# COPING WITH CHRONIC NEUROLOGICAL ILLNESS: AN ANALYSIS USING SELF-REGULATION THEORY

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# ABSTRACT

# COPING WITH CHRONIC NEUROLOGICAL ILLNESS: AN ANALYSIS USING SELF-REGULATION THEORY

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Self-regulation theory was used to examine how people cope with the diagnosis and management of chronic neurological illness. Three studies are reported, all of which examined the three main elements of self-regulation theory as outlined by Leventhal et al (1984), people's representations of their condition, the actions they took to manage and their evaluation of those efforts, and the outcome as assessed by their feelings about themselves, their emotional wellbeing and severity of disability.

A longitudinal study examined 20 people at three stages, before coming into hospital for tests and investigations for multiple sclerosis, 6 weeks and 6 months later. This study provided some support for representations as being important in guiding coping. However, both representations and people's own evaluations of their coping efforts were more predictive of outcome.

The second, cross-sectional study compared people being investigated for three differing chronic diseases; the previous 20 people being investigated for multiple sclerosis, 11 and 22 people being investigated for motor neurone disease and liver disease respectively. Results showed that how people represented their condition, and not the diagnosis, was related to outcome.

The third study was pseudo-longitudinal and examined people at different times since the diagnosis of multiple sclerosis. People at six months (n=20 from first study), 2 years (n=19), and over 7 years (n=25) from diagnosis were included. This study again highlighted the relationship between representations and outcome; perceiving more symptoms and adverse consequences being associated with poorer outcomes of all types. Coping was also associated with outcome, in particular, more social supports and greater satisfaction with that support being associated with higher Self Esteem, better emotional wellbeing and less severe disability.

It is concluded that self-regulation theory is a useful framework within which to understand how people cope with chronic neurological illness. In chronic illnesses with no cure or effective palliative treatments people's representation of their condition and evaluation of their coping efforts predicted outcome. The low level of psychological distress found in all studies suggests that while no particular coping actions are associated with better outcomes, it may be that taking some kind of action, rather than taking no action, in a situation where there is nothing the medical profession can do is sufficiently motivating to minimise depression.

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## Chapter 1 . Introduction

Impact of disease is in part due to the disease process and in part due to psychological, social and environmental factors. This thesis deals with the impact of progressive neurological disease where underlying pathology has been identified, but where impact on the individual is not entirely determined by the pathology.

Chronic progressive neurological disease as used here refers to diseases of the central nervous system that are of long duration, develop relatively slowly, and advance in severity, complexity and extent. The illnesses that are the focus of this study are multiple sclerosis and motor neurone disease which significantly contribute to chronic illness. Multiple sclerosis is the second largest cause of disability among the young adult population, second only to arthritis.

Before considering chronic progressive neurological illness, some similarities and differences in chronic neurological illnesses and other chronic illnesses need to be considered (Burish and Bradley, 1983). They use four dimensions they feel make up people's subjective definitions of their illnesses. The first is the cause of the illness. The major causes of many chronic illnesses are often related to a persons behaviour and lifestyle, eg. coronary heart disease. This is not the case with neurological illnesses, where as yet the aetiology is largely unknown, research having failed to indicate any lifestyle or behavioural factors linked to any of the major neurological illnesses which influences the onset or course of the disease process.

The second feature is time-line of the illness. Many chronic illnesses share a slow, insidious onset and endure over a long and indefinite period, and as in such conditions as multiple sclerosis and rheumatoid arthritis, follow an unpredictable course of remission and relapse on a short term basis, with a long term pattern of increasing severity and complexity. With motor neurone disease, the illness is usually unremitting and fatal, significantly reducing the life-span, and increasing the disability.

The third feature is the identity of the illness, and refers to people's ideas about what is actually wrong with their bodies or functioning. With several chronic and progressive illnesses there may not be observable symptoms present (eg. symptoms of cancer, rheumatoid arthritis and multiple sclerosis may disappear during periods of remission). Symptoms of multiple sclerosis and motor neurone disease may be vague and ill-defined eg. fatigue and muscle weakness, diagnosis may be a lengthy and protracted affair with considerable delay before specialist services are involved. The absence of specific diagnostic tests for multiple sclerosis means that it is diagnosed by default when persistent symptoms cannot be explained by other diseases.

The fourth dimension is the outcome of illness. With appropriate medical treatment or changes in lifestyle and behaviour, many chronic illnesses can be managed effectively, eg. diabetes, epilepsy, heart disease. With progressive neurological illnesses such as multiple sclerosis and motor neurone disease, no treatments, either palliative or curative are available, and the course of the illness is marked by increasing deterioration, disability and death.

These factors are of considerable importance when trying to decide the salient psychological issues for chronic progressive neurological illness. Leventhal and Nerenz (1985) have suggested that individuals develop an organised, commonsense theory for the regulation of their behaviours based on their beliefs about these four dimensions, their beliefs about treatment and their symptoms. How this theory accommodates chronic progressive neurological illness is the focus of this study.

Many of the issues relating to service usage and management reflect peoples understanding of their illness and the way they attempt to cope. As yet there is very little longitudinal research to guide the health professions in their overall management of the patient in relation to how people cope with their illness. An increased knowledge in this area should enhance the management of people with chronic progressive neurological illnesses. The aim of this thesis is to examine the usefulness of self-regulation theory (Leventhal & Nerenz,1984) as a framework for investigating how people cope with the diagnosis of progressive neurological illness, and those factors implicated in coping six months later.

**Chapter two gives an overview of progressive neurological illness and evidence from current research on its psychological effects. Chapter three argues the case for the wider application of psychological models to this field and looks at the main components of self-regulation theory and its origins in control theory. Chapter four outlines the usefulness of Leventhal's self-regulation theory in providing a framework within which to address the complex and varied psychological issues in progressive neurological illness. Chapter five outlines the methods and procedure used. Chapter six describes a longitudinal study looking at illness representation, coping and outcome before the diagnosis of multiple sclerosis, 6 weeks and 6 months later. Chapter seven is a cross sectional study and compares people coming into hospital for tests and investigations for three differing chronic diseases in terms of the elements of the model. Chapter eight is a pseudo-longitudinal study designed to look at the elements of the model at different stages of a chronic progressive neurological illness, chapter nine provides an overall discussion and summary.**

# Chapter 2. Psychological aspects of chronic progressive neurological illness.

## 2.1. Introduction

The aims of this chapter are twofold. Firstly, to outline the nature of neurological illness, in particular progressive neurological illness, and secondly to consider it's psychological effects.

## 2.2 The nature of neurological illness

Neurological illnesses are those where there is disease of the nervous system. There are basically three main categories of neurological illness. Firstly, those which are life threatening and/or shortening. More often than not these are the serious and progressively disabling disorders (eg. multiple sclerosis and motor neurone disease). Secondly, there are those disorders which are not life threatening or shortening but are accompanied by minor or no persistent physical disability (eg. epilepsy). And thirdly, non life threatening or shortening disorders but with persistent mild to moderate disability (cervical spondylosis, radiculopathy/myelopathy).

### 2.2.1 The incidence and prevalence of neurological illness

There has been no comprehensive estimate of neurological disease in the United Kingdom. However, it has been estimated that in America there will be one person in every hundred who each year will have a new neurological disorder, and that there will be a prevalence rate of almost thirty six persons in every ten thousand which at any one time should be under the care of a neurologist (Kurtzke 1982). While Kurtzke's examination was of the incidence and prevalence of neurological illness in the United States, many of his references are to the European literature, so it is likely that his figures apply reasonably well to the United Kingdom. Kurtzke's study represents the most comprehensive attempt at measuring the size of the burden of neurological disease in the population.

Based on these figures an English health district of 250,000 would yield an incidence rate of 2,500 and a prevalence rate of 9,000. These figures are supported by Stevens (1989) for the county of Gloucestershire which shows a similar pattern.

### 2.2.2 Progressive neurological illness and disability

Within the UK health care system, the investigation and management of people with chronic neurological illness is based within the framework of disability outlined by the World Health Organisation's International classification of impairments, disabilities and handicaps (1980). In this model, disease and impairment are seen as causing the objective outcomes of disability and handicap. The model does not incorporate people's own representations of their condition.

A major shared concern of people seen routinely in outpatient clinics is the presentation and management of symptoms (Earll, 1989). The symptoms of nervous disease are extremely varied, and interpretation is not a simple task, either for patients or neurologists. Determining the underlying pathology is hampered by lack of knowledge of the causes of many of the basic disease processes. Indeed, in the case of many chronic conditions intervention to attempt to ameliorate symptoms may be the only realistic means of achieving even a modest measure of clinical or personal control. Such limitations increase the importance of symptoms, for treatment is often directed at the relief of disabling symptoms and not the underlying disease cause. Yet symptom identification and description, particularly for those with chronic illness, are essentially problematic (Monks 1986). As Mathews and Miller (1972) pointed out, the patients description, often of totally unfamiliar sensations, has to be translated by the neurologist and explained in terms of physiological disturbance.

A recent report on the levels of disability among the population of the United Kingdom highlights the contribution progressive neurological disease makes to the overall levels of disability reported (Martin et al,1988). In their private household survey, they cite complaints of the nervous system as contributing 13% to the overall level of disability, and 30% from people living in communal establishments. This relationship was also found in a survey of disability carried out in the county of Gloucestershire (The Hidden Three Thousand,1988). The present study focuses on two progressive neurological diseases, multiple sclerosis and motor neurone disease.

## Multiple Sclerosis

Nationally, multiple sclerosis (MS), is the second largest cause of physical disability among young adults. This high morbidity rate places health care and service delivery under increasing pressure, not only from the economic constraints placed on the health service, but also from the need to improve both the delivery and quality of service offered to people.

MS is a common disease of the nervous system (Compston 1987), about 50,000 people in the United Kingdom and 500,000 Americans are estimated to have MS and a sex difference is apparent. Almost twice as many women as men are diagnosed with the condition. The disease incidence is difficult to ascertain, one of the major problems being that there are no specific diagnostic tests for MS, and there is considerable regional variation. It occurs mostly in the temperate climates of the world, particularly of the Northern hemisphere, and is virtually unknown in tropical areas. The definitive diagnosis of MS can only be made with pathological evidence from a post mortem. For practical purposes, it is necessary and possible to undertake a clinical diagnosis for patients using the available evidence on signs and symptoms in conjunction with para-clinical investigations such as imaging.

The most recent diagnostic criteria are those of the Poser Committee (Poser et al, 1983), and these are described in chapter 4. For a clinically definite diagnosis of MS there must ideally be evidence of two attacks on different parts of the CNS, each lasting more than 24 hours and separated by a period of at least one month. Hence there must be evidence that lesions are multiple in both time and space. Clinical evidence of lesions can be complemented with paraclinical evidence from electrophysiological procedures such as evoked potential tests and also by imaging procedures such as CT scanning and magnetic resonance imaging (MRI). In addition to clinical and paraclinical evidence there may also be laboratory support to a diagnosis of MS obtained from examination of cerebrospinal fluid (CSF) which may indicate immunological abnormality.

MS is a chronic, progressive disease that produces demyelination of the central nervous system nerve fibres. The condition generally runs a chronic and relapsing course, and in regions of high prevalence MS rivals stroke and trauma as a cause of neurological disability. There is no typical MS and therefore one consistent description is not possible. Onset is often in young adulthood, between the ages of twenty and forty, and follows an unpredictable course with considerable variation both within and between individuals. Symptoms may include weakness, loss of sensation, blurring or double vision, numbness, lack of balance, bladder problems, sexual problems and intellectual changes. As with any disease where the cause remains unknown there are no shortages of explanatory theories, with two attracting most attention with respect to the causative agent behind MS. The first is that some form of viral infection provokes an auto-immune response resulting in demyelination. The second is diet, in particular the intake of animal fats (O'Brien, 1987).

In the absence of any prospective cohort study of MS patients it is difficult to document the precise development of the disease from onset. The most common pattern for the disease (occurring in 90% of patients) is the multi-phasic sequence of relapse and remission. The remainder experience the disease in its progressive form from onset. Compston (1987) estimates that 60% of relapse- remitting cases will switch from relapsing to a progressive course at some stage in the disease. There is as yet no definitive cure for MS, but there are a number of treatments which may offer some benefit to some people. One of the main problems of assessing efficacy of treatment is the question of how to measure benefits of effectiveness to patients. As well as using disability indexes to assess impact, psychological well-being also needs to be quantified.

### Motor neurone disease

Motor neurone disease (MND), (or amyotrohpic lateral sclerosis (ALS)), is the name given in the British medical literature to a progressive, non-inflammatory, degenerative and fatal disease of the central nervous system. The disease affects the motor neurones in the brain and spinal cord. Motor neurones are those nerve cells that control muscles, hence degeneration causes weakness and wasting in the muscles supplying the limbs, face and throat, with the consequent problems of thick speech and difficulty chewing and swallowing. MND is progressive over a variable time period, with death usually resulting from respiratory failure. The overall mean survival from diagnosis is approximately four years, with about 10% surviving for over ten years (Mulder & Howard,1976). The disease may commence at any age in adult life, but it has a peak age of onset at fifty five to sixty years. The cause of the disease is unknown. Many theories have been proposed, the ones receiving the most attention being viral infection, heavy metal poisoning, metabolic disturbance and immunological defects. Between 5% and 10% of MND cases in most countries are familial, with an autosomal dominant pattern of inheritance.

MND is a clinical syndrome dependent for its diagnosis on clinical history, examination and electromyography. There is no single confirmatory diagnostic test. Thus the syndrome is primarily identified clinically, yet the diagnosis is one that is made with considerable agreement among independent examiners (Mulder & Howard, 1976).

Approximately 1:50,000 adults will develop MND in any one year, with 5,000 patients in the United Kingdom at any one time with some degree of regional variation. Almost twice as many men as women are diagnosed with MND. As yet there is no specific treatment that will arrest or slow down the progress of the disease. However, many of the symptoms and subsequent problems can be effectively minimised.

### 2.2.3 Perceptions and understanding of the symptoms of neurological illness

Several studies addressing the issue of neurological symptoms (Hawkes 1974, Fitzpatrick and Hopkins 1981a) have shown clearly that patients do not share the same perspective as doctors. Fitzpatrick and Hopkins (1981b) interviewed patients attending neurology outpatients clinics for headaches following consultation. They reported that they felt that they had not received adequate investigation, explanation or treatment. The authors concluded that peoples varying concerns with regard to their illness need to be more directly considered in explaining different responses to medical consultations.

Robinson (1988) suggests that the strategies adopted for dealing with symptoms are, on the basis of accumulating evidence, likely to be quite different between doctors and patients. He sees as fundamental to this difference the way symptoms are defined and classified. Robinson makes a distinction between the medical definition of symptoms as "..subjective disturbances which arise from disease.." which he sees as being impairment driven, and the patient oriented view of symptoms which he describes as "handicap driven". In this latter view the way that phemonena come to be classified as symptoms for patients is far more likely to be through their social, cultural or economic effects and settings and the handicaps they signify, than through their recognition as impairments, or even disabilities.

To understand how people cope with symptoms one needs to consider the meaning of those symptoms to the individual and the framework within which this is organised and communicated. Factors which have been shown to influence the experience of symptoms are the arousal of subjective emotion, being told one has an illness, unexplained or unexpected bodily signs, the need to relate concrete symptoms with abstract disease labels, familiarity of the symptom, and awareness of illness in others. These issues arise in the perception of all illness and theoretical models adapted to address them will be discussed in chapter 3.

## 2.3 The focus of psychology in neurological illness

### 2.3.1 Neuropsychology and neurological illness

Neuropsychology has been concerned with the relationship between brain and behaviour, both in animals and humans, and in devising elaborate and multifarious ways of measuring and quantifying that relationship. An extensive literature exists dealing with this area (Filskov and Boll 1981, Kolb and Whishaw 1980, Lezack 1983). More recently these findings have been applied to the field of rehabilitation, in particular the cognitive retraining of neurological patients. Miller (1985) points out that this relatively recent development has been fuelled by two factors.

The first is the realisation that many who suffer disease or damage to the central nervous system retain significant handicaps for the rest of their lives, and therefore need some form of rehabilitation. Cognitive retraining of neurologically impaired people reflects an approach to psychological intervention which views the impaired person as having certain cognitive deficits which must be changed if the person is to function in their environment. In this approach the aim is to change the person so they better fit this environment. An alternative approach regards the impaired person's environment as making inappropriate demands on their limited cognitive capacities. The environment is therefore changed to better fit these remaining capacities. Within both these broad approaches, psychological interventions can aim to overcome different areas of deficit. The second reason referred to by Miller for an increased emphasis on rehabilitation and a decreased emphasis on cognitive assessment is the development of sophisticated radiological techniques, such as magnetic resonance scanning, which undermines the importance of neuropsychological assessment in the diagnostic process.

Decrease in the traditional focus on assessment has stimulated investigation into other areas of neurological illness, in particular the psychosocial aspects of neurological illness (McCarthy and Brown 1989, Dakof and Mendolsohn 1986, Vanderplate 1984). Progressive illness may lead to changing views of the self. Issues of coping and adjustment are particularly salient in the management of progressive illness because the chance of recovery is often slight. Consequently, delaying deterioration and limiting discomfort, psychological and social disruption become important aims (McCarthy and Brown 1989). In addition, how people cope or respond to illness might well be influenced by cognitive and personality changes brought about by cognitive impairment as in Parkinson's disease, multiple sclerosis, Huntington's chorea or alzheimers disease.

### 2.3.2 Psychological effects of progressive neurological illness

One of the aims of the early psychological literature was to test the notion that people with neurological illness, and chronic illness in general, showed a high degree of psychopathology. Vanderplate (1984) commented in his review of psychological aspects of multiple sclerosis, that the methodology of most of the early studies do not allow one to ascertain whether personality patterns merely reflected generalised reactions to chronic illness. These earlier studies have mainly used retrospective reports and are confounded by disease variables, particularly in the case of multiple sclerosis and Parkinsons disease. Furthermore, symptoms of anxiety and depression may occur in response to the onset of symptoms but antedate the diagnosis. These issues can only be addressed by longitudinal studies.

Many investigations of chronically ill people assume that psychological attributes are specific to particular diagnostic characteristics. Cassileth et al (1984), in a study of seven hundred and fifty eight people, each with one of six different chronic illnesses, concluded that the psychological status of these chronically ill people reflected the population at large. She argued that adaptation represents not the demands of a particular stress, like a specific diagnosis, but rather the manifestations of enduring personality constructs and capacities. There is growing evidence that in chronic illness of all kinds, psychological disturbance is generally greatest in the early stages of illness (Meyerowitz 1983). Cassileth (1984) found that irrespective of diagnosis, patients with recently diagnosed illness had poorer mental health scores, as measured by the Mental Health Index, than did people whose illness had been diagnosed more than four months previously.

Dakof and Mendolsohn (1986) suggest that the potential effects of increasing debility may be counteracted by habituation to symptoms and by development of the means to cope with them. With respect to MND, McDonald et al (1988), refer to the dearth of psychological studies on patients with ALS, and cite four studies addressing psychological factors in ALS. Firstly, Brown and Mueller (1970) attempted to identify a characteristic personality pattern, and concluded that MND/ALS patients had personality traits of high independence and internal control. Secondly, Houpt et al (1977), attempted to replicate Brown and Mueller's study and found no overall increase in the degree of internal control: they found evidence of clinical depression in 22%. Thirdly, Peters et al (1978) administered the MMPI to 38 patients and found no distinct personality pattern, though all the men with ALS had significantly higher scores on the four scales of hypochondriasis, depression, hysteria and schizophrenia. Finally, Montgomery and Erickson (1987) found that 46% of people with the condition had increased anxiety and depression, but that high depression was unrelated to severity of disease.

On the whole, the most consistent finding to arise from this research paradigm, both for MND, MS and for other conditions, has been that people with chronic illness tended to be more depressed than healthy people. Friedman and Booth-Kewley (1985), have referred to this as the 'disease prone personality', depression preceding not resulting from disease. However, many of the studies they reviewed used cross-sectional or retrospective designs, measuring personality after the onset of disease, and it seems plausible that at least some part of the depression was the result, rather than the cause of the disease.

