister & Mair's (1968) meant when they emphasised that people are subject to constant flux - hence the utility of Personal Construct Theory in this context. That is, the theory regards people as non-static and changing in accordance with their varying observations of the world (Kelly, 1962).

## 6.4 Salience of Elements

Subjects attributed the greatest degree of salience to the public stereotype element. In other words, subjects were the most concerned about the manner in which they are perceived by others. Perhaps the explanation for this lies in the observation that diagnosis did not seem to improve subjects' self-concepts. This could indicate that, contrary to a basic assumption guiding this research, medical opinion, on its own, does not necessarily provide legitimation. Rather, it is public perception of ME and people with ME which is considered important. In other words, it is public acceptance of ME which has the legitimising effect, not the diagnosis. Medical diagnosis merely acts to facilitate the process of public acceptance. In any event, because the illness is so controversial, an ME

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[33] 'Threat' is defined in Personal Construct Theory as imminent, comprehensive change to the construct system and 'Anxiety' as the fear that one's construct system cannot deal with changing events (Bannister & Fransella, 1986).

diagnosis does not carry the weight that, say, a diagnosis of measles, or even, multiple sclerosis, would have. That is, other doctors and lay-people might regard an ME diagnosis as a 'quirk' of a particular doctor, or a term attributed to a host of symptoms to which a doctor cannot assign a definite diagnosis; or even a label attached to satisfy a hypochondriacal patient (Wallace 1991). In addition, and importantly for this point, as outlined in Chapter 1, ME sufferers have largely come to regard the medical profession with a degree of suspicion. Thus, the low salience accorded the act of diagnosis could be the result of negative encounters with medical scepticism. That is, because many were disbelieved, or diagnosed as suffering from psychological illness before obtaining the ME diagnosis, subjects may have come, perhaps as a defense mechanism, to the conclusion that diagnosis is not ultimately important. Besides, from a practical point of view, diagnosis, on its own, has no real therapeutic value, it merely acts to categorise a series of symptoms (Herzlich & Graham, 1973).

Notable, too, is that subjects attribute greater salience to the elements 'Ideal Self' and 'Self before Diagnosis' than they do to 'Self Now'. As mentioned above, this is possibly related to subjects feeling 'trapped' in the illness state. That is, between contracting the illness and getting well. Subsequent to contracting ME, sufferers were concerned with obtaining diagnosis, but now, post-diagnosis, they are concerned mainly with recovery. The illness itself is only something to be endured until the time of recovery.

A surprisingly high salience is attributed to the element 'Disliked Person' (the second highest level of salience). This could perhaps be explained in terms of the importance of the disliked person as a figure of <u>comparison</u>. For example, in Chapter 4, it was pointed out that some pre-test subjects indicated that they had, since contracting ME, acquired characteristics which they had previously despised in other people. A good example would be this statement made by Mandy:

> I don't want to go out because I feel I don't want people to see a fat, ugly person. I look like the kind of person I used to despise, fat, ugly with dirty hair.

To put it another way, the 'Disliked Person', though once a figure which could be <u>contrasted</u> with the Self (and therefore beyond the sphere of the Self), has become alarmingly similar to the Self since the subject contracted ME.

## 6.5 <u>Construct Salience</u>

All constructs considered by subjects to be highly salient appeared to embody the characteristics of the construct 'Strong/Weak'. For example, the following highly salient constructs have qualities of strength and weakness inherent in them: 'In Control/Lacks Control', 'Busy/Inactive' and

'Secure/Insecure'. These contrast with the least salient constructs, that is 'Abuses Self/Cares for Self' and 'Attractive/Unattractive' which seem unrelated to concepts of strength and weakness.

It should also be reiterated that when constructs are attributed a low degree of salience, this does not imply that subjects regard them as unimportant, but rather that other constructs are <u>more</u> important. Thus, for example, while many subjects might regard themselves as having become unattractive as a result of the ravages of ME, they would be more concerned with having lost control of their lives. Indeed, with regard to 'Abuses Self/Cares for Self', although a low saliency rating was attributed to this construct, it is evident that subjects do indeed perceive themselves to be taking <u>more</u> care since contracting ME, albeit not as much as they would like to. It was further shown that subjects regard lack of self-care similarly to weakness and lack of control. Thus, taking note of evidence that subjects attach a great deal of salience to 'Strong/Weak' and 'In Control/Lacks Control', and the relationship indicated by subjects between lack of self-care and the right pole of both these constructs, it is apparent that lack of self-care is regarded as a weakness, as well as being symptomatic of lack of control and, thus, symbiotic with what subjects perceive to have caused their illness in the first place.