Depression and other indices of psychological problems, occur fairly consistently only with chronic severe, disabling disease, such as multiple sclerosis, and with advanced stages of disease, such as motor neurone disease. However, severity rather than type of disability is associated with psychological distress in chronic illness. The adaptive capacity of people with multiple sclerosis has been seen more as a function of durable personality traits and life constructs, rather than specific illness variables (Counte et al 1983).

When asking questions about progressive neurological illness, one should ask not just why some people become depressed and have difficulty coping, but why, in the face of incurable disabling disease are the majority of people neither depressed nor even in serious psychological difficulty. With respect to Parkinson's disease, but equally applicable to other progressive illnesses, Dakof and Mendolsohn (1986) commented that we are largely ignorant of how some people see themselves as having changed for the better and not the worse by their illness. We are largely unaware of the psychological factors that act as buffers against psychological distress, and how peoples social environment both affects and is affected by their illness.

A more empirically sophisticated analysis of the relationship between psychological factors is presented in a longitudinal study by McDonald et al (In press). Patients with ALS were classified as having a positive or negative psychological profile. A positive profile was defined following factor analysis and consisted of :"low hopelessness, depression and perceived stress; expressive of anger; well-defined purpose; internal control; and high satisfaction with life". When followed up over 18 months, those with a positive psychological profile had a lower risk of dying and a longer survival time than those with a negative psychological profile, even allowing for length of illness, disease severity and age. It is possible that those with a positive psychological profile cope with their condition differently from those with a negative profile. The findings on chronic disease and distress can be interpreted within the framework of models of coping with chronic disease. In this study Cohen and Lazarus' (1983) definition of coping is used, where coping always involves some sort of stress and refers to what the person actually does in a particular stressful situation, and adaptation is used to refer to a broader concept that includes routine or automatic actions.

### 2.3.3 The need for psychological models

In most scientific contexts a model is distinguished from a theory, a theory being taken as a discourse about a model. Models may be seen as ways of enabling us to think about reality as we know it or believe it to be.

Boll (1985), in his discussion of developing issues in neuropsychology, stated that "it is of critical importance that neuropsychologists become aware of their psychological foundations .... psychologists have an opportunity and responsibility for the development of health care services to patients with neurological disorders and complaints". Psychological phenomena in neurology have frequently been considered only within disease categories, rather than psychological categories. Marteau and Johnston (1987) suggested that whilst the use of disease categories in research develops the understanding of the disease, by contrast, where psychological schemata have been used, the theoretical models have become more sophisticated and the methods of investigation more refined.

Maes et al (1987) make the case that it is not the absence of models or the lack of data that are the hallmark of research in the field of health, but rather the diversity of findings which lack integration. Most researchers collect data which may have clinical relevance but they fail to fit this into a more theoretical frame of reference, and furthermore use idiosyncratic measuring instruments which lead to non-comparable results. In health psychology, as in other branches of psychology, models are of value in providing a way of ordering the world, defining variables and providing shared constructs between researchers thereby making data obtained comparable, as well as facilitating explanation and prediction (Marteau,1985).

Horne & Weinman (in press) report an increasing interest in models which attempt to explain the interaction between the physical presence of disease and the patients subjective perception and interpretation of the disease within a broader context. The cognitive processes of perception, explanation and evaluation are used to identify the disease and give it "meaning", to recognise the tasks to be coped with and to select and evaluate coping strategies and so influence outcome. Several social cognition models have been proposed to explain illness behaviour and to account for the wide variation in response to disease (these will be discussed in chapter 3).

## 2.4 Conclusion

In conclusion, the impact of chronic neurological illness is complex involving both disease and psychological parameters. There is a lack of coherent explanatory data evidenced by previous research and a clear need for a psychological framework within which to address the complexities of the issues. Previous research highlights the reliance on traditional psychological models of psychopathology and neuropsychology. To develop our understanding of how people cope with chronic neurological illness, we need to evaluate the potential usefulness of health psychology models and to explore the degree to which psychological factors can mediate the impact of disease and impairment on disability and handicap.

# Chapter 3. Theoretical models

## 3.1 Introduction

This chapter provides an outline of those models most frequently employed to understand health and illness behaviour, which are broad enough to integrate people's beliefs and coping, and which might further our knowledge of chronic illness. Leventhal and colleagues (Leventhal, Nerenz & Steele,1984) self-regulation theory provides this integrative framework and is used in this study to explore how people with chronic neurological disease represent and cope with their illness.

One of the most compelling reasons for studying patients models of illness is that alternative approaches to prediction and control of illness (and health) behaviour have had such limited success (Lacroix,1991). However, these theories have tended to be uni-directional in approach with health behaviours viewed as outcome variables determined by conceptually distinct causal factors. "Few social and behavioural scientists would dispute that individuals' understanding of events is a primary determinant of their responses to those events. Indeed, the notion that individuals respond to the world as they view it, not necessarily as it is, has achieved the status of a truism" (Skelton & Croyle 1991).

Psychopathological and neuropsychological models have done little to enhance our understanding of how people cope with the threat posed by chronic neurological illness. In conditions where there is neither cure nor significant palliative treatment, the actions people take themselves may determine their clinical outcome. In view of the nature of such illness and the demands put on the individuals resources, models which take as the starting point the view of the person as active problem solver and not passive responder are considered most useful in considering how people might cope with chronic neurological illness. Models most commonly used in the health field include The Health Belief Model (Becker 1974; Janz & Becker,1984), those involving control and efficacy beliefs (Wallston & Wallston,1984; Bandura,1980), Stress and Coping model (Lazarus 1974, Lazarus and Folkman 1984), and Attribution Theory (Wong & Weiner 1981, Turnquist et al 1988). Each of these models contribute key aspects which are of importance to understanding how people cope with chronic illness. It is argued, however, that Leventhal's model of self-regulation (Leventhal, Nerenz & Steele,1984) incorporates these key elements and furthermore takes account of the extended time-line of chronic illness and the importance of symptoms as a link between illness representations and coping.

## 3.2 Models of Health Psychology

### 3.2.1 The Health Belief Model (HBM) (Becker,1974; Janz & Becker,1984).

This model attempted to explain cooperation with prevention and treatment recommendations partly in terms of subjectively perceived seriousness of and vulnerability to health threats. The HBM postulates that the likelihood of undertaking a health action is a function of the individual's beliefs along four dimensions:

(i) perception of the seriousness of the condition

(ii) perception of the individual's vulnerability to the condition

(iii) perception of the potential benefits of undertaking the particular health action

(iv) perception of the possible psychological and other cost or barriers related to the action.

In essence, the theory says that the likelihood of taking a particular action is a function of perceived threat and perceived benefit. Perceived threat is a function of perceived susceptibility, a subjective probability, and of perceived seriousness. Perceived benefit is the probability that threat will be reduced minus the perceived cost of the action, which will be reduced to a set of probabilities times values. Typically, these cognitions are brought into play by a cue to act such as a symptom or health message.

The HBM has been used in studies to explain and predict health behaviours in the face of a health threat, acute illness and chronic illness. The HBM was originally formulated for preventive health behaviour and then applied in studies of compliance with medical recommendations in the context of short term illnesses, it has been used more recently (Marteau,1985) in the context of chronic illness. Alonga (1980) found support for the health belief dimension of perceived seriousness in a study of women with diabetes in a weight reduction programme, those who perceived their diabetes to be more serious had lost most weight. A prospective study (Inui, Yourtee & Williamson,1976) found a significant relationship between perceived severity, vulnerability and benefits of taking medication and taking of anti-hypertensive drugs. HBM to date has proved most useful in the area of health decisions about undertaking disease-preventive actions. The model has been less successful in explaining and predicting health care behaviours in the context of chronic illness. Marteau (1985) puts forward several explanations for this. It may be that health decisions in chronic illness are influenced more strongly by factors other than health beliefs, such as the nature of family relationships, economic resources or the clinical team caring for the person. It may also be that health decisions in chronic illness are not based on health beliefs. It may also be the case that the measures used thus far have not tested the applicability of the HBM in this area. However, in chronic neurological illness where there is no cure or recommended medical regimen, perceived seriousness may well influence the actions people take themselves to manage their condition.

### 3.2.2 Control and Efficacy Beliefs (Wallston & Wallston 1984; Bandura 1980).

The concept of perceived control was applied to health by Wallston and colleagues who categorised people according to whether they attributed control over their health to internal or external factors. Much of their work has been involved in an attempt to apply this theory to understanding health behaviours. Generally it has been found that people with a more internal locus of control show more constructive health behaviours (Strickland 1987, Wallston & Wallston 1984). In the area of chronic neurological illness, Partridge & Johnston (1989) found that in a group of adults recently disabled by a stroke or wrist fracture, greater internality was associated with faster recovery, and that this could not be explained by initial severity or the patient's disability.

A person's decision to carry out a particular health-related behaviour is also influenced by beliefs about efficacy (Bandura,1980). Beliefs about self-efficacy are categorised according to whether they relate to general (generalised self-efficacy) or specific matters (specific self-efficacy). Social learning theory (Rotter, 1966) states that individuals may acquire their sense of self-efficacy from their assessment of the outcome of their own behaviour and the behaviour of others and feedback about their own behaviour which they receive from significant others (Bandura,1986). Efficacy and control beliefs are strongly influenced by the individual's past experience of success or failure in specific health-related domains. In particular, they may depend upon the person's beliefs about the cause of certain events and the extent to which their own behaviour was a key factor. As yet, in many of the chronic neurological illnesses, no specific causes have been identified as contributing to the onset or maintenance of illness. The extent to which a cause, attributable to either self or others, is identified by people with such illnesses, and the influence this has on coping and outcome, will be addressed in this thesis.

### 3.2.3 Attribution Theory (Turnquist, Harvey & Anderson,1988).

Attribution theory is concerned with the cognitive processes by which people explain the causes and outcomes of events, and maintains that when one encounters a sudden threat or change in one's environment, one will initiate a causal search in an effort to understand the reasons for that threat or change (Wong & Weiner 1981). Attributional search is thought to be initiated so as to understand, predict, and control threat (Kelly 1965).

Abramson and colleagues (1978) reformulated learned helplessness theory along attributional lines, suggesting that depression following bad events was determined by causal attributions about the events. This theory proposes that attributions for past successes and failures effect how new situations are dealt with. The central prediction of the reformulation is that individuals who have an explanatory style that invokes internal, stable, and global causes for bad events tend to become depressed when bad events occur. Peterson & Seligman,(1984) report a series of studies which provide empirical support for the helplessness reformulation. They conclude that explanatory style, in conjunction with actual bad events, precedes the development of depressive symptoms. In chronic neurological illness, attribution of cause to self may be predictive of poorer psychological outcome.

Janoff-Bulman (1979) looked at the content of attributions and distinguished between two types of self-blame, behavioural self-blame, involving attribution from some action taken in the past which is seen as a controllable modifiable factor, and characterological self-blame, involving an attribution to ones character or personality traits, seen as relatively unchangeable and non-modifiable. In a study of women who had undergone mastectomy for breast cancer, (Timko & Janoff-Bulman(1985) predicted that behavioural self-blame would be positively associated with the perception that one will be free of cancer in the future. The importance of Janoff-Bulman's contribution from the perspective of chronic progressive disease is the introduction of perception of past events into predictions about future responses.

Wortman & Dintner (1978) suggested that the assessment of the controllability of the causal factor may be of the utmost importance in predicting the nature and magnitude of the effect. Taylor and colleagues (1984) examined attributions and beliefs about control over cancer with reference to their association with adjustment to breast cancer. Interestingly, whilst 95% of their respondents made attributions for their cancer, no particular attribution (eg. stress, diet) was associated with better adjustment. This is a particularly important factor when considering the role of attributions in neurological illness where there are as yet no identifiable causes in the majority of cases, and no lifestyle or behavioural factors implicated in their onset.

Attempts have been made to link people's explanations for illness with how they cope. The assumption that accepting personal causal responsibility for an illness is associated with a constructive approach to managing it, as consistent with attributional theories, has received some indirect support from studies using a general measure of locus of control. Causal attributions appear to be relevant to understanding many aspects of medical practice, but, it has not been possible to identify one type of attribution which is universally adaptive. Rather it would seem that certain attributions are adaptive in certain situations but not in others.

### 3.2.4 Stress & Coping Model (Lazarus,1966; Lazarus and Folkman,1984).

Within this model, coping is defined as the persons constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources. The central idea of this model is that coping fulfils a mediating role in the relationship between the stresses of the illness and health behaviour outcomes. Lazarus' model emphasises the role of a constant interplay of cognitions and emotions in various behavioural outcomes. In this model coping is defined as a process and not a trait. Processes refer to what the person actually does in a particular stressful encounter, and how this changes over time. This model underlines the central role of psychological mediation through the concept of appraisal and the relational character of stress and coping, that is, they depend on both the demands placed on the organism and the resources available for dealing with those demands. If environmental or internal demands are not appraised as stressful, or if a person has the resources to meet these demands fully, no coping efforts may be elicited (Cohen and Lazarus 1983).

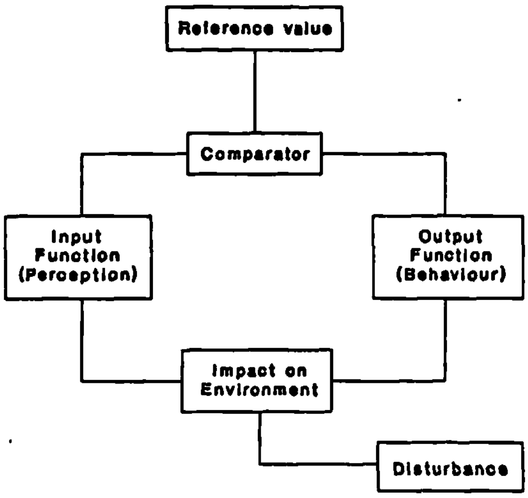
The models described so far attempt to explain specific aspects of health cognition and behaviour. However, there is need for a more general model which encompasses a broader range of cognitions and links these with coping behaviours and their outcome as well as with the emotional response to illness. Leventhal and Nerenz (1985) reject the prevalent theories in this area as not representing how the patient conceptualises or represents illness threats. They reject the HBM because it is based on the assumption that people react to illness in terms of perceived seriousness and vulnerability, attribution theories are rejected for similar reasons.

## 3.3 Self-regulation theory

### 3.3.1 Introduction

Self-regulation theory is derived from control theory and is used to describe the process individuals use to control and direct their own actions. Although behaviour is not exclusively controlled by self representations, it has become increasingly apparent that the representations of what individuals think, feel, or believe about themselves are among the most powerful regulators of many important behaviours. The central unit in control theory is the negative feedback loop (Fig.3.1)(Carver & Scheier,1982a).

Fig.3.1 Control theory;
the negative feedback loop



Carver & Scheier,1982

The component processes of the system are quite simple. The input function is the sensing of a present condition. That perception is then compared against a point of reference via a mechanism called a comparator. If a discrepancy is perceived between the present state and the reference value, a behaviour is performed (output function), the goal of which is to reduce the discrepancy. The behaviour does not counter the discrepancy directly but by having an impact on the system's environment (ie.,anything external to the system). Such an impact creates a change in the present condition, leading to a different perception, which in turn is compared anew with the reference value. This arrangement thus constitutes a closed loop of control, the overall purpose of which is to minimise deviations from the standard of comparison.

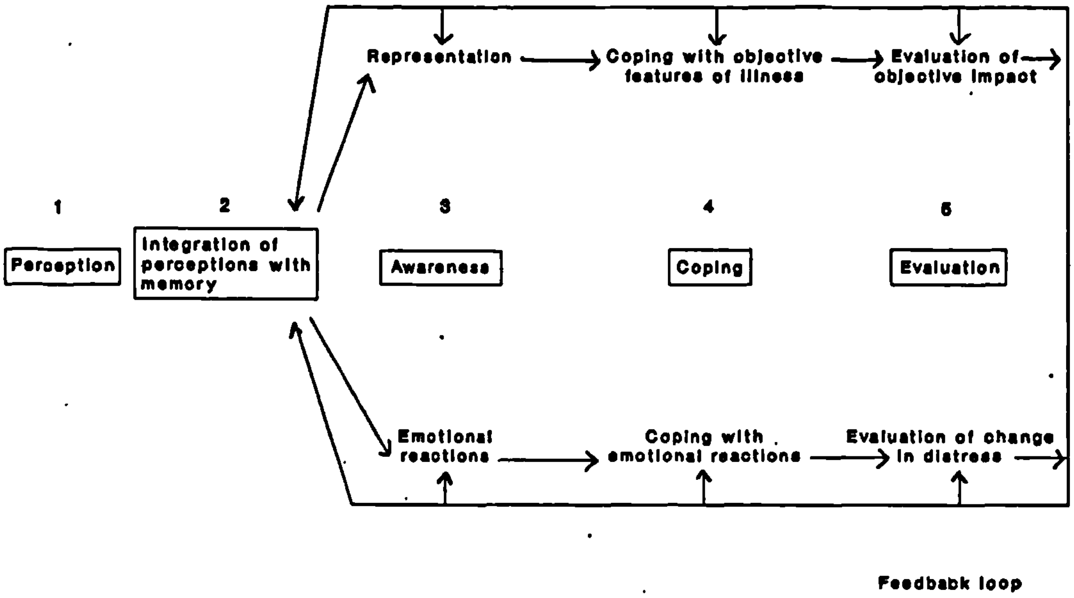
As Hyland (1987) points out, this is nothing new, the related idea that behaviour is shaped by its consequences is a well established part of behavioural theories. The main argument in control theory, however, is that the reference criterion in a control system corresponds to an individuals goal or purpose and that the behaviour of such systems corresponds to purposive behaviour. The negative feedback loop reduces the discrepancy between the system's "purpose" (i.e., reference criterion) and the system's "perception of the environment" (i.e., perceptual input), thereby directing behaviour toward the goal specified in the reference criterion. The system does not control it's environment; instead, it controls its perception of the environment. Markus and Wurf (1986) outline three component processes that are involved in the process of self-regulation. These include goal setting, cognitive preparation for action, and a cybernetic cycle of behaviour. Markus & Wurf (1986) have extensively reviewed the current thinking and knowledge in the area of self-concept and self-regulation. Self-concept is now seen by some authors (Suls 1982) as one of the most significant regulators of behaviour and is considered to be a critical variable in how smoothly self-regulatory processes function.

Good health, however it is defined, constitutes a reference value just like any other reference value. Furthermore, self-regulation with regard to that value has all the earmarks of self-regulation in other domains (Carver & Scheier 1982b). For example, merely checking one's pulse or blood pressure, or trying out the flexibility of ones hand and fingers is an intelligible activity when viewed in control-theory terms. That is whatever information is obtained by any of these actions is meaningful when it is compared with some reference value. Indeed, when people do such things, it is usually for the express purpose of determining whether there is a discrepancy between the present state and the "normal" state. Compared with health reference values, a discrepancy implies a state of less-then-ideal health (Leventhal,Meyer & Nerenz,1980). It is predicted that the result will be the taking of some action in an attempt to shift reality back toward the standard of comparison. Seeing a doctor for a check-up is conceptually the same process. The doctor uses ways of obtaining otherwise inaccessible information about one's present state and can prescribe a broader range of potential behaviours to aid in discrepancy reduction if a discrepancy is perceived. But in all these cases whether people use the doctor as a perceptual-behavioural adjunct or use only the perceptual channels and behavioural options that are normally available to them can be seen as constituting discrepancy-reducing feed back loops.

### 3.3.2 Leventhal's self-regulation model of illness (Leventhal, Nerenz & Steele,1984).

The work of Leventhal and colleagues was a concerted attempt to apply principles of control theory to the field of illness. The model attempts to account for the diversity of adaptation by helping to identify specific ways in which the environment can interact with the processing system to join self and illness. It is as such also an information processing model. (Fig.3.2).

Fig.3.2 Self-regulation theory



Leventhal et al, 1984

The basic premise of this model is that individuals regulate or minimise their health related risks and act to reduce these risks in ways consistent with their perceptions of them. Over the last two decades, Leventhal and colleagues have been developing a model to describe and predict how people cope with stressful health threats (Leventhal & Everhart,1979; Leventhal,Meyer & Nerenz,1980; Leventhal,Nerenz & Straus,1980; Leventhal & Johnson,1983; Leventhal, Safer & Panagis,1983; Leventhal, Zimmerman & Guman,1984; Leventhal, Nerenz & Steele,1984; Leventhal, Prohaska & Hirschman,1985; Leventhal & Nerenz,1985; Leventhal & Dieffenbach, 1991). They conceptualise the individual as an active problem-solver whose behaviour reflects an attempt to close the perceived gap between current health status and a goal or ideal state.

The initial work described in these papers consisted of a series of studies of fear messages warning people to take health-promotive actions such as stopping smoking, taking tetanus injections, making use of seat belts, and driving safely. Most of the work concentrated on adaptation over relatively short periods of time, for example, six minutes in a cold pressor, one to two hours for endoscopy, five to twenty four hours for labour, three to twelve days for surgery, and one to four weeks for tetanus shots. Many illnesses require repeated adaptive efforts over relatively long periods of time, perhaps many months and years.

This model has proved useful in understanding patients undergoing treatment for cancer (Love et al, 1989), hypertension (Meyer, Leventhal & Gutman,1985), diabetes (Gonder-Frederick & Cox, 1991), and HIV/AIDS (Farmer & Good, 1991). A common finding was that patients formed coherent representations of their illness within the structured components of identity, cause, cure, consequences and time-line as predicted by the model. The importance of illness representations for behaviour was illustrated by Meyer and colleagues (1985) who observed a clear relationship between representations and behaviour in their study of hypertensive patients. Patients who held an acute representation of hypertension were more likely to drop out of treatment then those who believed it to be a chronic condition. In a group of patients who had continued in treatment 80% agreed with the statement "people cannot tell when their own blood pressure is up". However, 92% believed that they could tell their own blood pressure was up by monitoring such symptoms as headache, stress and tiredness. In addition, patients tended to act consistent with their own representations and not that of the medical profession. The model has been expanded and developed to deal with the long term adaptation required by chronic illness (Leventhal et al,1984; Nerenz & Leventhal,1986).

A primary feature of Leventhal's model is the idea that the underlying system is composed of a series of stages for guiding adaptive action. The first of these stages, representation, involves the reception and interpretation of information for the definition of the potential or actual health threat and the emotion accompanying it. The second stage involves the assembly, selection, sequencing and performance of response alternatives for coping with both the problem and the emotion. The third stage is one of appraisal, to determine to what extent the goals specified by the representation have been reached. Information from the appraisal stage feeds back into the prior stages and can alter the individuals coping strategies and/or the way the problem is defined or represented. The system is recursive. Each adaptive episode alters the underlying memory structures and thereby changes subsequent adaptive episodes. The main theme is that the person is actively constructing a definition or representation of their illness and basing or regulating their behaviour in terms of this representation. It is a complex model of an adaptive system in which adaptation to stressful situations is viewed as the product of a system of mediating factors in which coping is the skill component. Within this planning and response execution is part of a set of mediating factors that determine the success or failure of the individuals adaptive efforts. However, Nerenz and Leventhal (1986) make the point that it is not an hypothesis about adaptation, eg. that feelings of control reduce distress, but rather a model of an adaptive system. Coping response refers to one of several factors comprising this mediating system.

The second important feature of the model is that of parallel processing, or the assumption that at least two types of feedback loops are active in self-regulation in most illness situations, one dealing with danger and the other with emotion. The two pathways interact as the individual adapts to each specific situation with the interactions occurring both consciously and preconsciously. These two parallel pathways are reflected in Lazarus' problem focused and emotion focused coping.

The third important feature is that the processing system is hierarchically organised. It is important to view the system controlling health behaviour as a set of hierarchically arranged control mechanisms (Leventhal et al 1985). Every stage, the representation, action-plans and appraisal, can be thought of as a series of hierarchically arranged layers going from highly abstract material at the top end to more concrete, situationally bound material at the bottom. The concrete level of representing danger and the concrete level of coping involve perceptual and attentional processes which combine incoming information with perceptual memories or perceptual schemata. Combining stimuli with perceptual categories or perceptual schemata produces perceptions of illness and perceptions of feelings. eg. "I see that my arm is weak and the muscles are wasting and I feel frightened and angry because of it". The memories or schematic structures that combine with new information can be memories of specific prior episodes of illness or generalised prototypes of classes of illness.

Abstract or conceptual processing, on the other hand, is more similar to what is typically regarded as cognitive interpretations of situations that are close to consciousness. Leventhal feels that this reflects two abstract rules, namely that pain follows injury or mechanical damage, and secondly, that the more severe the pain the more severe the injury. Concrete perceptual and abstract conceptual processing may be either automatic or deliberate, volitional, and controlled. Different levels of processing may generate similar and mutually supportive outputs or dissimilar and conflicting outputs. Discrepancies between seeing and thinking, eg. between being ill and being told you look well, are likely to stimulate emotional arousal and intensive efforts at resolution, at least in the early stages. But discrepancies between seeing and thinking do more than arouse emotion and a need to know. Discrepancies between seeing and knowing with respect to the body arouse powerful emotions such as fear and depression and also stimulate a sense of bewilderment, doubt about ones sanity, and a sense of alienation, or detachment of the mind from the body. These affective reactions are likely to have important consequences for coping.

The stages in guiding adaptive action are first, that people develop a representation of their condition which may or may not match the medical representation; components of the representation found in previous studies include the identity of the illness (both label and symptoms), perceived cause, perceived consequences, perceived time line and perceived cure. Secondly, coping efforts are directed at the person's own assessment of it. Thirdly, people make their own evaluations of their coping efforts and this may be different from other people's evaluations.

### (i) Representation stage

The representation of the illness or health threat includes variables involved in the identity of the illness. These can be both abstract, such as labels (eg."multiple sclerosis"), and concrete such as signs and symptoms (eg."double vision"). This representation is also based on beliefs about cause, consequences and duration.

Identity. An illness is identified by symptoms and by a disease label. As far as is known, individuals in all societies perceive and report physical symptoms. "Despite the pervasiveness, importance and sheer amount of time and money devoted to discussion and curing common physical symptoms and sensations, very little empirical work has been devoted to examining the psychological and perceptual factors related to sensory experience" (Pennebaker 1984). In chronic neurological illness, where due to a lack of knowledge of aetiology or cure, the major focus of the neurologist is in the treatment of symptoms, with limited understanding of the relationship between sensory experience and symptoms and lack of attention to the sensory experience of the patient.

Leventhal et al (1980) propose that there are at least three different reasons why symptoms play so important a role in linking illness representations and coping for chronic conditions. First, because the condition lasts over a long period of time, the symptom provides the only continual and readily available information for monitoring and appraising the impact of environmental events and practitioner's and self- prescribed treatments on the underlying condition. Secondly, it seems that people treat symptoms as highly valid indicators of illness. And thirdly, symptom appraisal can take place with little attention and effort. The ease of such automatic behaviours makes them efficient ways of determining one's illness status. Pennebaker (1982), cites a series of studies that show that the person is most likely to notice subtle sensations and symptoms when the environment is lacking in information. However, it is difficult to know if people in "boring" environments are exaggerating internal states or if those in more demanding settings are suppressing or ignoring sensations or symptoms. A second critical aspect of the perceptual process concerns how individuals organise and selectively search for information, they are more likely in evaluating the external environment to encode schema-relevant than schema- irrelevant information, and attribute greater weight to information consistent with relevant schema. They have shown that individuals organise sensory information in systematic ways, and that they selectively search for physical sensations that are consistent with the schema they hold. Also integral to this process is the expectations people have and how they decide that they are ill.

The arousal of subjective emotion appears to intensify body sensations such as pain and distress, and can also generate a wide range of psychophysiological responses resulting in sensations to which are added other non-illness sensations. Being told one has an illness appears to increase symptomatology, people attend more to bodily sensations to make sense of illness labels. This highlights the need for abstract concepts such as labels to be matched by more concrete symptoms. Watson & Pennebaker (1991) in a study investigating health complaints among students found positive affect to be largely unrelated to symptom reporting indicating that people can report leading an active, happy, interesting life while simultaneously complaining of numerous physical problems. When people notice unexplained or unexpected bodily signs, they search for information to interpret them (Meyer et al,1985; Nerenz & Leventhal,1986). This need to relate concrete symptoms and abstract disease concepts can produce much bias in symptom report data (Pennebaker 1984). Research into symptoms and illness illustrates the importance of the labelling process (Pennebaker,1982). From the doctors perspective operating within the biomedical model, vague and ill-defined symptoms might not necessarily be recorded if they appear incompatible with or surplus to the disease label. Perhaps one of the most common assumptions made in the perception and reporting of symptoms is that the person to whom the symptoms are reported organise their bodily sensations in the same way as the person who experiences the symptoms.

The distinction in Leventhal's model between symptoms and labels is of particular interest to chronic progressive neurological illness. The initial symptoms of some illnesses can be very slight, with no accompanying pain or discomfort. The early symptoms of motor neurone disease often consist of twitching (fasciculations) in the affected muscles, and is a useful diagnostic sign for the doctor (Mathews & Miller,1972), but frequently goes unnoticed or unremarked by the person. Observation of clinical practice suggests that most patients and their families are not familiar with the label "motor neurone disease" and the label/diagnosis, when given is frequently accorded the same level of seriousness as they have given the symptom. The seriousness of the diseases course and consequences are not available to the person without further information. Thus the disease label and the symptoms may, without additional information mislead the patient about the level of threat involved. This highlights the importance in the appraisal of perceived seriousness, a central component in the Health Belief Model (Becker 1974).

Cause. Attributions are commonly made following negative and unexpected events (Timko and Janoff-Bulman, 1985). It is not therefore surprising that the diagnosis of a chronic illness sets in motion the psychological process of searching for a cause. Whereas the scientifically validated causes of many chronic illnesses such as heart disease are often related to a persons lifestyle, this has as yet not been implicated in the major neurological illnesses, where the aetiology of diseases such as multiple sclerosis and motor neurone disease are still largely unknown.

Several researchers have found that attributing responsibility (cause) for severe accidents (Bulman & Wortman,1971; Janoff-Bulman & Wortman, 1977) or cervical cancer to oneself rather than to chance, influences the effectiveness of coping strategies adopted by the person. However, the majority of work in this field has examined acute, severe, and dramatic one-time illness experiences or accidents. Lau and Hartman (1983) make the point that this research does not deal with the importance of causal attribution in chronic progressive illness, where the onset is frequently slow and insidious, and the prognosis uncertain and unpredictable. There are no published accounts of whether attributions influence the emotional response, actions taken, or appraisal of the outcomes of action in chronic progressive disease, or any indications as to the direction of effect to be expected.

Another issue that needs to be addressed when considering attribution in chronic illness is the frequently long delay between the onset of symptoms and the diagnosis of disease. The individuals causal attribution of symptoms is an important part of the appraisal process, and one factor that can contribute to delay in appraising the symptom as a sign of illness, and account for the time taken to seek professional advice (Leventhal, Safer & Panagis, 1983).

Consequences. The consequences of chronic illness comprise the perceived physical, social, and economic consequences of the disease and its felt emotional consequences. Again, the perceived consequences of chronic illness may be an important factor in determining whether what, if any, action is taken. Watson & Pennebaker (1992) suggest that limitations, restrictions of daily activities, like symptoms, are based on perceived changes in body states, though as yet there is no published work looking at the consequences of chronic illness and their impact on coping and outcome. There is a complex literature addressing the psychological impact of illness on longevity (McDonald et al, in press), role performance, behaviour, symptomatic experience and other indicators of quality of life (Kaplan,1990). The impact of serious chronic illness is clearly not limited to the patient but may also have a profound effect on the family.

Time-Line. Models of illness representations suggest that illness representations fall into classes which define three specific commonsense models of illness based on the expected duration or time-line of the episode. Leventhal and colleagues (1980) propose three such models. Firstly, acute illnesses, which are symptomatic and curable. Secondly, cyclic, which are symptomatic, removable but recurrent. And thirdly, chronic, where the illness is a stable part of the self regardless of their symptomatic nature. It appears that many individuals attempt to regulate their responses to chronic illnesses in a manner appropriate to acute illnesses.

Leventhal demonstrated the utility of these distinctions by showing that the temporal expectations associated with these models have important effects on behaviour. Meyer et al (1985), in a study of hypertensives found that half of a newly treated sample dropped out after treatment by the six month follow-up interview if they initially represented hypertension as an acute disorder. By contrast, of those newly treated patients whose initial representation of hypertension was that of a chronic or long-lasting disorder, only 17% dropped out. Learning also took place, as those patients who shifted from an acute to a chronic representation of the disorder remained in treatment. Research also showed that nearly all illness episodes are initially represented as acute, even when people fall ill with diseases which are known to be chronic and fatal.

Cure. Lau and Hartman (1983) have added cure to the list of representations. They conceptualise this along the familiar dimensions of stability, locus and controllability. Content analysis of descriptions of common illnesses obtained from college students found support for the four components proposed by Leventhal and identified a fifth component, cure, which relates to beliefs about how one recovers from an illness. Lau and Hartman suggested that this component is one that is more likely to be detected in descriptions of acute illnesses where recovery is expected than it is in the case of chronic conditions.

### (ii) Coping

Leventhal et al (1984) state that representation sets the goals for coping and the criteria for appraisal. Over the previous decade research has been characterised by an interest in the actual coping processes that people use to manage the demands of stressful events, as distinct from trait-oriented research, which focuses on personality dispositions from which coping processes are usually inferred, but not actually studied (Folkman et al 1986). The starting point for much of this research is the conceptual analysis of stress and coping offered by Lazarus (Lazarus & Folkman 1984, Folkman et al 1986).

Definition of coping. Coping is defined as the person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources (Lazarus & Folkman, 1984). There are three key features of this definition. First it is process oriented,meaning that it focuses on what the person actually thinks and does in a specific stressful encounter, and how this changes as the encounter unfolds. Secondly, coping is viewed as contextual, that is influenced by the person's appraisal of the actual demands in the encounter and resources for managing them. The emphasis on context means that particular person and situation variables together shape coping efforts. Thirdly, coping is defined simply as a person's efforts to manage demands, whether or not the efforts are successful.

Lazarus(1974) states that cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment or symptom is relevant to his or her wellbeing, and if so, in what ways. In primary appraisal, the person evaluates whether for eg. there is potential harm or benefit with respect to commitments, values, or goals, or threat to self-esteem. In secondary appraisal the person evaluates what if anything can be done to overcome or prevent harm or to improve the prospects for benefit. Various coping options are evaluated, such as altering the situation, accepting it, seeking more information, or holding back from acting impulsively and in a counterproductive way. Primary and secondary appraisals converge to determine whether the person-environment transaction is regarded as significant for well-being, and if so, whether it is primarily threatening or challenging. Coping strategies refer to the actions following the decision that something needs to be done, eg. trying a home remedy. This is a dynamic process, with feedback between the stages. The person appraises the situation, takes action to manage the situation, then re-appraises the situation; it is an iterative process.

Function of coping. Within the model, the purpose of representation is to guide coping (Leventhal et al 1984). Coping has two widely recognised major functions (Cohen 1987) : problem-solving and emotion-regulation. Problem-solving functions involve dealing with internal or environmental demands that create threat, such as studying for an exam or confronting a noisy neighbour. Emotion-regulating functions involve efforts to modify the distress that accompanies threat- for eg., by denying that the threat exists or by drinking to excess. Although most stressors elicit both types of coping, problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured (Folkman & Lazarus, 1980).

Problem-focused coping can potentially involve several distinct activities: planning, taking direct action, seeking assistance, screening out other activities, and sometimes even forcing oneself to wait before acting, referred to by Carver et al (1989) as "restraint coping". Planning is thinking about how to cope with a stressor. Planning involves coming up with action strategies, thinking about what steps to take and how best to handle the problem. This activity clearly is problem focused, but it differs conceptually from executing a problem-focused action. Moreover, planning occurs during secondary appraisal, whereas active coping occurs during the coping phase. Folkman et al (1986) suggested that one may need to know the context before being able to distinguish which function a coping strategy serves.

While the distinction between problem-focused and emotion-focused coping is an important one, many researchers ( Carver 1989, Cohen 1987) view it as too simplistic. In reviewing the literature, Carver et al (1989) suggest that research typically finds that responses to The Ways of Coping scale (Folkman & Lazarus,1985) form several factors rather than just two. In general researchers view factors other than problem-focused coping as variations on emotion-focused coping. However, these factors often diverge quite sharply in character, to the extent of being inversely correlated. That is, some emotion-focused responses involve denial, others involve positive reinterpretation of events, and still others involve the seeking out of social support. These responses are very different from each other, and they may have very different implications for a person's success in coping.

Coping resources: social support. Leventhal looks at social support as a coping resource highlighting the importance of both the qualitative and quantitative aspects of the support. It has been suggested that the quantity element has positive effects on health and that the quality has a buffering effect (Thoits,1982; Cohen & Wills 1985). Cohen & Wills (1985) in their review of social support conclude that there is evidence consistent with both models. Evidence for a buffering model is found when the social support measure assesses the perceived availability of interpersonal resources that are responsive to the needs elicited by stressful events. Evidence for a main effect model is found when the support measure assesses a person's degree of integration in a large social network. Both conceptualisations of social support are correct in some respects, but each represents a different process through which social support may affect well-being.

Social contact is hypothesised to have beneficial effects on both mental and physical well-being. Apart from that the research domain can be characterised as one of considerable heterogeneity. However, Payne and Jones (1987) conclude their review of measurement and methodological issues in social support by saying that even given the ad hoc measures of social support so far used the evidence from cross-sectional and longitudinal studies "is good enough to claim with reasonable confidence that social support can influence the severity of stressors and the psychological experience of individuals. In the long run it probably affects physical health too". They recommend the use of measures of social support in longitudinal studies.

Coping and adaptation. It important to distinguish coping from adaptation. Adaptation is a broader concept that includes routine or automated actions. What distinguishes coping is the special mobilisation of effort and the drawing upon frequently unused resources or potentials. Automatic actions such as turning off burners after cooking or driving defensively, normally take little energy or conscious attention. These activities are adaptive behaviours rather than coping behaviours. They form an important repertoire of behaviours that can prevent crisis (such as fire or road traffic accidents), and even facilitate ones ability to cope in situations of crisis. In diseases with slow onset and gradual and insidious increase in symptoms, what you might be seeing is adaptation and not coping in the sense used by Cohen & Lazarus (1983).

Outcomes of coping. It is important to distinguish between the lay term "coping" which refers to the outcomes of coping (Cohen 1987), and the actions people take to cope. Psychological outcomes of coping include emotional reactions (eg. how depressed or anxious one is), general well-being, and performance on tasks. Cohen recommends that since a particular coping mode may have different effects on psychological, social, and physiological outcomes, it is important to keep these concepts separate and study their interrelationships.

Coping and self-regulation. Both Hyland (1987) and Carver et al (1989) have discussed the role of coping within self-regulation. Carver et al (1989) in a theoretically based discussion on coping strategies stated that it was time to give more thought to what self-regulatory functions are implicit in people's coping efforts. Their research has been guided by two theoretical models, the Lazarus model of stress and their model of behavioural self-regulation. Failure, long-term disappointment and chronic progressive illness are common and not every one's coping strategies lead to a maladaptive outcome. Hyland (1987) states that control theory suggests three ways in which the "self-protect mechanism" prevents a transient mismatch from becoming a prolonged control mismatch. One important method of avoiding prolonged control mismatch is to re-define the perceptual input (the perception relevant to the control loop) so as to eliminate detected error. As a control system controls its perception of the environment not its environment, a person can alter their perception of events so that failure is no longer perceived. For example, a person may no longer define a symptom as such, and it is therefore no longer a threat to health.

A second method is to reduce error sensitivity in the loop by reducing the discrepancy between the reference criterion and perceptual input by perceiving the input to be less important. For example, the person may decide that the tingling in their left hand is not really important at all and does not actually interfere with anything they want to do . This mechanism for avoiding prolonged control mismatch may function as a kind of automatic self-protect device. Thus it may just be forgotten. If the individual reduces error sensitivity, then this may, but need not necessarily lead to a change in goal. Croyle & Jemmott (1991) make a strong case for the reduction of perceived danger and threat via social comparison, and Leventhal & Diefenbach (1991) have shown the impact "prevalence" information has on "diagnostic" information.