To sum up the point: Even non-salient constructs have relevancy for subjects and should not be ignored.

## 6.6 Lack of Care

With reference to the construct 'Abuses Self/Cares for Self', being correlated with 'Strong/Weak', attention is once again drawn to a comment made in Chapter 4 where it was suggested that subjects tacitly accept that it was their temperament and hard-working lifestyle (lack of care) which caused their ME. As illustrative statements, consider the following:

> I was a typical subject for it - I was very active, I was always in the fastest lane and I wasn't happy unless I was filling every minute with mind things or body things. That was the way I liked it. I like working. I like to be busy. So I was on the run, I had a very demanding job. So I was really on the hop. I think that mentally and emotionally I worked on the same sort of fast track. I didn't like wasting time. It was almost like running past myself. (Gladys.)
>
> Maybe that's one of my downfalls. I haven't allowed ME to be disruptive at all. Maybe it's my drive to do things that made things worse for me. I had to accept that I've got this ME ... I pamper myself more - it's something I've got to live with and accept. (Mary.)
>
> I come from an English working-class background where you're very conditioned to carry on when you're ill. (Julie.)

Apparent from the above quotes is the sense that subjects regard themselves as not having taken enough care of themselves prior to contracting ME. Subsequently they have come to realise that, in order to get better, they must take better care of themselves. The main point is that subjects imply that, though they may have once viewed 'pushing' themselves as a sign of strength, they have now come to view such behaviour as weakness.

## 6.7 Principle Components Analysis

The results obtained from the Principle Components Analysis are illustrated in Figure 2. As commented above it is extraordinary to note the degree to which elements and constructs cluster together, with very few elements or constructs being markedly isolated. (Though, as pointed out in Chapter 5, the element 'Public Stereotype of ME sufferers' lies on the axis designating Component 1 and is also the most outlying element. These factors underscore the salience of this element for subjects.) Essentially elements, and their corresponding constructs, can be divided into two distinct spheres: That of 'Ideal Self' and that of 'Self Now'. It can be shown, with reference to the positive relationship recorded between 'Self Now' and 'negative' elements such as 'Disliked Person', that subjects regard 'Self Now' as undesirable. The 'Self Now' cluster, is <u>relatively</u> dispersed in comparison to the 'Ideal Self' cluster. This could indicate <u>slightly</u> less agreement on the part of subjects as to the interrelations of 'undesirable' elements. Interesting, as well, is that the 'Ideal Self' element is <u>fairly</u> isolated from the other elements in the 'Self Now' cluster. Again, this might represent a <u>slight</u> reluctance amongst subjects to fully associate their ideal selves with other elements in the cluster, most likely for definitional, rather than evaluative reasons. Worth noting, too, is that, without fail, subjects seem to attribute 'desirable' construct poles to 'desirable' elements, and undesirable construct poles to undesirable elements. For example, the construct poles 'Strong', 'In control', 'Secure', and so on are situated in proximity to the 'Ideal Self' cluster of elements, while 'Weak', 'Lacks Control' and 'Insecure' are situated near the 'Self Now' cluster.

The obvious isolation between what has been termed the 'Ideal Self' cluster and the 'Self Now' cluster is interesting from a psychodiagnostic point of view - particularly in the light of the debate concerning the rate and origin of psychological disturbance amongst ME sufferers (see Chapter 1 above). Essentially, it must be pointed out that large gaps, such as that which exists between actual and ideal self in this Principle Components Analysis are indicative of psychopathology. Notably, anxiety and obsessional neurosis as well as depression (Ryle, 1975; Norris & Makhlouf-Norris, 1976). These particular psychopathologies have been reported in ME populations (see Chapter 1, or, David 1991).