A third method is to change the reference criteria entirely or change the standard of goal attainment. Having developed an illness such as multiple sclerosis the person may argue that at least it is not life threatening even though it might be handicapping, and may change the reference from physical well-being to psychological well-being.

### (iii) Evaluation of coping

The third stage is one of evaluation to determine whether the coping response has moved the individual closer to or further from the goals specified by the representation. Information from the evaluation stage feeds back into the prior stages and can alter the individual's coping strategies and/or the way the problem is defined or represented.

### (b) Determinants of the relationship of self and illness

Research over the last decade on the self has been well reviewed by Markus and Wurf (1987) and points to the self-concept as mediating and regulating this behaviour. The aspect of self-concept to receive the most attention has been that of self-esteem. Epstein (1986), in his review of the self-concept identified the maintenance of self-esteem as one of the basic functions of self-theory. These self-theories are developed as conceptual tools for accomplishing certain ends. He concludes his review by recognising a general factor of self-esteem which includes a wide variety of self-assessments and has broad ramifications for other variables. Increases in self-esteem produce increases in feelings of "happiness, integration, energy availability, freedom and expansiveness". Decreases in self-esteem produce increases in feelings of "unhappiness, disorganisation, anxiety and constriction". Within control theory, self-esteem can be seen as a reference comparator, a threat to which can stimulate action to reduce the perceived discrepancy.

Perhaps the central issue in chronic illness is how the representation of the illness is related to the underlying self-system. Leventhal, Meyer et al (1980) focuses on the following issues. How does the illness become part of the self, does it retain its independence as a situationally specific event. Can the illness be represented as an independent entity and be seen as cyclic or chronic. Gutmann et al (1981), cited by Nerenz et al 1986, in a study of coronary by-pass patients found that patients who developed a permanent time-line actually fell into two different categories; chronic and at-risk. Patients holding a chronic representation saw themselves as ill, appeared depressed, and showed little inclination to engage in rehabilitative activities. Patients holding an at-risk representation felt it important to participate in rehabilitative and preventive activities to avoid recurrence of the acute, symptomatic phase of their coronary disease.

## 3.4 Conclusion

Many of the models health behaviour attempt to explain specific aspects of health cognition and behaviour. However, when attempting to understand how people cope with chronic neurological illness, there is a need for a more general model which encompasses a broader range of beliefs, and links these with coping actions and outcomes.

**Investigations of the structure of lay illness models are few in number but consistent in finding six components according to which experiences of illness are cognitively organised. These components are symptoms, diagnostic label, cause, cure, timeline, and consequences of ill health, as suggested by studies of patient groups as well as subjects free of current medical disorder (Bishop et al 1987, Lau & Hartman, 1983, Leventhal et al, 1980, Meyer et al, 1985). This stands in contrast to the contents of lay illness models, which have emerged as idiosyncratic by virtue of ties to prevailing circumstances (Schober & Lacroix, 1991).**

**The theoretical framework used in this study is Leventhal's self-regulation model and provides an overall framework to integrate peoples beliefs, the actions they take to manage, and their evaluation of those actions. It is a dynamic model based on control theory that enables coping with chronic neurological illness to be studied as an iterative process. The main arguments of this model are that the way the individual represents health threats or symptoms guides coping responses and suggests criteria for appraising outcomes, and that the development of the representation will reflect interactions between the objective and emotional processing systems.**

# Chapter 4. Methodology

**4.1 Introduction**

**4.2 Influence of the theoretical framework on the methodology**

**4.3 The questions asked**

- **4.3.1 Study 1: What are the concurrent, predictive and feedback relationships between the elements of the model over the early stages of a progressive neurological illness?**
- **4.3.2 Study 2: What are the concurrent relationships between the elements of the model and do they vary between illnesses?**
- **4.3.3 Study 3: What are the concurrent relationships between the elements of the model and do they vary over time for the same illness?**

**4.4 The measures**

- **4.4.1 Contextual and person-centred information**
- **4.4.2 Illness representation**
- **4.4.3 Coping**
- **4.4.4 Evaluation of coping**
- **4.4.5 Outcome**

**4.5. Administration of measures**

## 4.1. Introduction

The aim of this chapter is to discuss the influence of the theoretical framework on the methodology, and to give an overview of the studies, their aims and the measures used. Ethics committee approval was sought from both the local and regional research committees and granted. Three studies were carried out to investigate how people cope with chronic neurological disease. The usefulness of self-regulation theory as a framework for understanding peoples representation of their illnesses and the implications for coping was examined.

## 4.2. Influence of the theoretical framework on the methodology

"...the field of health psychology is best served by those who are ecumenical in orientation and who permit their questions to dictate their methods rather than the reverse" (Karoly 1985). With this in mind, an extensive search of models and theories in the field of health psychology ultimately focused on self-regulation theory. This was felt to be the most promising framework in which to address the question of how people cope with the diagnosis of progressive neurological illness, and what factors are implicated in coping at later stages.

The focus of self-regulation theory in health psychology research has been to explore the usefulness of using the theory as a framework " to guide the choice of approaches to study interesting psychological problems in specific clinical areas......rather than to establish the validity of our model" (Nerenz 1987). Because of this research focus, there is no questionnaire that could be considered to be about the model without being about a specific disease or treatment. Furthermore there is no known research using this theoretical framework in progressive neurological illness.

A semi-structured interview was designed to include the model (Appendix A1). In addition, a series of standardised questionnaires were administered to assess various components of the model.

### 4.3 The questions asked

Three studies were carried out to address different aspects of the model and to examine the usefulness of self-regulation theory as a framework for understanding peoples representations of their illness and the implications for coping:

#### 4.3.1 Study 1. What are the concurrent, predictive and feedback relationships between the elements of the model over the early stages of a progressive neurological illness?

#### 4.3.2 Study 2. What are the concurrent relationships between the elements of the model and do they vary between illnesses?

#### 4.3.3 Study 3. What are the concurrent relationships between the elements of the model and do they vary between stages of the same illness?

### 4.4 The measures

The measures used were guided by the theoretical framework used and will be discussed within this context. The interview schedule (Appendix A1) was designed using as a basis the model outlined by Leventhal and colleagues (1984). The schedule was composed of two types of question; closed questions that required field coding and open questions for free answers. All free answers were coded by the author and a colleague. Inter-rater agreement is provided for each question.

#### 4.4.1 Contextual and person-centred information

Individual and contextual factors were included as previous work "suffered by insufficient attention to more stable factors" (Leventhal 1987). These questions were asked in the semi-structured interview and provided a description of the persons age, sex, current health status, daily health practice, self concept and beliefs about illness. Questions concerning marital status, education, housing, employment and economic/class were also included and were designed to construct a picture of the social and economic resources for each individual.

In addition, specific questions about how the individual sees themselves were added in an attempt to explore "how the individual goes about reconstructing the self concept given variation in his/ her psychological representation of the disease and support network" (Leventhal 1987). All answers in this section required field coding.

4.4.2 Illness representation.

Identity

♦ Label: " Many, if not all people, have their own ideas about what might be wrong with them. In *your opinion, what do you think might be wrong with you?*" (Q20, p3). Free text was recorded and coding carried out retrospectively.

Codes: nothing, correct label, description without label, other condition, unclassifiable.

Inter-rater agreement - Study 1, (T1): 17/20. Study 2,(LV) 9/22

All disagreement was accounted for by 2 categories, "description without label" and "other condition". Two codes were therefore used, "correct label" and "incorrect label". This resulted in 100% rater agreement.

♦ Symptoms: "What symptoms have you had over the past week?" (Q14,p2) The number of symptoms reported was recorded and the response written down and the type of symptom coded later using a coding frame devised by Monks (1986) specifically designed for exploring the bases of symptom description among people with MS. Data from the present study was sent to Monks who blind coded it, 81% agreement was achieved on the first occasion.

Cause

Question: "Most people have some ideas about how they got their condition, what ideas do you have?" (Q20, p3). Answers were recorded verbatim and coded retrospectively.

Codes: no idea, attributable to own behaviour, not attributable to own behaviour.

Inter-rater agreement: Study1, (T1) 18/20. Study2 (LV) 20/22

## Consequences

- Seriousness: Two questions assessing perceived seriousness were used, the answers to both were field coded:

Question assessing rated seriousness - "Overall, how serious do you think the consequences of your symptoms/condition are?" (Q22, p4). Response choice: "very serious", "somewhat serious" or "not very serious?"

Question assessing ranked seriousness - people were asked to rank 10 common illnesses in terms of seriousness. These were, headache, cancer, bad circulation, heart attack, diabetes, mental illness, arthritis, stroke, influenza and bronchitis (Q30,p5). They were then asked what position they would place their own condition (Q32,p5).

- Problems and difficulties: "What problems and difficulties has your symptoms/condition caused you over the past week?" (Q23,p4). The answer to this was recorded verbatim and coded retrospectively.

Codes: none, physical, social, emotional, economic.

Inter-rater agreement: Study2, (MS) 11/12. Study3 (MS3) 21/25

- Limitations: Feltons (1984) Limitations Scale was administered within the context of the semi-structured interview. This scale consists of two parts:

Part 1: This elicits what activities the person is able to do without help, "Which of the following things are you well enough to be able to do without help?" (Q28,p5).

Part 2: Elicits what activities are interfered with "Does your condition/symptoms interfere or prevent you from doing any of the following things?" (Q29,p5).

Response choice: Response choice for both parts is "yes" or "no".

Cure

Question: "Do you think that there is anything that can be done to cure your condition?" (Q21, p3). Answers to this question were recorded verbatim and coded retrospectively.
Coding: no, action by self, action by others, action by self and others, unclassifiable.
Inter-rater agreement: Study 2: (LV)21/22. Study 3: (MS3)25/25

Timeline

Question: "How do you think your symptoms will be in 6 months time compared to how they are now?" (Q15,p2). Response choice: no symptoms at all, better, about the same, worse, don't know.

### 4.4.3 Coping

Coping was defined as the actions people take to manage their symptoms/condition. Questions were designed to determine what action people take to deal with the perceived objective and emotional consequences of their condition, in addition, social support as a coping resource was measured. Four categories of action were measured using the semi-structured interview and social support was measured using a standardised questionnaire.

Actions taken to "keep healthy generally".

Question: "Are there things that you do to keep yourself healthy?" If "yes", "what things do you do?" (Q13, p2). Answers were recorded verbatim and coded retrospectively.
Codes: nothing, exercise, diet, exercise and diet, other activity.
Inter-rater agreement: Study 1, (T1) 18/20, Study 2 (MND) 9/11.

Actions taken to manage specific problems and difficulties.

Those people who reported specific problems and difficulties were asked
Question: "What have you done about them?" (Q24, p4). Answers were recorded verbatim and

coded retrospectively.

Codes: nothing, problem focused, emotion focused, information, other.

Inter-rater agreement: Study 2, (MND)9/11. Study 3 (MS3)18/25

Actions taken to increasing understanding.

Question: "What have you done to try and make sense of or to try and understand your symptoms/condition?" (Q33, p6). Answers were recorded verbatim and coded retrospectively.

Codes: nothing, problem focussed, emotion focussed, information related, other.

Inter-rater reliability: Study 1, (T1) 18/20, Study 2, (MND) 11/11.

Agreement was 100% when information was coded as problem focussed.

Actions in addition to those advised by GP.

Question: "Most people, as well as going to their own GP try other treatments, home remedies or activities. What have you tried and did it help?" (Q35, p6). Answers were recorded verbatim and coded retrospectively.

Codes: nothing, lifestyle changes, alternative therapy, lifestyle and alternative, other.

Inter-rater agreement: Study 2, (MND) 9/11, Study 2, (LV) 11/25.

Agreement was improved to 22/25 when alternative therapy and other were collapsed into one category.

Social Support

Sarasons 6 item Social Support questionnaire (Sarason et al,1987) was considered most appropriate within the theoretical framework of the study and had been shown to have validity in predicting behaviour. Most items are concerned with emotional support, the scale is probably most appropriate to assess emotional support (Tardy 1985). In selecting a measure an important consideration was the length due to the time taken to complete the structured interview. The scale, as a whole, is function based with each item concerning a specific supportive function, however, only total and mean number and satisfaction scores are recorded. This yields a score range of 0-54 for number of social supports (SSQ6N) and of 6-36 for satisfaction with social support (SSQ6S). The SSQ6 is reported by Sarason et al (1987) to show satisfactory psychometric properties, with high internal consistency for both number and satisfaction sub-scales (alpha=0.90-0.93), high test-retest reliability and a single factor accounting for the majority of the variance in each of the subscales respectively. In addition, the correlation between SSQ6N and SSQ6S is reported to be relatively modest (r=0.37 to 0.58), suggesting that the two components are best treated separately. Sarason et al (1983) report considerable evidence on the validity of the original scale, including positive correlations between SSQN, SSQS and self-esteem.

### 4.4.4 Evaluation of coping.

Question: "Overall, how well do you feel you have managed?" (Q36,p6).
Response choice: very well, quite well, not sure, not very well, very badly.

### 4.4.5 Outcome

Outcome was examined in three broad areas:
(a) Impact on "self"
(b) Emotional wellbeing.
(c) Disability.

#### (a) Impact on "self".

One of the key issues in self-regulation theory is the role of self-concept in mediating and controlling behaviour. Perhaps the central issue in chronic illness is how the representation of illness is related to the underlying self-system. This was examined in two ways, peoples responses to three questions on the semi-structured interview and Rosenberg's Self Esteem Questionnaire.

◆ Questions on the semi-structured interview:

Question: "Have your symptoms/condition made you think or feel differently about yourself?" (Q25, p4). Answers were recorded verbatim and coded retrospectively.

Codes: no changes, positive changes, negative changes.

Inter-rater agreement: Study 1, sample 2 5/5. Study 3 15/15

Question: "People with symptoms/condition often say they have "gained" something. What do you feel you have gained?" (Q20, p4). Answers were field coded into "something" or "nothing".

Question: "People also say that they loose al ot from having symptoms/condition. What have you lost?" (Q27, p4). Answers were field coded into "something" or "nothing".

People found the latter two questions difficult to answer and duplicated their responses to the previous question, they were therefore not included in the analysis.

◆ Self-Esteem scale (10 item), Rosenberg (1965): Robinson and Shaver (1973) in an extensive review of measures of self-esteem and related constructs recommends the SE scale as representing one of the best of the scales specifically designed to measure self-esteem and has high reliability. The SE scale, while designed initially for use with adolescents, has been widely used with adult samples as well (Robinson & Shaver 1973) and is perhaps the measure most frequently used to look at the impact of stress/illness on the self. This scale has been used extensively and found to have high construct validity across diverse samples of patients (Felton et al 1984, Leek 1991). The SE scale was used to evaluate the individual's overall sense of being capable, worthwhile and competent. Items were answered using the more usual Likert format rather than the Guttman format, from "strongly agree" - "strongly disagree".

(b) Emotional wellbeing.

Three standardised measures were used to assess emotional wellbeing:

◆ Hospital Anxiety and Depression scale (14 items) Zigmond and Snaith (1983): Unlike other measures the HAD includes both anxiety and depression. The scale was used to detect transitory states of depression and anxiety and to give an indication of the severity of emotional disorder.

This scale was developed as a self-assessment mood scale for non-psychiatric medical populations (see appendix 4) and has been found to be acceptable for use with medical populations (Wallace et al 1987, Maguire & Selby 1989).

- General well-being: Affect Balance scale (10 items) Bradburn (1969): The 10 item positive and negative affect sub-scales of the Bradburn Affect Balance scale (Bradburn 1969) were used to assess positive and negative mood states over the past few weeks. While there are other measures of wellbeing, Felton & Revenson (1984) used this scale as a measure of well being with patients with various chronic disabling diseases and suggested that maintaining a balance of positive feeling toward one's life and self in the process of contending with stress has been described as an important consequence of effective coping. Brown and McCarthy (1988) also used this scale in a UK sample of patients with Parkinsons disease. Whereas Bradburn (1969) used a yes/no choice, the scoring used by Brown & McCarthy (1989) was adopted, items being scored on a four point agreement scale from "not at all" to "a great deal". A high score on this represents positive wellbeing.

- Satisfaction with Life (Bradburn 1969): In addition three items measuring Satisfaction with Life were also administered Robinson and Shaver (1973) found that when respondents in social surveys were asked to report on their general satisfaction with life, people who express satisfaction at one time period are quite likely to express satisfaction if interviewed some months later. Expressions of satisfaction then are much more stable at the individual level than one might at first imagine. Particularly significant is the finding that persons of high self-esteem or personal competence express more satisfaction with life. Satisfaction has also been found to be greater among people who suffer less from anxiety, worry and psychosomatic symptoms.

- Interviewers evaluation of coping: The GAIS (Derogatis, 1976) was used to record the interviewer's global impressions of the patients psychological adjustment and represents psychological adjustment across a 100-point continuum broken into ten deciles (levels) by numerical and adjectival descriptors. Each decile has a brief narrative paragraph delineating the quality of adjustment at that level: the rater utilises this information to arrive at a single descriptive value.

## (c) Disability and clinical outcome

Three measures of clinical outcome were used:

- Poser diagnostic criteria: The most recent diagnostic criteria are those of the Poser Committee (Poser et al 1983). This committee, acknowledging the uncertainty still surrounding the clinical diagnosis of MS, distinguish between two groups of cases "definite" and "probable" MS, each with two subgroups of clinical and laboratory supported. The Poser criteria are reproduced below:

  1. Clinically definite multiple sclerosis
     - a. Two attacks and clinical evidence of two separate lesions.
     - b. Two attacks, clinical evidence of one and paraclinical evidence of another separate lesion.
  2. Laboratory-supported definite multiple sclerosis
     - a. Two attacks, either clinical or paraclinical evidence of one lesion and cerebrospinal fluid oligoclonal bands.
     - b. One attack, clinical evidence of one and paraclinical evidence of another separate lesion, and cerebrospinal fluid oligoclonal bands.
  3. Clinically probable multiple sclerosis
     - a. Two attacks and clinical evidence of one lesion.
     - b. One attack and clinical evidence of two separate lesions.
     - c. One attack, clinical evidence of one lesion and paraclinical evidence of another, separate lesion.
  4. laboratory-supported probable multiple sclerosis
     - a. Two attacks and CSF oligoclonal bands.

  Note: An "attack" is the occurrence of a symptom or symptoms of neurological dysfunction which lasts for more than 24 hours.

- OPCS Disability Rating Scale (Martin et al, 1988): The OPCS surveys of disability in Great Britain were commissioned by the DHSS in 1984. The surveys focus of disability, "a restriction or lack of ability to perform normal activities, which has resulted from the impairment of a structure or function of the body or mind".

An innovatory feature of the surveys was the construction of an overall measure of severity of disability which can be used to classify people with different numbers and types of disabilities. In essence, the severity of disability in the thirteen areas of disability is first established and then the three highest of the thirteen separate scores are combined to give an overall score from which people are allocated to one of ten overall severity categories (category 1 least severe, category 10 most severe). This measure was chosen because it was brief, population based and not specific to either patient or condition, and had judges rated validity as opposed to a statistically factored structure.

◆ Kurtzke's Expanded Disability Status Scale (KDDS)(Kurtzke 1983): In the context of neurological diseases and multiple sclerosis in particular, Kurtzke's measure has become widely used. As the name suggests the measure is focused on disability arising from neurological damage in eight "functional systems" (eg. pyramidal, cerebella, brainstem). The scale ranges from 0 (normal neurological examination) through increasing levels of disability to 10 (death due to multiple sclerosis). The scale is ordinal and can be used to chart disease progress in terms of impact on disability. A modified version of this was used successfully by Leek (1991).