However, no definite conclusions regarding the presence of psychopathology shall be claimed to arise from this study as the methodology was not designed to test hypotheses concerning psychopathological epidemiology and origins (for example, the inclusion of relevant control groups). However, it should be commented that, even with sound evidence as to the prevalence of psychopathology in this population, the medical evidence reviewed in Chapter 1, though currently inconclusive, nevertheless provides ample data concerning the prevalence of various viral, physical, neurological and myalgic disorders in ME populations to warrant the conclusion that the disorder is unlikely to be primarily psychological in origin. At the very least, psychopathology could be said to be a function of the unique trauma of experiencing an illness such as ME. Basically, it would be surprising if affective disorders were absent from this particular population. Alternatively, as David, Wessely & Pelosi (1988) have suggested, the dichotomy between organic and functional aetiology is spurious. Rather than working from an 'either/or' perspective, researchers and practitioners should, until more definite, conclusive aetiological agents are identified, regard ME as multifactorial in origin.

## 6.8 Implications and Utility of Research

The research set out to be descriptive rather than evaluative. That is, rather than concerning itself with the causes and consequences of the behaviours and emotions of people with ME, the aim was to document whether they perceive change in their self-conception to have occurred since contracting their illness. Having said that, it shall now be attempted to outline the utility of the research.

(1) It has been documented that ME sufferers perceive change to have occurred in their self-conceptions as a result of their illness. Furthermore, this change seems to have been for the worst.

(2) It is shown that ME sufferers are extremely concerned with the way they are perceived by others. That is, with their public stereotype. Contrary to expectation, medical diagnosis does not seem to have acted to improve the negative self-concept engendered by ME. This finding is surprising in that, to reiterate, diagnosis has often been regarded as playing an important social 'policing' role (Herzlich & Graham, 1973). That is, diagnosis 'weeds out' the so-called 'genuinely' sick from the malingerers. The findings of this research <u>imply</u> that, while the medical profession may have the power to provide legitimation for an illness, an illness still has to be accepted by the wider community; a factor which represents the limits of medical 'power'. This would explain the high salience attributed to the <u>public</u> stereotype and the low salience attributed to the role of diagnosis. Of course, the devaluing of diagnosis could also reflect general ambivalence <u>amongst this particular population</u> towards the medical profession. Further research could clarify this issue (see below).

## 6.9 Possible Methodological Limitations

The aim of this section is to discuss potential limitations to the research design. It should be emphasised from the beginning that measures were taken to avoid these 'threats' from endangering the internal validity of the study. Indeed, the section which follows serves to reiterate measures taken to protect the validity of the study.

(1) The test used, (that is, the repertory grid) is not a standardised instrument. Though this issue is discussed at length above, it should be stressed that the repertory grid was chosen for this study because, firstly, the research is principally guided by Personal Construct Theory, and secondly, because the repertory grid is useful as an instrument for the measurement of change (Bannister & Mair, 1968).

Additionally, constructs were supplied (after they were elicited from a pre-test sample), rather than solicited directly from subjects. But, while it would be preferable to allow subjects to supply their own constructs (Fransella & Bannister, 1977), this would be impossible in the context of a large research project such as this. High construct/element correlations (see Chapter 5) could be taken as indicative of high subject identification with the supplied constructs (Adams-Webber, 1970; Fransella & Bannister, 1977). Such high identification could, of course, be accounted for by demand effects. However, the nature of the repertory grid is such that subjects are not aware that relations between their perceptions are being elicited, rather than the perceptions themselves (Bull, 1984).

(2) Schnetler (1989: 74) has pointed out that the semantic differentiation scale (similar in structure and utility to the repertory grid) requires a certain "level of conceptual proficiency" and therefore recommends caution in using this and related instruments. Indeed, the repertory grid can appear fairly daunting to a subject who has never completed one before. In addition, though a two-page instruction pamphlet was drawn-up and supplied to subjects, effectiveness of this was not pre-tested on them (though the instructions were pre-tested on a small, non-ME, sample). It is possible that some subjects failed to comprehend the instructions and therefore completed the grid in a haphazard fashion. However, the consistent, clear-cut data found during the study suggest that this was not the case. In addition, the high rate of questionnaire-return (as well as the speed with which questionnaires were returned - the vast majority within a fortnight of mailing) is strong evidence that subjects understood the method for completion of the grid (Dixon, 1989). Subjects would be unlikely to struggle with a questionnaire which perplexes them.

(3) There is also the problem of the lack of control which dogs any research conducted via the post. That is, as Dixon

(1989) has pointed out, the researcher cannot verify that the subject completed the questionnaire and not, for example, a parent, spouse or even a prankster. Such occurrences, however, are probably rare. It is worth noting that, in an attempt to avoid this problem, several respondents to the initial appeal for ME sufferers to contact the author were excluded from the study because the initial contact-letter was written by a parent or spouse on behalf of the potential subject..

(4) The issue of representativeness in postal research is also raised by Dixon (Ibid) who points out that people who respond to postal questionnaires are often those with a particular interest in the subject being researched, and those who do not respond may be a group with particular views which are lost to the research. This is a particularly salient point in light of the nature of this research. That is, subjects were recruited via the national press. This could have attracted ME sufferers with particular characteristics, such as concern for the way they are viewed (stereotyped) by the public. There is very little that can be done to counteract this possibility. For example, even a control group would, besides the problems identified in Chapter 3 above, also have been recruited in a similar fashion, and hence would be vulnerable to the same bias. Essentially, it can only be emphasised that the sheer volume of the response (over 300 replies) and the size of

the sample ultimately included for analysis in the research (n = 50) should act against population bias.

## 6.10 Suggestions for Further Research

There is certainly a need for more psychological research to focus on ME. A number of further questions are raised by the present study which may prove useful starting points for further investigations in this area.

(1) The issue of the meaning of diagnosis for ME sufferers needs to be explored. In other words, what mechanisms are at play in the low salience attributed by subjects to their diagnosis? Does diagnosis play a less significant legitimating role in society than generally contended, or are subjects merely responding to the negativity they have often encountered in the medical profession?

(2) With the medical profession becoming more receptive to ME as an entity (Beechey, 1989), and more positive coverage being accorded ME in the media, it would be interesting to monitor changes in the salience of the public stereotype for sufferers. It is possible that, as more acceptance is conferred upon ME by the public, less concern will be showed by sufferers towards their public stereotype.

(3a) A follow-up of the sample utilised in this study, could prove informative. It would be useful to monitor any change which has occurred in construction patterns as well as in inter-element, construct/element relationships. This is actually crucial, as Personal Construct Theory views people as constantly <u>changing</u> (Bannister & Mair, 1968).

(3b) Alternatively, a longitudinal study could be implemented where ME sufferers are observed, starting from a period as close to their diagnosis as possible. In such a study, the repertory grid could be re-administered once a month for about 18 months. Changes in construction could be monitored with reference, for example, to changing environmental factors (important as Personal Construct Theory sees people as constantly interacting with the changes in their environment, [Kelly, 1962]). Additionally, changes (if any) in <u>retrospective</u> constructions could be monitored.

(4) It would be instructive to follow-up subjects subsequent to their recovery. This would answer questions such as whether concern about the public stereotype of ME remains salient even after recovery. Would, sufferers, now freed from the illness which they regard as a weakness, still attribute a high salience-rate to the construct 'Strong/Weak'? Which

constructs/elements gain or lose salience after recovery?

## 6.11 Conclusion

This research endeavored to go beyond the debate which motivates much of the research into ME at present in that it attempted to understand the person with ME. Rather than examining the illness, the person's reactions to the illness were of principle interest. In the public sphere, ME is often viewed as 'Yuppie Flu' (though this is changing), a term which carries negative connotations and which acts to negate the reality of the pain and disability which constitute this illness. At the moment, ME is a stigmatised illness, with the attitude prevailing that ME sufferers are, through their own workaholicism, responsible for their own condition (Beechey, 1988; Wessely, 1990). Alternatively, they are seen as malingerers, or depressed people seeking to shirk their responsibilities.