## 4.5 Administration of measures

Fig.4.1 shows the timing of the administration of the measures for all of the studies.

| | | Study | |
|---|---|---|---|
| Time of administration of all measures: | 1 | 2 | 3 |
| Before admission to hospital for tests and investigations | ◆ | ◆ | |
| * During admission to hospital for tests and investigations | ◆ | | |
| 4-6 weeks & 6-7 months following discharge from hospital | | | ◆ |
| 2 & 7+ years following diagnosis | | | ◆ |

(* KDDS only)

## Chapter 5 : The studies

## 5.1 Introduction

Three studies were carried out, a longitudinal, cross-sectional and a pseudo-longitudinal study. One group of patients, those being admitted for tests and investigations for multiple sclerosis, was involved in all three studies.

## 5.2 Study 1: Illness representation and coping in people being investigated for chronic neurological illness: a prospective longitudinal study.

A cohort of twenty people attending a neurology outpatient clinic in one of two district general hospitals serving the county of Gloucestershire between January 1988 and July 1989 and who met the following criteria were included.

### 5.2.1 Selection criteria

There were two main selection criteria:

(a) People with suspected multiple sclerosis.

(b) The neurologist, having seen a person as an outpatient on at least one occasion, considered that an admission to hospital for the purpose of carrying out investigations for suspected multiple sclerosis was the next step in the clinical management.

### 5.2.2 Sample description

A cohort of twenty people with suspected multiple sclerosis were interviewed prior to routine admission to hospital for tests and investigations and twice in the following six months. Their representations about their conditions, coping, evaluation of their coping and outcome were assessed at each time. The links between the elements of the model and their relationship over time was explored. Factors predictive of outcome were examined.

### 5.2.3 Procedure

The research procedure was designed to be compatible with the clinical management and to minimise any inconvenience to the patient and is described below:

Fig.5.1 Clinical management and research procedure.

| Time scale | Clinical Management | Research Procedure |
|---|---|---|
| (a) Before admission to hospital | Attends OP clinic | |
| | Need for admission identified | |
| | | Admission date+ study letter sent |
| | | 1st interview |
| (b) Admission to hospital | Admitted to ward | |
| | | KDSS by doctor |
| | Discharged with OP clinic app. | |
| (c) After discharge:4/6 weeks | Psychologist visits at home | |
| | OP clinic with consultant | |
| | | 2nd interview |
| | Further visits as required | |
| (d) After discharge:6/7 months | | 3rd interview |

#### (a) Before admission to hospital.

People identified as needing admission to hospital for tests and investigations for multiple sclerosis received a standard admissions letter with the hospital information booklet. The study letter was sent out together with this to all people who met the study criteria. This was sent out by the neurology departmental secretary approximately seven days after the outpatient clinic appointment and usually gave the person about fourteen to twenty one days notice of admission. A week later everyone receiving a letter inviting them to take part in the study was telephoned and, if consent was given, a time was arranged for the psychologist to visit the person at home. No one refused. All interviews took place in the persons' home as the study dealt with everyday rather than hospital related cognitions, emotions and behaviours. In addition, clinical experience suggested that rapport was more easily and rapidly established away from the hospital. Most interviews took place during the day, but where the person was working and unable to take time off work, an evening interview was arranged. The person was interviewed where possible on their own, although the spouse was frequently present for at least the introductory part of the interview when the rationale for the study was explained. Before the interview took place the rationale for the study and a description of what the interview would entail was given:

> "This research project is concerned with people's views about their condition and what they expect from their hospital admission. It is your ideas that we are interested in. From the results of the study we hope to be able to identify how peoples own views and experiences influence the way they cope with their condition, and how this varies between people and between different conditions. The interview will involve me talking with you for about an hour and a half. I shall also be asking you to fill in some forms while I am here to take back with me. All the information collected during this study is confidential. It doesn't go into the hospital notes. It is not discussed with the hospital staff. Everyone is allocated a research number, so names do not appear on the collated data. All the information is then pooled and individual people will not be identified. Do you have any questions you would like to ask me before we start?"

Patients were then interviewed. Each interview took about an hour and a half, and followed the same format. The interview followed the format laid down in the interview schedule When this was completed, each patient was asked to complete a series of questionnaires. The scales were explained and the relevance of these scales to the study was stressed and the confidential nature of the answers underlined. At this interview, patients were also asked if they would agree to be contacted approximately four to six weeks, and six months following discharge from hospital.

### (b) Admission to hospital.

Patients admitted to hospital underwent a series of routine tests and investigations over the 2-3 day admission period. The lumber puncture has been a diagnostic aid for a number of years, and is a means of extracting some of the cerebospinal fluid which surrounds the central nervous system for laboratory analysis. A sample of fluid is withdrawn by use of a fine needle inserted between two of the lumbar vertebrae in the lower back. The CSF is abnormal in about 50% of multiple sclerosis sufferers and one such abnormality is a high concentration of protein in the

CSF. More specifically, patients with multiple sclerosis tend to have high levels of immuno gamma globulin in the CSF. Routine blood and urine samples are taken during the admission, and a detailed neurological examination undertaken.

Another test used to determine whether demyelination has occurred by measuring the speed at which nerve impulses are transmitted from the eye to the brain is the Visual Evoked Response test. This is a non-invasive test and involves the patient sitting in front of a black and white chequered screen and fixating a spot on the screen.

It was explained to patients that the results of the tests would not be available during their hospital stay and that an outpatient appointment would be arranged for approximately four weeks following discharge from hospital. In those circumstances where the patient wishes to discuss the possibility of having multiple sclerosis then this discussion takes place prior to discharge with the caveat concerning the outcomes of the tests. If the discussion regarding the diagnosis had taken place whilst the patient was in the ward, it was explained that part of the routine was for the psychologist to visit them at home in order that they may have the opportunity to discuss this information and how they felt about it. Independent of diagnosis, a second research interview with the psychologist was arranged for about six weeks following discharge. This was arranged either before the patient left hospital or by phone shortly afterwards.

(c) After discharge from hospital.

On discharge from hospital patients were given a routine follow up appointment to attend the outpatient clinic in about four weeks. This allowed time for the results of all the tests to be available in order that the results be discussed with the patient. If the diagnosis had been discussed with the patient whilst in hospital then the appointment with the psychologist was usually arranged before the outpatient appointment with the consultant.

At the outpatient appointment, if the results enabled a diagnosis to be reached, then the consultant discussed this with the patient at the outpatient follow up appointment and a further appointment arranged for about three months. The patient was informed that it was routine practise to put them in touch with the psychologist in order that they may have the opportunity to discuss this information and how they felt about it. If available during the clinic the psychologist arranged a time with the patient to visit them at home, suggesting that they be accompanied by anyone they felt to be appropriate. If a diagnosis was not discussed with the patient at this clinic then a further appointment with the consultant was arranged for about three months.

At the routine visit from the psychologist the patient was encouraged to discuss any issues they felt relevant, including their reactions to the information. Information was only provided if requested following a brief description of what was available. In most instances the booklet "So You Have MS" published by the MS Society was given, plus some basic information on diet and exercise. Information concerning self-help groups was provided to people with MS. A follow up appointment was arranged if requested, and patients were encouraged to contact the psychologist if at any time in the future they felt the need to do so.

The psychologist visited for research purposes approximately two weeks after the initial outpatient follow-up appointment and approximately 6 months following discharge at which time the interview schedule plus all the questionnaires were repeated.

## 5.3 Study 2 : Illness representation and coping in people being investigated for differing chronic illnesses: a cross-sectional study.

This study compared people waiting to be admitted to hospital for tests and investigations for one of three chronic illnesses, MS, MND and liver disease. People from the previous study at this stage were compared to people being investigated for chronic liver disease and those being investigated for MND. These conditions were chosen as their clinical management, at this stage, is very similar, there being no definitive diagnostic tests. The onset of chronic liver disease differs from that of chronic neurological disease in that very frequently the symptoms are non-specific and the presence of disease only detected following a blood test. This study enabled a comparison of the impact of very differing illness histories on representation and coping, as well as providing a third diagnostic group for comparison.

### 5.3.1 Sample and procedure

(a) A cohort of 11 people with suspected motor neurone disease were interviewed prior to admission to hospital for test and investigations. The same clinical management and research procedures were used as for this stage of study 1.

(b) A cohort of 22 people attending a gastroenterology outpatient clinic in one of three hospitals serving Gloucestershire between June and November 1989 and who met the following criteria were included. The criterion for inclusion was that the gastroenterologist, having seen the person on at least one occasion, considered that an admission to hospital for the purpose of carrying out a liver biopsy for suspected liver disease was the next step in the clinical management of the person. Their representations, coping, evaluation of coping and outcome were assessed at this stage. The procedure used for study 2 replicated the "before admission" stage of the previous study.

(c) The cohort of 20 people with suspected MS described in the previous study were used in this study and were compared to the above samples.

## 5.4 Study 3: Illness representation, coping, appraisal and outcome in people previously diagnosed with multiple sclerosis : a pseudo-longitudinal study.

This study allows for a comparison of the elements of the model, the links between them and a comparison of coping outcomes at different times since the diagnosis of the disease. People from study 1 who had been newly diagnosed with multiple sclerosis were compared at six months, with two additional samples of people with diagnosed multiple sclerosis. Those people having the diagnosis of multiple sclerosis for 2 years and those people having the diagnosis for longer than 7 years. This allows for a comparison of emotional outcomes to be made between two groups of patients who have had the diagnosis of MS for 6 months, 2 years and greater than 7 years.

### 5.4.1 Sample description

Sample MS1: twenty people diagnosed with MS within the previous 6 months. Participants in study 1 had therefore completed 2 earlier interviews.

Sample MS2 : nineteen people with a diagnosis of multiple sclerosis for approximately two years. Nineteen people diagnosed as having multiple sclerosis 22-26 months previously were interviewed. Their representations, coping, appraisal and outcome were determined. The relationship between the elements of the model at a different stage in the disease process was addressed. The effect of time-line on the representation and coping was determined. The criterion for inclusion was that the person had been seen routinely by the neurologist and that this had led to tests and investigations resulting in the diagnosis of multiple sclerosis.

Sample MS3: twenty five people with the diagnosis of multiple sclerosis for greater than seven years. Thirty seven people previously diagnosed with multiple sclerosis were contacted, 25 people agreed to be interviewed. Of the remaining 12, 3 had died, 2 refused and 7 failed to reply.

### 5.4.2 Procedure

The procedure with respect to the measures used and the format of the interview was the same as the interview for study 1. For MS2 and MS3 a letter was sent informing the person of the study and asking for their help. People were asked to complete and return a tear off slip stating whether they wished to take part, and if so specifying convenient times to call. Reminders were sent to people not replying within the specified time period. People were contacted within two to four weeks following receipt of all letters with a proposed time to call, all visits took place between April and July 1989 in the persons' home.

# Chapter 6. Study 1 : Results and discussion

## 6.1 Introduction

The statistical analysis reported in this study and the ensuing studies were guided by three main texts: Nonparametric statistics (Siegal 1988) Quantative data analysis for social scientists (Bryman & Cramer 1990) and Using Multivariate Statistics (Tabachnick & Fidell,1989). All statistics were carried out using SPSS PC+ programmes. The central analyses of the study were concerned with peoples representation of their condition, coping, evaluation and outcome before being admitted to hospital for diagnostic tests and investigations, and on two occasions following discharge from hospital.

### Abbreviations used in text and results tables

The names used in some of the tables have been abbreviated. In addition, the times of the interviews have also been abbreviated both in the text and in the tables.

| | | | | |
|---|---|---|---|---|
| Time of interviews: | T1 | first interview before admission to hospital | | |
| | T2 | second interview, 4 weeks following discharge | | |
| | T3 | third interview, 6 months following discharge from hospital | | |
| Coping: | hlt | keep healthy generally | | |
| | prb | specific problems and difficulties | | |
| | inf | seek information | | |
| | lif | change lifestyle | | |
| | act | total number of actions taken | | |
| Social Support: | S(N) | social support (number) | | |
| | S(S) | social support (satisfaction) | | |
| Emotional outcomes: | anx | HAD Anxiety | S | Self |
| | dep | HAD Depression | Se | Self Esteem |
| | wel | Wellbeing | | |
| | hap | happiness | | |
| | cha | change | | |
| | acc | accomplishment | | |

## 6.2 Demographic characteristics

Twenty people with suspected multiple sclerosis were eligible to take part in this study and all agreed to take part over the three time periods. Following the semi-structured interview, questionnaires were completed by 19 people at T1 and all people at T2 and T3. Of the 20 people, 15 were women and 5 were men with an average age of 36 years (26-52) and no significant age difference between the sexes. Fifteen of the cohort were living with their partners/spouses and children, 4 with parents or siblings and only 1 person living alone. Three people were divorced or separated.

Seventeen people were either in full or part time employment, only 1 person moving from full to part time employment at time 3. Two people were unable to work at each time because of their condition. Of those people in work, 15 had either skilled, intermediate or professional jobs.

Of the partners, 18 were either in full or part time employment. 1 partner at T3 was not working because of their partners condition, 1 partner was unemployed at T1 and T3.

## 6.3 Description of the elements of the model and change over time

### 6.3.1 Illness representation

Five components of illness representation were assessed using the semi-structured interview; identity, cause, consequences, cure and timeline (Table 6.1).

Table 6.1: Illness representation at each time (number(%) of people).

| | T1 | T2 | T3 |
|---|---|---|---|
| **Identity:** | | | |
| correct label | 8(40%) | 13(65%) | 16(80%) |
| reporting symptoms | 17(85%) | 18(90%) | 13(65%) |
| **Cause:** | 11(55%) | 11(55%) | 9(45%) |
| **Consequences:** | | | |
| rated as More Serious ("very serious" + "somewhat serious") | 13(65%) | 13(65%) | 11(55%) |
| ranked as More Serious (ranked 1-5) | 8(40%) | 10(50%) | 6(30%) |
| specific problems | 13(65%) | 8(40%) | 10(50%) |
| limitations | 14(70%) | 14(70%) | 12(60%) |
| **Cure:** | 12(60%) | 6(30%) | 3(15%) |
| **Timeline:** | | | |
| expect to be better: | 8(40%) | 7(35%) | 4(20%) |

### (a) Identity

Label: Eight people had the correct label at T1 with a further 6 people having a fairly accurate description of the condition, "had a virus, it's attacked the sheath covering the nerve", "inflammation of the nerves". At T2 and T3, 13 and 16 people respectively had the correct label. All but one of the 8 people who held the correct label at T1 maintained that label at T2 and T3.

Symptoms: Seventeen, 18 and 13 people respectively reported symptoms at T1, T2 and T3. A single factor repeated-measures MANOVA showed a significant difference in the number of symptoms reported over time (Fig.6.1), with significantly more people reporting fewer symptoms at T3 compared to T1 (Sign test: Binomial 2-tailed p=.03). People having the correct label did not differ from those without the correct label in the number of symptoms reported. For further analysis, where contingency tables have been used, people were divided at the median, those people with 2 or less symptoms and those with 3 or more. Fig.6.2 shows the types of symptoms people reported over the three time periods. A total of 135 symptoms were reported, 56 at T1, 43 at T2 and 36 at T3. At each time over 70% of symptoms were abnormal sensations such as pins and needles, tingling, numbness, tightness, weakness, 'giving out' and dragging. With the remaining symptoms being accounted for by tiredness, fatigue or difficulty, and irritability.

(b) Cause

The number of people attributing a cause to their condition changed very little over time, with about half attributing some cause. Of the people who did attribute a cause to their condition, 5 attributed it to their own behaviour on all three occasions. Explanations remained constant and included "lifting heavy equipment", "I'm a bit hyperactive", "overworking" and "took sidex sprays that were out of date and went up into eyes". For the purposes of further analysis, data were collapsed into those who attributed a cause and those who did not.

(c) Consequences

Seriousness: There were no significant changes in the ranking or rating of seriousness over the time period. Thirteen, 13 and 11 people respectively rating their condition to be either "very serious" or "somewhat serious". Fig 6.3 shows the ranking people gave to the seriousness of their condition. A single factor repeated-measures MANOVA showed no significant difference in rankings over time (F=.07,df=2,p=.93). For the purposes of further analysis, where contingency tables have been used, data were collapsed into those people ranking or rating their condition as More Serious (ranking 1 to 5; rating "very serious" + "somewhat serious") and those people ranking or rating their condition as Less Serious (ranking 6-10; rating "not very serious).

Fig.6.1 Identity: number of symptoms reported at each time

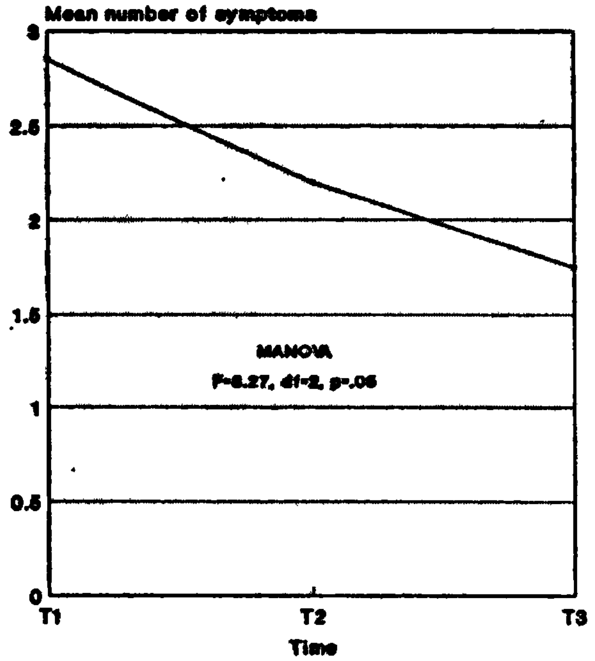


Fig.6.2 Identity: type of symptom reported at each time

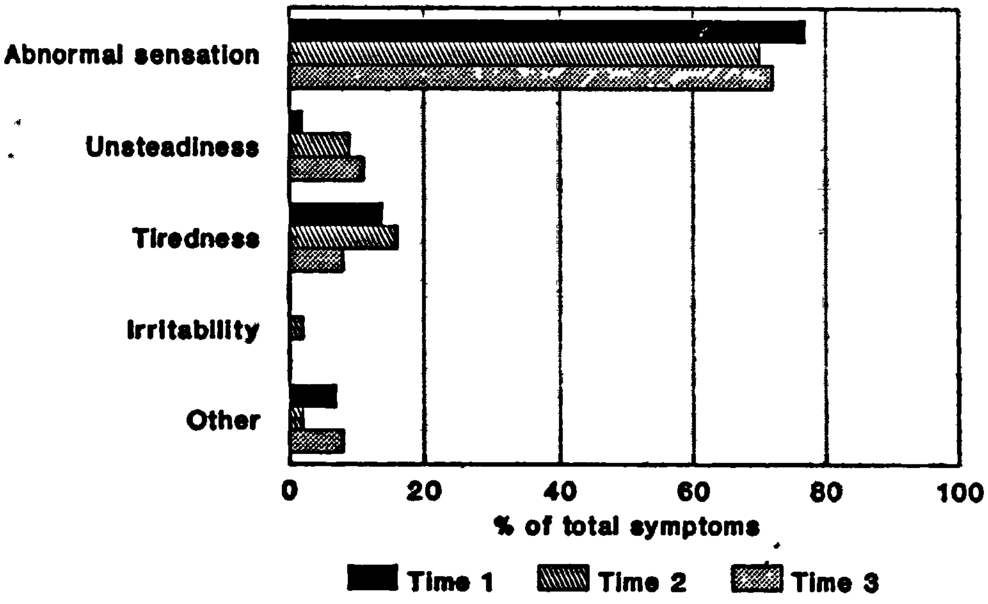
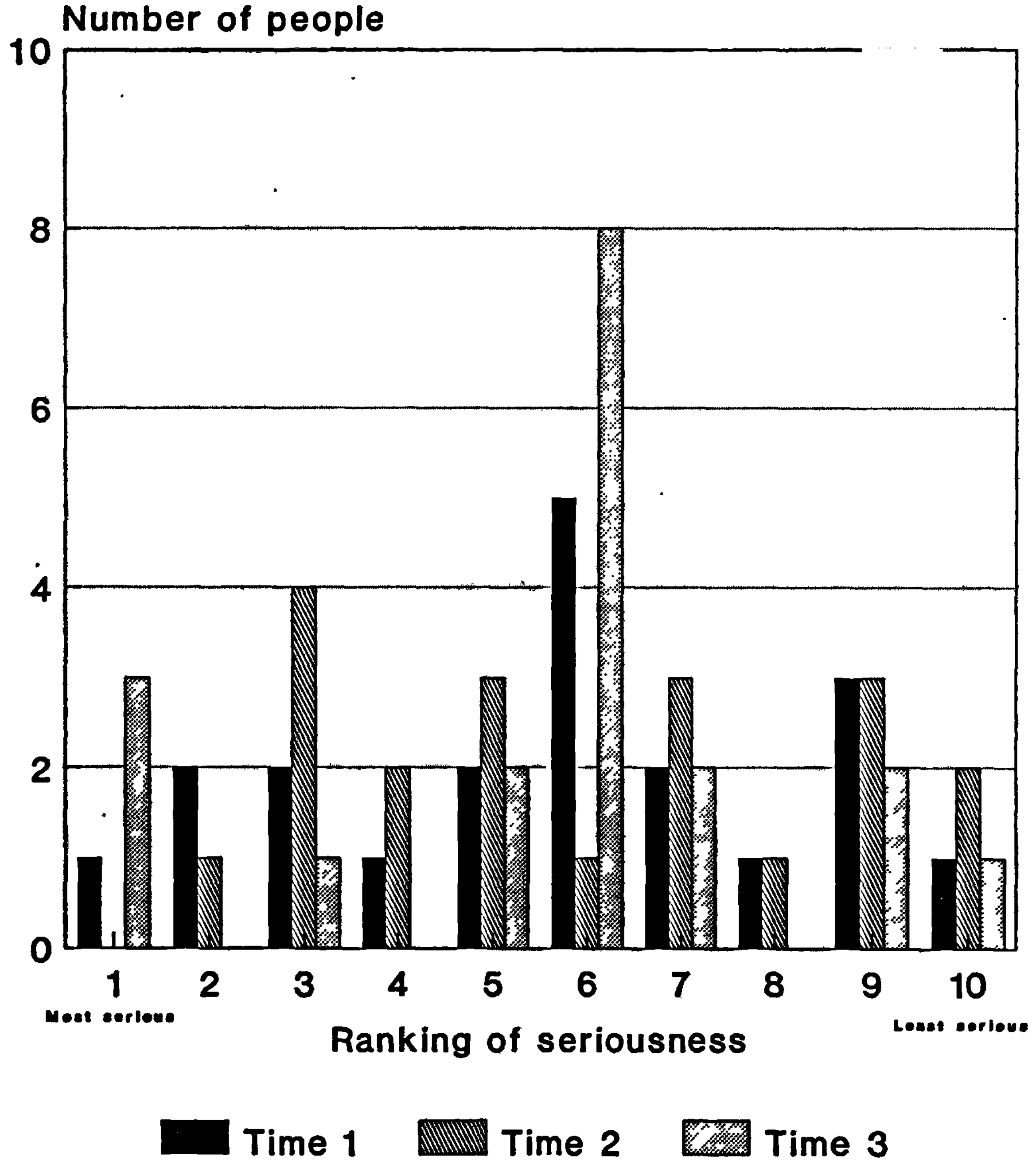


Fig.6.3 Consequences: ranking of seriousness at each time



| | | | |
|---|---|---|---|
| Mean | 5.7 | 6 | 5.7 |
| SD | 2.6 | 2.6 | 2.5 |
| Range | 1-10 | 2-10 | 1-10 |

Table 6.2: Ranking of seriousness before & after diagnosis and at 6 months (number of people).

| | After diagnosis | | | |
|---|---|---|---|---|
| | T2 | | T3 | |
| | More Serious | Less Serious | More Serious | Less Serious |
| T1 Before diagnosis: | | | | |
| More Serious | 0 | 8 | 0 | 7 |
| Less Serious | 6 | 6 | 3 | 5 |

All 8 people who ranked their condition as More Serious at T1, ranked their condition as Less Serious at T3, and ranks at T1 were negatively correlated with those at T2 and T3. (Pearson's r =-.45, p=.05, -.54, p=.03 respectively).

Problems and difficulties: Thirteen, 8 and 10 people respectively reported some problems or difficulties over time. For the purpose of analysis, data were collapsed into those people with problems and difficulties and those with none.

Limitations : Fig.6.4 shows the type of limitations people reported at each time, and Fig 6.5 the total number of limitations reported at each time. A score of 1 means the person reported difficulty in one of the domains measured by the scale, 2 implies difficulty in 2 domains, a maximum score of 9 implies difficulties in all areas measured by the scale. Half the people were either not limited at all by their condition or were limited in only one domain on each occasion. The relationship between the number of limitations at each time was examined (table 6.3).

Table 6.3: Relationship between the number of limitations at each time

| | T2 | T3 |
|---|---|---|
| T1 | r=.56** | r=.64** |
| T2 | | r=.73*** |

Pearson's r, p=<.01**, p=<.001***

Fig.6.4 Consequences: type of limitation reported at each time

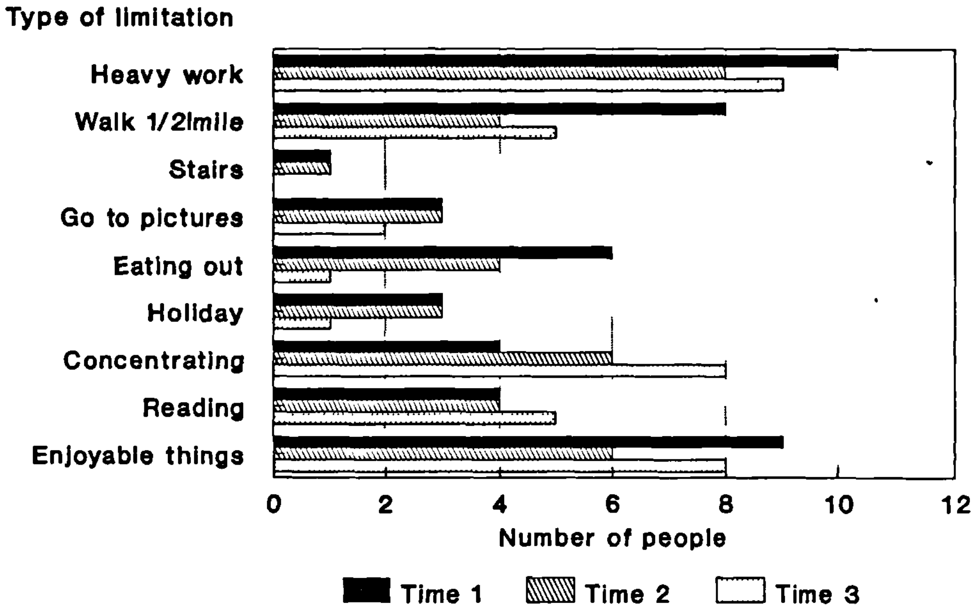
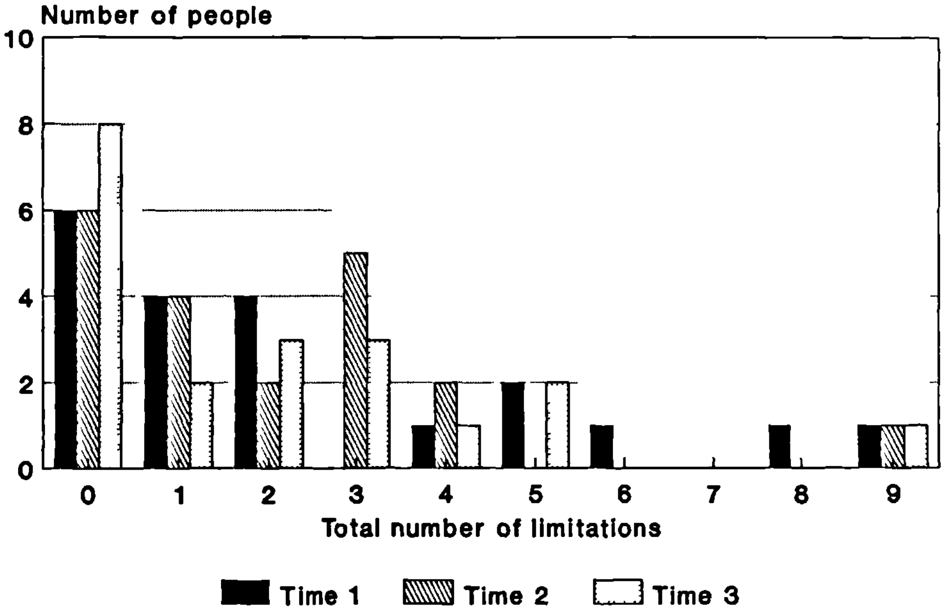


Fig.6.5 Consequences: number of limitations reported at each time



Limitations at one time predicted the number of limitations reported at later times. People who had more symptoms at T2 and T3 reported more limitations at both times (table 6.4).

Table 6.4: Relationship between limitation and symptoms at each time.

| | Number of limitations at each time. | | |
|---|---|---|---|
| | T1 | T2 | T3 |
| Number of symptoms | r=.22 | r=.66*** | r=.66*** |

Pearson's r. ***p=.001

### (d) Cure

While 12 people thought there was a cure for their condition at T1, only 6 and 3 people felt this to be the case at T2 and T3. Of the 12 people who felt there was something that could be done to cure their condition at T1, 6 felt there was something they could do about it themselves. At T2 only 6 people felt there was a cure, 3 relating to something they could do, at T3 this figure had decreased to 1 person with a belief in their own ability to effect a cure. For the purpose of further analysis, at each time, data were collapsed into people who believed in a cure and those who did not.

### (e) Timeline

Peoples beliefs about the course of the illness are summarised in Fig.6.6. While 8 people expected to be "better in 6 months" at T1, this belief reduced to 7 and 4 at T2 and T3 respectively. Clearly a chronic timeline is held by the majority of people even before diagnosis, although at no time did anyone expect to be "worse" in 6 months. For the purposes of further analysis, data were collapsed into people who "expected to be better" and those who did not.

Fig.6.6 Timeline at each time

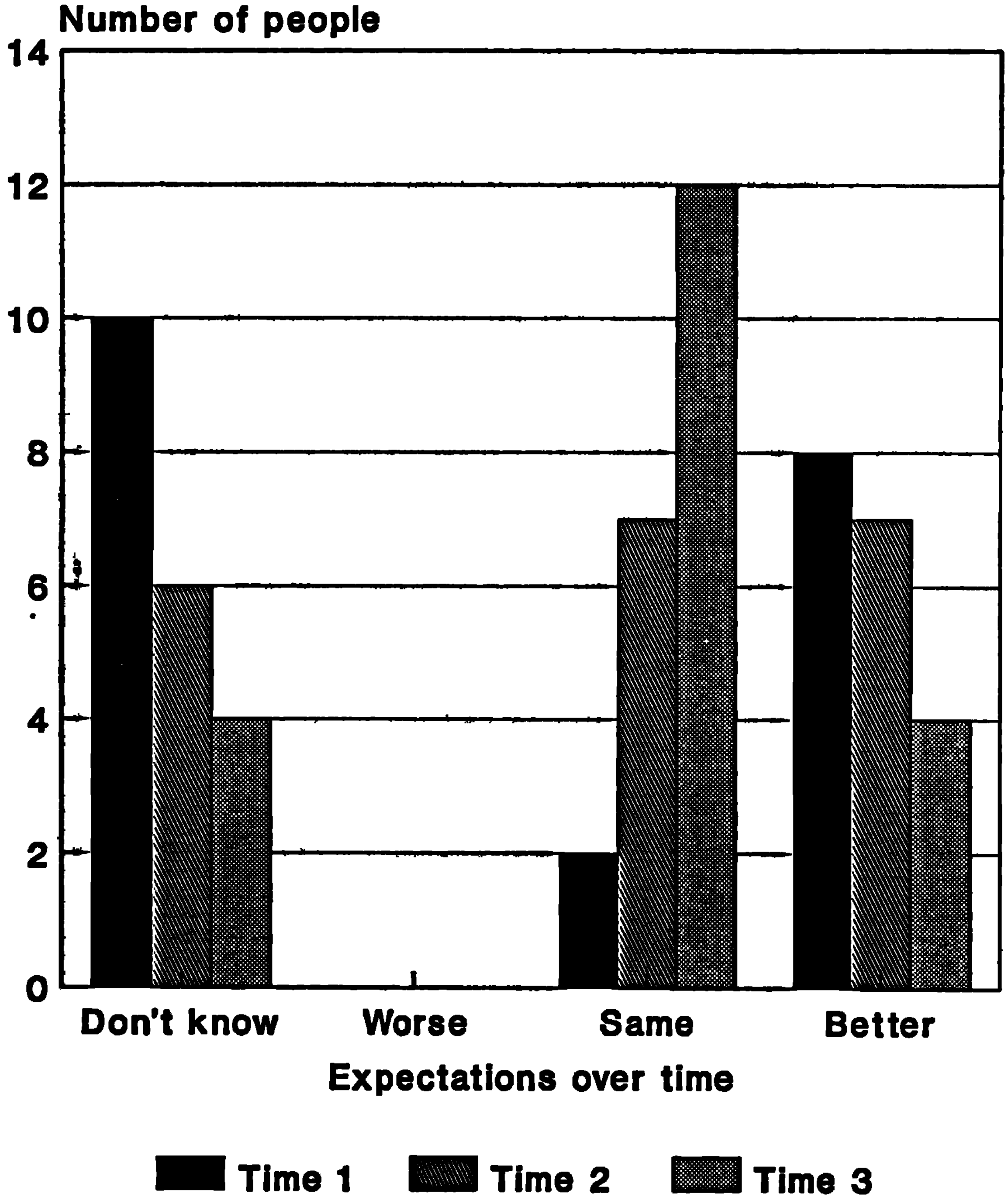


Fig.6.7 Coping: actions taken to cope at each time

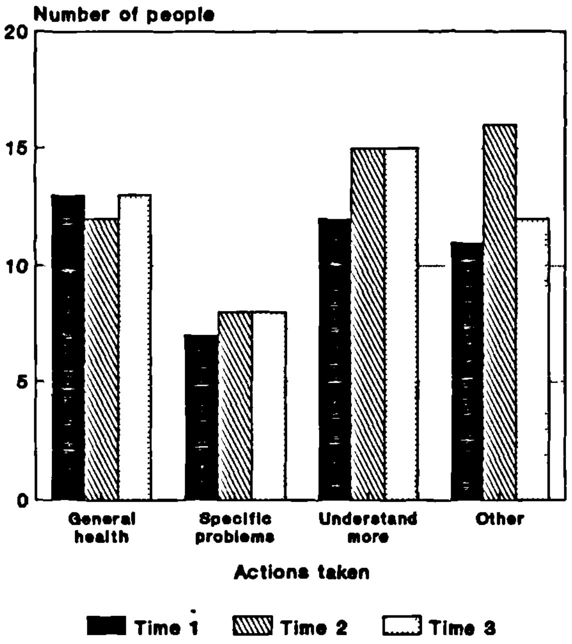
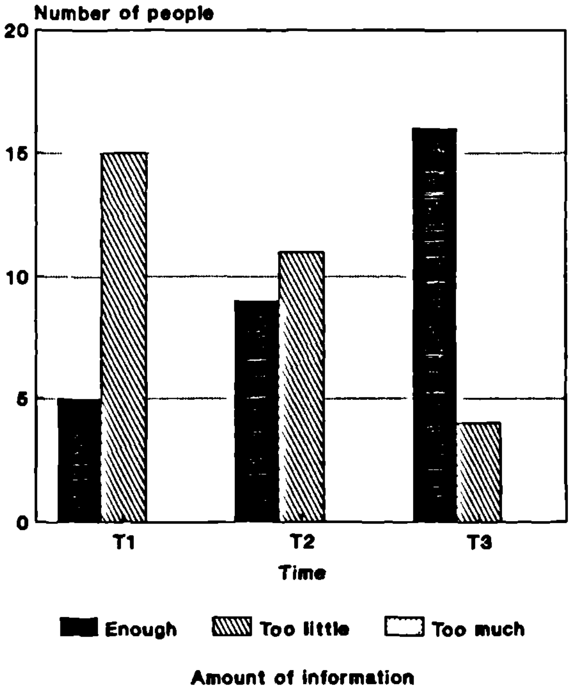


Fig.6.8 Coping: satisfaction with information at each time



### 6.3.2 Coping

Five categories of action were assessed to measure coping:

(a) Actions taken to keep healthy generally.

(b) Actions taken to manage specific problems and difficulties.

(c) Actions taken to increase understanding.

(d) Actions taken other than those advised by doctor.

(e) Total number of types of actions taken.

(f) In addition, social support as a coping resource was measured.

For analysis, the actions taken were collapsed into taking action versus taking no action at all (Fig.6.7)

(a) Actions taken to keep healthy generally: Approximately two thirds of the people undertook some activity to keep themselves healthy, this remained constant over time. At T1, the main activity was exercise. While still the predominant activity at T2 and T3, the range widened, with people incorporating diet into their strategy.

(b) Actions taken to manage specific problems and difficulties: At T1, 7 of the 13 people had taken some action to manage specific problems and difficulties caused by the condition. At T2, 8 of the 9 and at T3 all 8 people who had specific problems and difficulties were taking action to manage those problems.

(c) Actions taken to increase understanding: Of the 12, 15 and 15 people taking action to increase their understanding of their condition at T1, T2 and T3, 10, 11 and 12 people respectively were seeking information. For further analysis, actions taken to increase understanding will be analysed in terms of those people seeking information and those not. People were also asked whether they had enough information. The results are shown in Fig.6.8. At T1, significantly more people said that they had "too little" rather than "enough"(Binomial test, $p=<.05$). At T3, significantly more people said that they had "enough" information rather than "too little"(Binomial test, $p=<.01$). No one reported having "too much" information at any time.

(d) Actions taken in addition to those advised by GP: 11, 16, and 12 people respectively had taken action in addition to that recommended by the general practitioner at T1, T2 & T3 respectively. These activities mainly consisted of changes in diet and exercise.In addition, 4 and 2 people respectively had sought alternative remedies at T1 and T2. In all further analysis this will be referred to as lifestyle changes.

(e) Total number of types of actions taken: A new COPING variable was computed which classified people as taking either none or, 1, 2 or 3 types of actions, the results are shown in Fig.6.9. Most of people were taking between 2 and 3 types of action at each time. There were no significant correlations (using Phi as a measure of association) between taking an action of one type and taking an action of another type.