This is unquestionably an unfortunate state of affairs, as negative public and medical response to ME probably further provokes the decline in self-esteem experienced by sufferers. Indeed, Sharpe (1991) has warned that a low self-esteem engendered by a stigmatised illness can lead to the exacerbation of symptoms and the unnecessary prolonging of the illness. It is for this reason that professionals need to be especially empathetic when viewing ME. They need to take the lead in clearing away the myths and mistruths which cloud perceptions of the illness. Such a venture would require sensitive research. What Bannister (1991) noted with regard to disabled people, is true for research in the area of ME. That is, it is not good enough to merely know or sympathise with people with ME, but rather to cultivate an understanding which can lead to meaningful interaction.

There are tools available for such research. Personal Construct Theory and the repertory grid proved useful with this population. After all, the theory is concerned with the person in a state of change and ME sufferers are people burdened by change. Most of them are previously healthy people afflicted with a mysterious illness. They are people who have changed their outlooks on life; people whose lifestyles have undergone extreme change; people who look forward to a future positive change - their recovery. It is for these reasons that ME is of concern to psychologists; reasons which have nothing to do with psychopathology. ME sufferers are people who need to be guided through a period of flux, fear, anger, pain and low self-esteem.

Therefore, it is with concern that the paucity of psychological literature dealing with ME is noted. Clearly the experience of ME needs to be studied. People with ME suffer from a unique, debilitating illness and, regardless of the eventual conclusions reached regarding the aetiology of this illness, psychologists, with insight into the experience of ME, are in a unique position to use clinical resources available to them to develop methods of support, dissociated from value-laden interventions based on obsession with cause rather than effect.

## Appendix A

## **Letter to the press appealing for people with ME to take part in the research**

Dear Editor

I am a Masters student in the Department of Psychology at the University of Cape Town. My research concerns the experiences of people living with a chronic illness known variously as Myalgic Encephalomyelitis (M.E.) / Chronic Fatigue Syndrome / CFIDS / "Yuppie Flu", etc.

I would very much like to get into contact with:
(1) People who have been diagnosed as having M.E. by a medical doctor
(2) People who suspect that they have suffered from this malady for a number of months, but who have failed to obtain a diagnosis from a medical doctor. That is, their illness has been labelled as psychological in origin or they have been dismissed as hypochondriacs.

Would people who are willing to assist me in my research please write to me at the address below, detailing their address, sex and age as well as the duration of their illness. It would also be useful to me if they could include a short account of their experience with M.E. I'll contact them at a later date to ask them to complete a short questionnaire.

I am bound by professional ethics and full confidentiality is ensured.

The results of my research will be made available to any research-participant who requests them.

Yours Faithfully

Mark Weinberg

Appendix B

# PERSONAL FACT SHEET

The following short questionnaire deals with important additional information. All answers shall remain strictly confidential.

Name: (Optional) ________________________________

Age: ________

Date of Birth: ______________________

Sex: __________

Occupation: ________________________

Are you currently suffering from ME? ☐ Y ☐ N

Roughly, how long have you had ME? (ie. Months since you began to feel ill)

______________________

When were you diagnosed as having ME? (if applicable)

______________________

If you have been diagnosed, was it by a medical doctor?

☐ Y ☐ N

Are you receiving treatment from:

A Medical Doctor? ☐

Other? ☐

Nobody? ☐

If you ticked "other", please specify:

________________________________________________________________

________________________________________________________________

________________________________________________________________

What are you doing to treat yourself? (eg. taking Prozac, Taking Yoga, Hypnosis, etc)

What do you find helps best? (if anything?)

Additional comments (Anything you would like to add!!)

Thank-you for taking the time to complete this questionnaire. You have been most helpful!

## Instructions for Completion of Grid

**Please read the following twice and very carefully:**

The attached questionnaire is known as a Repertory Grid. I realise that filling in the grid may prove tiring, but hopefully you'll learn more about yourself while completing it. To prevent the task of completing the grid from becoming debilitating, I recommend that you complete it over several days. For example, you could complete three rows a day.

Adjectives: To the left of the grid you will see a list of descriptions, eg.**"Strong/Weak"**, **"In Control/Lacks Control"**, etc. For our purposes, these should be seen as **adjectives.** You will notice that each adjective is separated by a slash (/) from adjectives with opposite meanings.