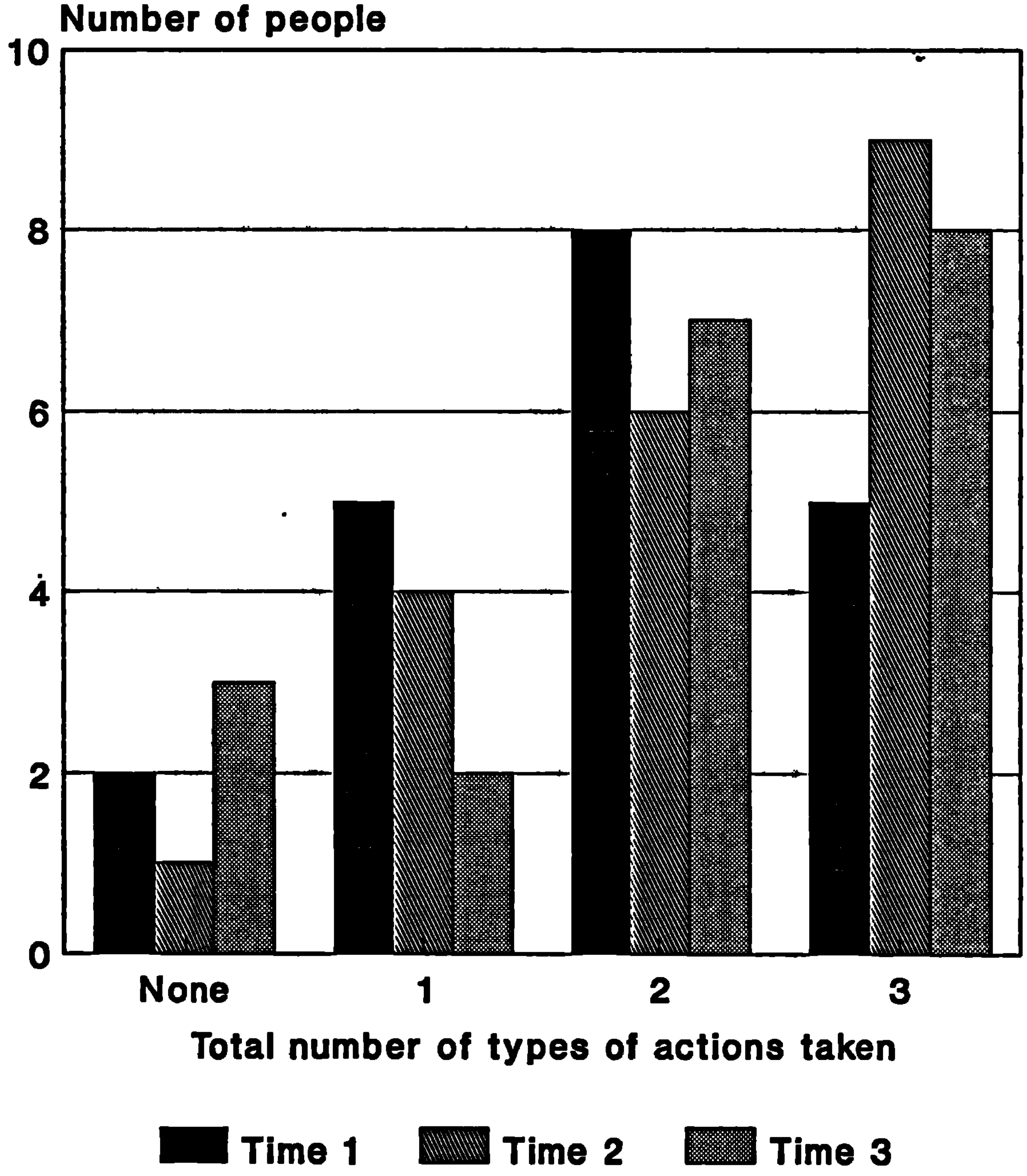
(f) Social support as a coping resource (Sarason 6-item 1983): The function of social support as a coping resource was examined. Two measures were used, the number of social supports and satisfaction with social support (Table 6.5).

Table 6.5: Social support: number and satisfaction (mean(SD)).

| Social supports: | T1 | T2 | T3 |
|---|---|---|---|
| number | 3.2(2.2) | 3.7(2.6) | 4.8(3.6) |
| satisfaction | 18.6(13.2) | 19.8(14.1) | 24.6(18.3) |

A single factor repeated-measures MANOVA showed a significant linear relationship for the number of social supports to increase over time (F=37.6,df=2,p= <.000), this was not significant for satisfaction with social supports (F=2.2,df=2,p=.13). The relationship between number and satisfaction was also examined. Results show a strong correlation at all times (T1,r=.99, T2,r=.80, T3,r=.84. p=<.001, Pearson's r).

Fig.6.9 Coping: total number of types of actions taken at each time



### 6.3.3 Evaluation of coping

It can be seen from Fig. 6.10 that most people felt that they had coped either "quite well" or "very well", with nobody feeling that they had coped "very badly". Using a Sign Test there was no significant change over time. In all further analysis, the data will be collapsed into Very Well = "very well", Less Well = all responses other than "very well".

### 6.3.4 Outcome

Outcome was examined in three broad areas:

(a) Impact on the "self".

(b) Emotional wellbeing.

(c) Severity of disability.

(a) Impact on the "self"

This was examined in two ways, perceived changes in feelings about self as a result of symptoms/condition as measured by people's response to three questions on the semi-structured interview and Rosenberg's Self Esteem questionnaire.

Perceived changes in feelings about self: The number of people feeling either positively or negatively about themselves as a result of their symptoms/condition is summarised in Fig.6.11. Most people felt differently about themselves as a result of their symptoms/condition. There was a significant difference between the categories at all times (Binomial test:T1,p=.01, T2,p=.04, T3,p=.02) with more feeling negatively rather than positively.

Fig.6.10 Evaluation of coping at each time

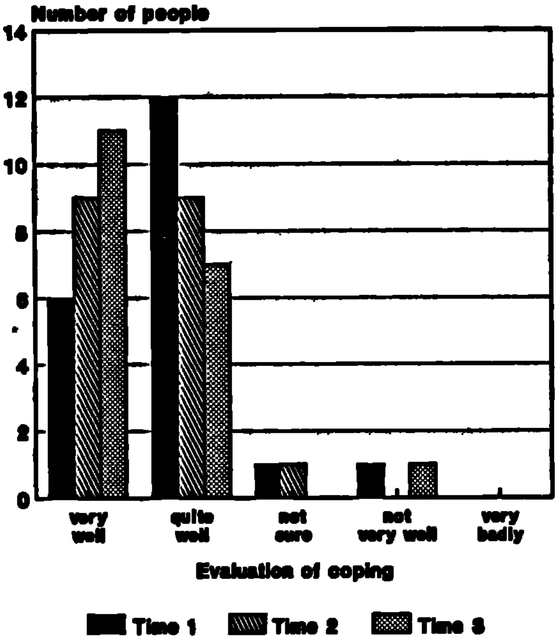
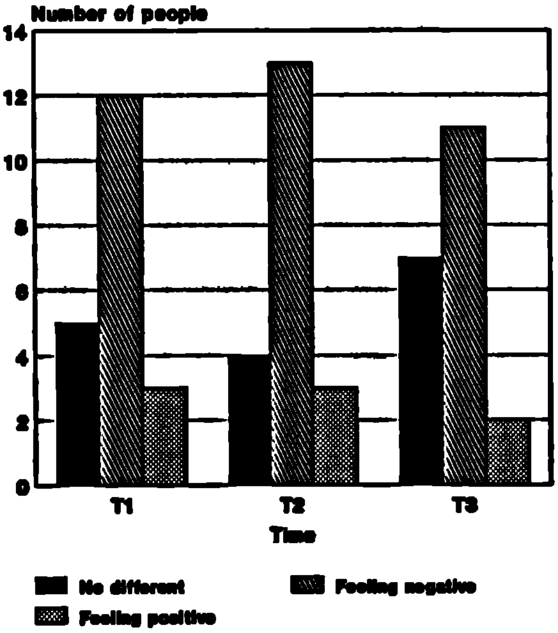


Fig.6.11 Impact on self: feelings about self at each time



<u>Self Esteem</u>: The mean Self Esteem scores for each time are shown in Table 6.6.

Table 6.6: Self Esteem (mean(SD) and range).

| | | | |
|---|---|---|---|
| T1 | 35.5(7.1) | 23-50 | (n=19) |
| T2 | 36.5(7.2) | 23-50 | (n=20) |
| T3 | 37.3(8.2) | 22-49 | (n=20) |

A single factor repeated-measures MANOVA showed no significant differences in Self-Esteem over time (F=1.43,df=2,p=.25), however, people with negative feelings about themselves had lower Self Esteem scores at all times, this was significant at T3 (Table 6.7).

Table 6.7: Self Esteem and feelings about self (mean(SD)

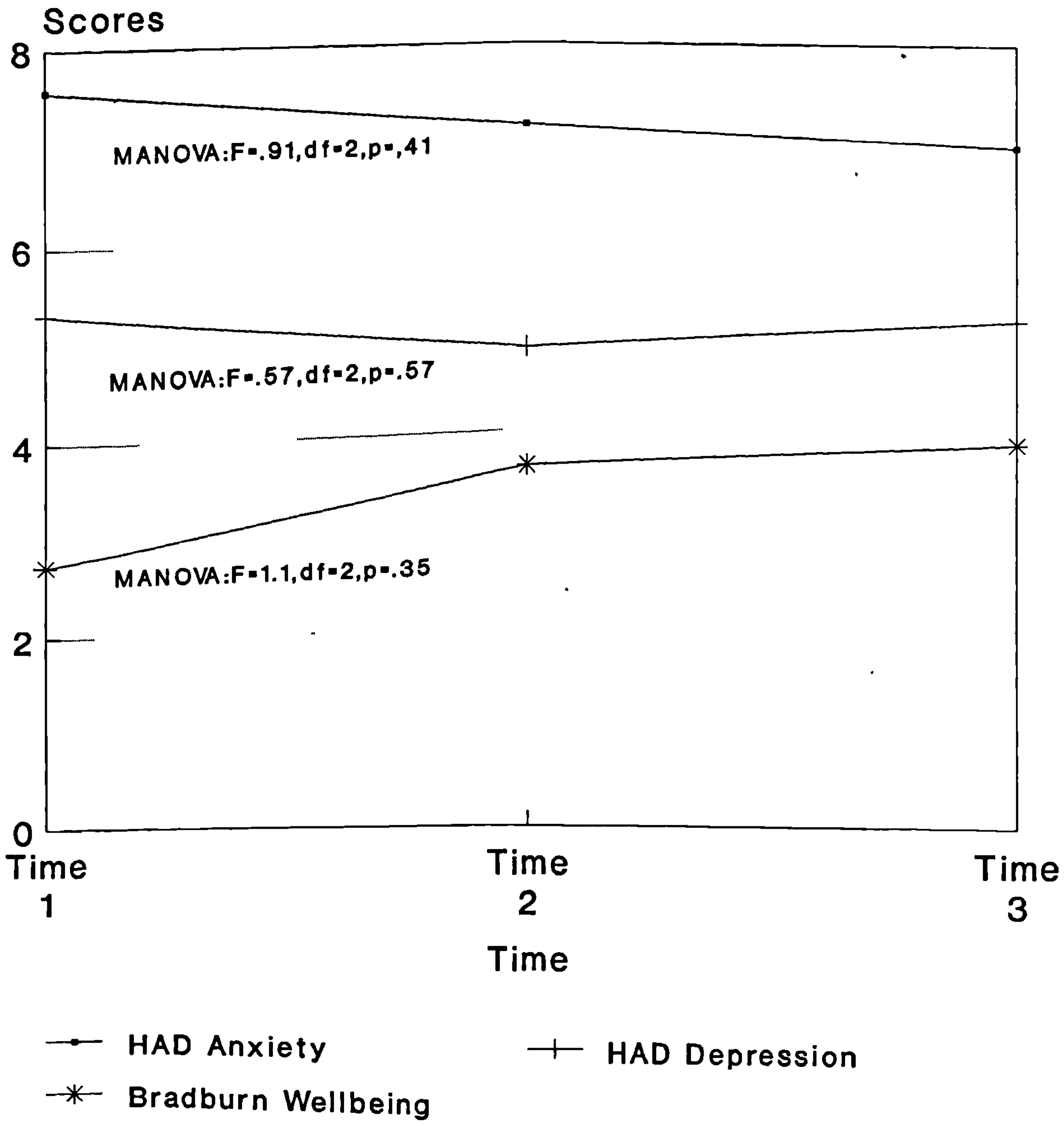
| | Self Esteem scores | | |
|---|---|---|---|
| | T1 | T2 | T3 |
| Negative feelings | 33.7(6.5) | 34.9(6.5) | 33.7(7.7) |
| Other feelings | 39.3(7.2) | 40.0(7.1) | 41.2(7.2),p=<.05 |

Unpaired t-test

(b) Emotional well being.

Three aspects of emotional wellbeing were assessed; mood, using the HAD Anxiety and Depression Scales, general wellbeing using the Wellbeing scale and Life Satisfaction using Bradburn's three questions. Fig.6.12 summarises the mean HAD Anxiety, Depression and Wellbeing scores at each time. A single factor repeated-measures MANOVA showed no significant differences over time for HAD Anxiety, Depression or Wellbeing. Only 15% and 10% of people scored over 10 on the HAD Anxiety & Depressions scales respectively, compared to 22% in the normal population, considered to be indicative of clinical anxiety or depression (Zigmond &

Fig.6.12 Emotional wellbeing:HAD Anxiety HAD Depression & Wellbeing at each time



Snaith,1983). While no such norms are available for the Wellbeing scale, 13, 16 and 14 people had positive wellbeing scores (the higher the score, the better the wellbeing). This sample is not psychologically distressed as measured by these indices.

The responses to the three questions measuring satisfaction with life are summarised in Fig.6.13. The majority of people were either "pretty happy" or "very happy" (Very Happy) with little change at each time. Less than a quarter wanted to change "many things" about their lives, and approximately half reported having accomplished all the things they would like to "up to this point" in their lives, at each time. For the purposes of this analyses, the data were collapsed in the following way:

- Happiness: "very happy" + "quite happy" = Very Happy; "not too happy" = Less Happy.
- Change: "like to continue much the same way" = stay the same; those people wanting to "change some parts of it" (their lives) + "change many parts of it" = desiring some change.
- Accomplishment: this question is a Yes/No choice.

Relationship between self esteem, mood, general wellbeing and life satisfaction: Those people who reported feeling Very Happy were compared to those people who reported feeling Less Happy (Table 6.8).

Fig.6.13 Emotional wellbeing: life satisfaction at each time

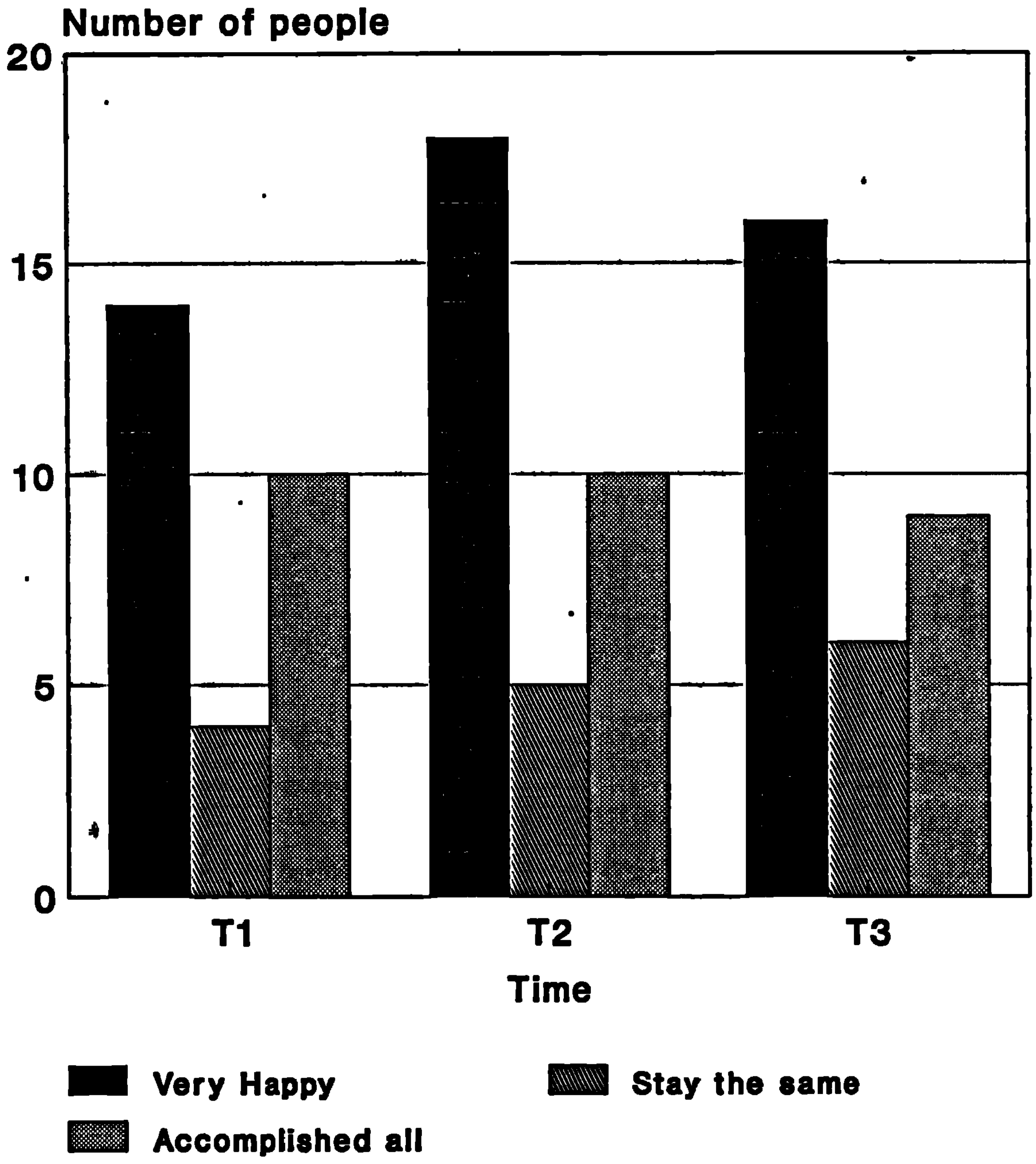


**Table 6.8: Self Esteem, mood and general wellbeing : mean differences for different levels of satisfaction with life.**

| | | Self Esteem | HAD Anxiety | HAD Depression | Wellbeing |
|---|---|---|---|---|---|
| Happiness: | T1 | 8.4* | -5.0** | -5.3** | 8.9*** |
| (More Happy-Less Happy) | T2 | 11.6♣ | -7.1** | -6.8** | 11.3*** |
| | T3 | 7.7 | -4.6** | -5.4** | 8.3** |
| ♣ =no variance in one sample | | | | | |
| Change: | T1 | 6.0 | -0.2 | -3.4 | 2.6 |
| (stay same-change) | T2 | 7.7* | -1.0 | -3.0 | 2.9 |
| | T3 | 11.3** | -4.2** | -4.3* | 6.5* |
| Accomplishment | T1 | 6.2* | -1.1 | -2.7 | 3.3 |
| (yes-no) | T2 | 6.7* | -1.9 | -2.9 | 5.3** |
| | T3 | 8.2* | -2.3 | -3.3 | 5.4* |

Unpaired t-Test *p=<.05, **p=<.01, ***p=<.001

♦ People who reported that they were Very Happy had:

- higher Self Esteem (T1)
- lower HAD Anxiety (T1,T2,T3)
- lower HAD Depression scores (T1,T2,T3)
- better Wellbeing scores (T1,T2,T3)

♦ People who wanted to stay the same had:

- higher Self Esteem (T2,T3)
- lower HAD Anxiety (T3)
- lower HAD Depression (T3)
- better Wellbeing scores (T3).

- People who had accomplished most of the things they would have liked to had:
  - higher Self Esteem scores (T1,T2,T3)
  - higher Wellbeing scores (T2,T3).

Predictive relationship between mood, general wellbeing and Self Esteem: HAD Depression and Self Esteem at T1 strongly predicted HAD Depression, Wellbeing and Self Esteem at T3. HAD Anxiety and Well Being at T1 predicted HAD Anxiety and Depression, Wellbeing and Self Esteem at T3. The strongest predictor of HAD Depression, Wellbeing and Self Esteem at T3 is HAD Depression at T1. Neither HAD Depression nor Self Esteem at T1 predicted HAD Anxiety at T3 (Table 6.9)..

Table 6.9 : Relationship between emotional wellbeing and Self Esteem at T1 and T3

| | T3 | | | |
|---|---|---|---|---|
| | HAD Anxiety | HAD Depression | Well-being | Self Esteem |
| T1 | | | | |
| HAD Anxiety | .60** | .59** | -.56** | -.47* |
| HAD Depression | .47 | .74*** | -.72*** | -.73*** |
| Wellbeing | -.61** | .66*** | .65** | .61** |
| Self Esteem | -.40 | -.57** | .63** | .77*** |

Pearson's r, p= <.05, **p= <.01, ***p= <.001

Interviewers evaluation of coping and relationship to standardised outcome measures: The interviewer evaluated the persons coping at each time using the GAIS (Derogatis 1976), the mean ratings are classified as "very good adjustment"(Table 6.10).