**Nouns**: Above the grid, you will see phrases such as **"Self Now"**, **"Ideal Self"**, etc. These, for our purposes, should be seen as **nouns.**

In completing the grid, you will be indicating which **adjective** (ie. which side of the slash) **best describes each noun.** You will do this, using a 9-point scale, by filling numbers into the blocks. Therefore, I want you to see the adjectives on the left of the slash as represented by the numbers 1-4, while the adjectives on the right of the slash are represented by the numbers 6-9. The slash itself should be seen as the neutral number 5.

eg. Strong/Weak is represented as follows:
**1 2 3 4 /5/ 6 7 8 9**
Strong / Weak

The following table indicates the meaning of each numerical loading:

**1= the adjective on the left of the slash is an excellent description of the noun**

**2= the left side of the slash is a very good description of the noun**

**3= the left side of the slash is a fairly good description of the noun**

**4= the left side of the slash is more descriptive than the right, though neither side is terribly accurate**

**5= neutral - both sides/neither side describe/s the noun adequately.**

**6= the right side of the slash is more descriptive than the left, though neither side is terribly accurate.**

**7= the right side of the slash is a fairly good description of the noun**

**8= the right side of the slash is a very good description of the noun**

**9= the right side of the slash is an excellent description of the noun**

The following <u>example</u> may be useful as an illustration of how to complete the grid:

The following hypothetical grid has already been filled in:

| | Ice Cream | Medicine | Soup |
|---|---|---|---|
| Hot/Cold | 9 | 5 | 1 |
| Sweet/Bitter | 2 | 9 | 5 |
| Cheap/Expensive | 7 | 9 | 3 |

(LEFT) 1 2 3 4/5/6 7 8 9 (RIGHT)

Let's consider each row individually:

| | **Ice-cream** | **Medicine** | **Soup** |
|---|---|---|---|
| **Hot/Cold** | **9** | **5** | **1** |

In the above line, we see that the nouns, **Ice-cream, Medicine and Soup** were rated in terms of how **hot** or **cold** they were perceived to be. Ice-cream is "cold", so the **right** side of the slash was considered extremely descriptive, hence the extreme rating of 9. Medicine was thought to be neither "hot" nor "cold", hence the rating of 5. Soup was considered to be "hot", so the **left** side of the slash was considered an excellent adjective, hence the extreme rating of 1. Note that <u>each</u> noun is rated.

The next adjectives were:

| | **Ice-cream** | **Medicine** | **Soup** |
|---|---|---|---|
| Sweet/Bitter | 2 | 9 | 5 |

Here we see that "sweet" was considered to be a **very good** description (2) of ice-cream (the noun in question); whereas "bitter" was considered an **excellent** description (9) of medicine. Soup was regarded as **neither** "bitter" nor "sweet" (5).

The next adjectives were:

| | **Ice-cream** | **Medicine** | **Soup** |
|---|---|---|---|
| Cheap/Expensive | 7 | 9 | 3 |

Here we see that "expensive" was a **fairly good** (7) description of ice-cream; "expensive" an **excellent** (9) description of medicine and "cheap" a **fairly good** description of soup (3).

"Self" as used in this questionnaire refers to <u>yourself</u>. "Nouns" such as "Healthy Person", "Admired Person" and "Disliked Person" <u>each</u> refer to someone <u>you know</u> who fits that description. <u>Please be sure to fill in every block.</u>

## Appendix D

### Repertory Grid

| | Self Now | Ideal Self | Healthy Person | Future Self | Public Stereotype of M.E. Sufferers | Admired Person | Disliked Person | Self Before M.E. Diagnosis | Self Before M.E. |
|---|---|---|---|---|---|---|---|---|---|
| Strong/Weak | | | | | | | | | |
| In Control/Lacks Control | | | | | | | | | |
| Decisive/Indecisive | | | | | | | | | |
| Busy/Inactive | | | | | | | | | |
| Hard Working/Malingerer | | | | | | | | | |
| Selfish/Appreciative | | | | | | | | | |
| Efficient/Inefficient | | | | | | | | | |
| Secure/Insecure | | | | | | | | | |
| Attractive/Unattractive | | | | | | | | | |
| Abuses Self/Cares for Self | | | | | | | | | |
| Achiever/Loser | | | | | | | | | |
| Independent/Dependent | | | | | | | | | |

(LEFT) 1 2 3 4 5 6 7 8 9 (RIGHT)

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