Table 6.10. Interviewers evaluation of coping (mean(SD) and range).

| | | |
|---|---|---|
| T1 | 80.5(11.7) | 53-95 (n=19) |
| T2 | 81.8(14.4) | 51-98 (n=20) |
| T3 | 86.7(15.0) | 52-100 (n=19) |

A single factor repeated-measures MANOVA showed no significant difference over time (F=2.3,df=2,p=.11). The standardised measures of outcome and the clinical evaluation as measured by the GAIS were compared (Table 6.11)

Table 6.11 : Relationship between standardised outcome measures and interviewers clinical evaluation at each time.

| | | Standardised measures | | | |
|---|---|---|---|---|---|
| | | HADA | HADD | Wellbeing | Self Esteem |
| | T1 | -.31 | -.12 | .30 | .26 |
| Interviewers evaluation | T2 | -.58** | -.54** | .77*** | .66** |
| | T3 | -.68*** | -.82*** | .79*** | .66** |

Pearson's r, **p=<.01, ***p=<.001.

There was a strong agreement between the standardised measures of outcome and the interviewers clinical evaluation using the GAIS at T2 and T3, but not at T1.

(c) Severity of disability

Poser diagnostic criteria: Table 6.12 shows that 12 of the 19 people were categorised by the consultant neurologist using the Poser criteria as having "definite" multiple sclerosis

Table 6.12 : Number of people in each of the Poser categories.

| | Multiple sclerosis | |
|---|---|---|
| | Definite | Probable |
| Clinically supported | 7 | 7 |
| Laboratory supported | 5 | 0 |

OPCS Disability Scale: No person was rated as disabled using the OPCS Disability Scales at T1, with only 1 and 3 people being rated as disabled at T2 and T3. This measure was not sensitive with this population and was not included in further analysis.

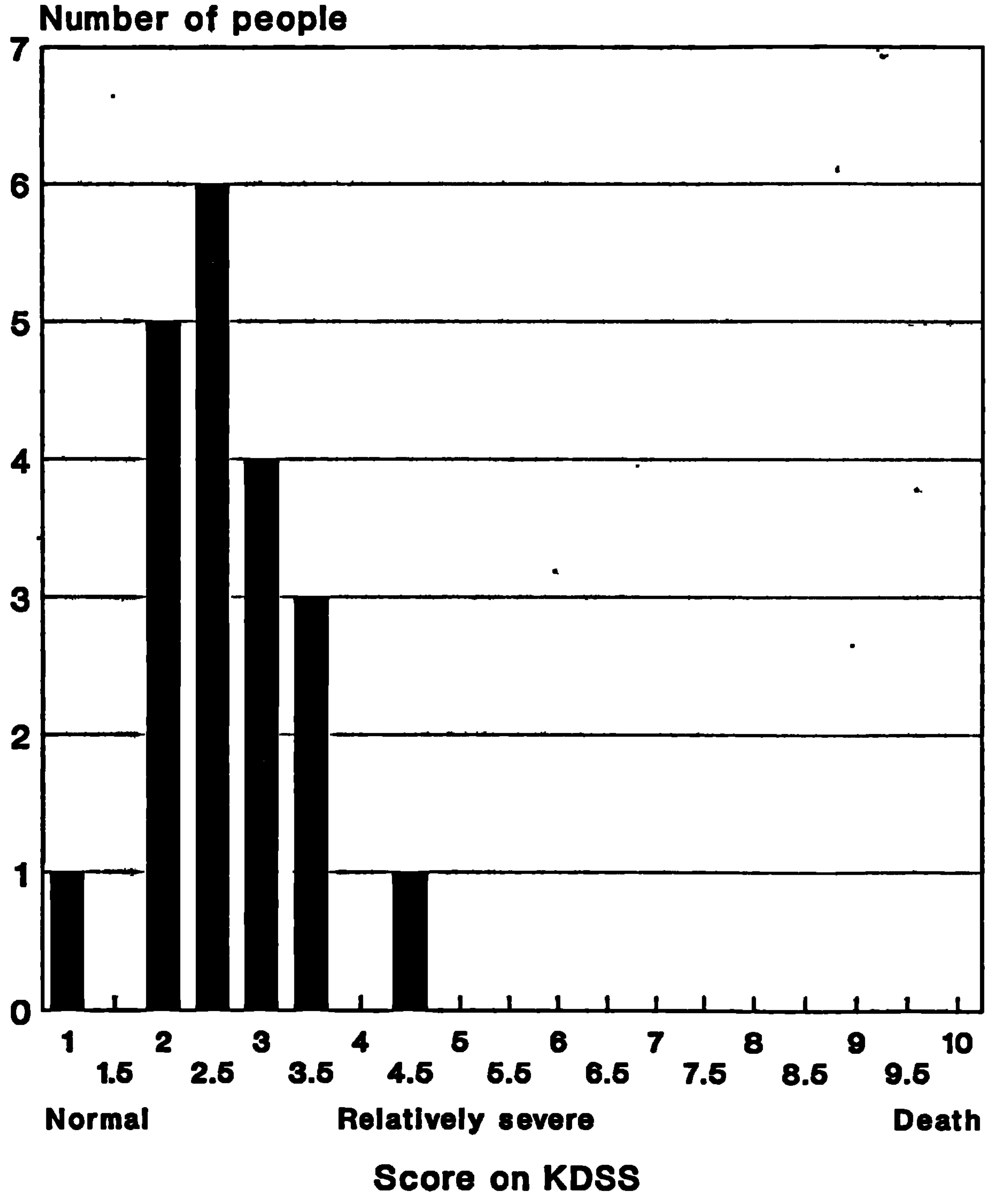
Kurtzke's Expanded Disability Status Scale (KDSS): Fig.6.14 shows the distribution of scores on the KDSS.

(iv) Relationship between disability measures: The relationship between the KDSS and the Poser criteria was examined (Table 6.13), there were no significant relationships (Fishers Exact).

Table 6.13 : Kurtzke Expanded Disability Status Scale

| | | KDDS administered while in hospital | | | |
|---|---|---|---|---|---|
| | | None | Min(1-2.5) | Mod-sev(3-4.5) | Sev(5-10) |
| POSER | Probable | 0 | 4 | 3 | 0 |
| | Definite | 0 | 7 | 5 | 0 |

Fig.6.14 Severity of disability:
KDSS during admission to hospital



## 6.4 Relationships between elements of the model

MANOVA's, Unpaired t-Tests, Pearson's r and Fisher's Exact test were used to examine the following relationships:

(i) Representation and coping

(ii) Representation and evaluation of coping

(iii) Representation and outcome

(iv) Coping and evaluation of coping

(v) Coping and outcome

(vi) Evaluation of coping and outcome

Each of the above relationships will be reported in four parts, firstly, the interactions between the elements of the model and time. Secondly, the concurrent relationships between each of the elements of the model at each time; thirdly, the predictive relationships and fourthly the feedback relationships. Where significant relationships between the elements of the model have been found using MANOVA's, t-Test's have been used to show the precise nature of the relationships. These results are summarised in table form at the beginning of each section, with the data organised as below:

| | | Coping | | |
|---|---|---|---|---|
| | | T1 | T2 | T3 |
| Representations | T1 | C | P | P |
| | T2 | F | C | P |
| | T3 | F | F | C |

C = Concurrent
P = Predictive
F = Feedback

In all the tables the following signs have been used:

. result not statistically significant

-> direction of prediction

All MANOVA's are in Appendix B in graphic form.

### 6.4.1 Representation and coping

The relationships are summarised in the Table 6.14 & Fig 6.15.

## Table 6.14: Relationship between representation and coping.

|  | COPING |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | T1 |  |  |  |  |  |  | T2 |  |  |  |  |  |  | T3 |  |  |  |  |  |  |
|  | Hlt | Prb | Inf | Lif | Act | Sn | Ss | Hlt | Prb | Inf | Lif | Act | Sn | Ss | Hlt | Prb | Inf | Lif | Act | Sn | Ss |
| REPRESENTATIONS |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| T1 Identity: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Label | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .05 | . | . | .02 | . |
| Symptoms | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Rated seriousness | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .03 | . | . |
| Ranked seriousness | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .01 | . | . |
| Problems | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Limitations | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cure: | . | . | . | . | . | . | . | . | . | . | . | . | .04 | .03 | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| T2 Identity: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Label | . | . | . | . | . | . | . | .05 | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Symptoms | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Rated seriousness | . | . | . | . | . | . | . | . | . | . | . | .05 | . | . | . | . | . | . | .02 | . | . |
| Ranked seriousness | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Problems | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Limitations | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cure: | . | . | . | . | . | . | . | . | . | . | . | . | .02 | . | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| T3 Identity: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Label | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .03 | . | . |
| Symptoms | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Rated seriousness | . | .03 | . | . | . | . | . | . | . | .02 | . | .007 | . | . | . | . | . | . | .02 | . | . |
| Ranked seriousness | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .01 | . | . |
| Problems | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Limitations | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Cure: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |

## Figure 6.15: Relationship between representation and coping (statistical procedures used).

|  | Health generally | Specific problems | Seek information | Change lifestyle | Total actions | Social support N | S |
|---|---|---|---|---|---|---|---|
| Identity: |  |  |  |  |  |  |  |
| Label | ----------- | Fishers Exact test------- | ---------- | ---------- | ---------- | MANOVA + t | Test |
| Symptoms | ----------- | MANOVA + t-test ------ | ---------- | ---------- | ---------- | ---------- | ---------- |
| Cause: | ----------- | Fishers Exact test ------ | ---------- | ---------- | ---------- | MANOVA + t | Test |
| Consequences: |  |  |  |  |  |  |  |
| Rated seriousness | ----------- | " | " | ---------- | ---Pearson's r | " | " |
| Ranked seriousness | ----------- | MANOVA + t-test ------ | ---------- | ---------- | ---Pearson's r | " | " |
| Problems | ----------- | Fishers Exact test ------ | ---------- | ---------- | ---------- | MANOVA + t | Test |
| Limitations | ----------- | MANOVA + t Test ------ | ---------- | ---------- | ---------- | ---------- | ---------- |
| Cure: | ----------- | Fishers Exact test ------ | ---------- | ---------- | ---------- | MANOVA + t | Test |
| Timeline: | ----------- | " | " | ---------- | ---------- | MANOVA + t | Test |

### Part 1. Interactions between representations, coping and time.

◆ People who had the correct label at T1:

- became more satisfied with their social supports over time (F=3.58,df=2,p=.04).
- increased their number of social supports over time (F=8.16,df=2,p=.006).

◆ People who ranked their condition as More Serious at T2 increased the number of their social supports over time (F=3.9,df=2,p=.03).

### Part 2. Concurrent relationships between representation and coping.

◆ People who had the correct label were more likely to be taking:

- actions to keep healthy generally (T2)
- more types of actions overall (T3)

◆ People who rated their condition as More Serious (T2,T3), and ranked their condition more seriously (T3) were more likely to be taking more types of actions overall.

◆ People who believed in a cure had a greater number of social supports (T2)

### Part 3. Predictive relationships between representations and coping.

◆ People with the correct label were more likely to be seeking information (T1->T3)

◆ People who had rated their condition more seriously were more likely to be taking more types of actions overall (T1->T3, T2->T3)

◆ People who had ranked their condition more seriously were likely to be taking more types of actions overall (T1->T3)

◆ People who believed in a cure had more social supports and were more satisfied with those supports (T1->T2)

### Part 4. Feedback relationships between coping and representation.

◆ People who had rated their condition as More Serious were more likely to have taken

- no action to manage specific problems and difficulties (T1->T3)
- taken action to seek information (T2->T3)
- taken more types of actions overall (T2->T3)

### 6.4.2. Representation and evaluation of coping

The relationship between representations and evaluation of coping were examined using MANOVA's, Unpaired t Tests and Fishers Exact test. They are reported in three parts; concurrent, predictive and feedback, and summarise in Table 6.15:

Table 6.15: Summary of relationships between representations and evaluation of coping

| | EVALUATION OF COPING | | |
|---|---|---|---|
| | T1 | T2 | T3 |
| REP'TIONS | | | |
| T1 Identity: | | | |
| Label | . | . | . |
| Symptoms | . | . | .002 |
| Cause: | . | . | . |
| Consequences: | | | |
| Rt'ed serious | . | . | . |
| Rk'ed serious | . | . | . |
| Problems | . | . | . |
| Limitations | . | . | . |
| Cure: | . | . | . |
| Timeline: | . | . | . |
| T2 Identity: | | | |
| Label | . | . | . |
| Symptoms | . | . | . |
| Cause: | . | . | . |
| Consequences: | | | |
| Rt'ed serious | . | . | . |
| Rk'ed serious | . | . | . |
| Problems | . | . | . |
| Limitations | . | .007 | . |
| Cure: | . | . | . |
| Timeline: | . | . | . |
| T3 Identity: | | | |
| Label | . | . | . |
| Symptoms | . | . | .02 |
| Cause: | . | . | . |
| Consequences: | | | |
| Rt'ed serious | .05 | . | . |
| Rk'ed serious | . | . | . |
| Problems | . | . | . |
| Limitations | . | .008 | .001 |
| Cure: | . | . | . |
| Timeline: | . | . | . |

There were no interactions between representations, evaluation of coping and time.

Part 2. Concurrent relationship between representations and evaluation of coping.

- People who had more symptoms were more likely to evaluate themselves as having managed Less Well (T3: Fishers Exact,p=.02).

- People with more limitations were more likely to evaluate themselves as having managed Less Well (T2:F=10.86,df=1,p=.007; T3:F=13.49,df=1,p=.001).

Part 3. Predictive relationships between representations and evaluation of coping.

- People with more symptoms were more likely to evaluate themselves as having managed Less Well (F=13.39,df=1,p=.002).

Part 4. Feedback relationships between evaluation of coping and representations.

- People who had evaluated themselves as having managed Very Well:
  - were more likely to have rated their condition as Less Serious (T1->T3:Fishers Exact,p=.05).
  - had significantly fewer limitations (T2->T3: F=13.49,df=1,p=.008).

### 6.4.3 Representation and outcome

The concurrent, predictive, feedback and interactive relationship between representations and emotional wellbeing were examined.These are summarised in Table 6.16

**Table 6.16 Summary of relationships between representations and outcome**

| | OUTCOME | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | T1 | | | | | | | | T2 | | | | | | | | T3 | | | | | | | |
| | S | Se | Anx | Dep | Wel | Hap | Cha | Acc | S | Se | Anx | Dep | Wel | Hap | Cha | Acc | S | SE | Anx | Dep | Wel | Hap | Cha | Acc |
| REP'TIONS | | | | | | | | | | | | | | | | | | | | | | | | |
| T1 Identity: | | | | | | | | | | | | | | | | | | | | | | | | |
| Label | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Symptoms | . | . | . | . | . | . | . | . | . | .03 | . | .04 | . | . | . | . | . | .02 | . | .04 | .02 | . | . | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: | | | | | | | | | | | | | | | | | | | | | | | | |
| Rt'ed serious | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Rk'ed serious | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Problems | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Limitations | . | . | .04 | . | .02 | . | . | . | . | .02 | .04 | .02 | .04 | .01 | . | . | . | . | . | .01 | .05 | . | . | . |
| Cure: | .02 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| T2 Identity: | | | | | | | | | | | | | | | | | | | | | | | | |
| Label | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Symptoms | . | .05 | . | . | . | . | . | . | . | .01 | . | .01 | . | . | . | . | . | .03 | . | . | . | . | . | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: | | | | | | | | | | | | | | | | | | | | | | | | |
| Rt'ed serious | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .03 | . | . | . | . | . | . | . | . |
| Rk'ed serious | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Problems | . | .04 | . | .04 | . | . | . | . | . | . | . | .006 | . | . | . | .03 | . | .008 | . | .02 | .02 | . | .01 | . |
| Limitations | . | . | . | .03 | . | . | .007 | . | . | .003 | . | .000 | .006 | . | . | . | . | .005 | . | .000 | .02 | . | . | . |
| Cure: | . | .02 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| T3 Identity: | | | | | | | | | | | | | | | | | | | | | | | | |
| Label | . | . | . | . | . | . | .02 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Symptoms | . | .01 | .03 | .02 | .02 | . | . | . | . | .002 | .003 | .009 | . | . | . | .03 | . | .000 | .001 | .001 | .000 | .03 | .04 | . |
| Cause: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Consequences: | | | | | | | | | | | | | | | | | | | | | | | | |
| Rt'ed serious | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | .05 | . | . | . | . | .04 | . |
| Rk'ed serious | . | . | . | . | . | . | . | . | . | .02 | . | . | . | . | . | . | . | .03 | . | . | . | . | .04 | . |
| Problems | . | . | . | . | .03 | . | . | . | . | .04 | . | . | .03 | . | . | . | . | .02 | .003 | .03 | .002 | .03 | . | . |
| Limitations | . | . | . | .04 | .004 | . | .02 | . | . | .008 | .03 | .007 | .008 | .008 | . | . | . | .001 | .01 | .000 | .003 | .03 | .005 | . |
| Cure: | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| Timeline: | . | . | . | . | . | . | . | .02 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |

**Relationships between representations and Self Esteem, HADs, Wellbeing and Disability were examined using MANOVA's and Unpaired t Tests, as were relationships between symptoms, ranked seriousness, limitations and Life Satisfactions. All other relationships were examined using Fisher's Exact Test.**

## Part 1. Interactions between representations, outcome and time.

◆ People who rated their condition as Less Serious at T2 & T3 reduced their anxiety over time (F=4.56,df=2,p=.02; F=3.44,df=2,p=.04).

◆ People who ranked their condition as Less Serious at T1 improved their Wellbeing over time (F=5.15,df=2,p=.01).

◆ People with no problems and difficulties at T3 became less anxious over time (F=4.98,df=2,p=.01).

◆ People who believed in a cure at T1 became less anxious and depressed over time (F=11.95,df=2,p=.02; F=5.02,df=2,p=.01).

◆ People with no desire to change at T1 ranked their condition more seriously over time (F=6.41,df=2,p=.005).

## Part 2. Concurrent relationship between representations and outcome

◆ People with more symptoms :

- had lower self esteem (T2,T3)
- had higher HAD Depression scores (T2,T3).
- had higher HAD Anxiety (T3)
- had poorer Wellbeing scores (T3)
- were more likely to report feeling Less Happy (T3).
- were more likely to feel that they had accomplished all they wanted to (T3).

◆ People who ranked and rated their condition as More Serious:

- had higher self esteem (T3).
- were less likely to want to change either some or many parts of their lives (T3).

◆ People with problems and difficulties :

- had lower self esteem (T3).
- had higher HAD Anxiety scores (T3).
- had higher HAD Depression scores (T2,T3).
- had poorer Wellbeing scores (T3).
- were more likely to be Less Happy (T3).
- were more likely to feel that they had accomplished all the things they would have liked to (T2).

◆ **People with more limitations:**

- **had lower the Self Esteem (T2,T3)**
- **had higher HAD Anxiety scores (T1,T3).**
- **had higher HAD Depression scores (T2,T3).**
- **had poorer Wellbeing scores (T1,T2,T3).**
- **were more likely to be feeling Less Happy (T3).**
- **were more likely to want to change either some or many parts of their lives (T3).**

◆ **People who did not believe in a cure were more likely to have negative feelings about themselves (T1).**

**Part 3. Predictive relationships between representations and outcome.**

◆ **People with more symptoms had:**

- **lower Self Esteem scores (T1->T2, T1->T3, T2->T3).**
- **higher HAD Depression scores (T1->T2, T1->T3).**
- **poorer Wellbeing scores (T1->T3).**

◆ **People with no problems and difficulties had:**

- **higher Self Esteem scores (T2->T3).**
- **lower HAD Depression scores (T2->T3)**
- **better Wellbeing scores (T2->T3).**
- **were more likely to want to change either some or many parts of their lives (T2->T3)**

◆ **People with more limitations were more likely to have:**

- **lower self esteem (T1->T2, T2->T3).**
- **higher HAD Anxiety scores (T1->T2).**
- **higher HAD Depression scores (T1->T2, T1->T3, T2->T3).**
- **poorer Wellbeing scores (T1->T2, T1->T3, T2->T3).**
- **reported feeling Less Happy (T1->T2).**

## Part 4. Feedback relationships between representations and outcome.

◆ **People who had the correct label were more likely to have wanted to change some or part of their lives (T1->T3).**

◆ **People with more symptoms were more likely to have had:**

**- lower Self Esteem (T1->T2, T1->T3, T2->T3).**

**- higher HAD Anxiety (T1->T3, T2->T3)**

**- higher Depression (T1->T3, T2->T3)**

**- poorer Wellbeing (T1->T3)**

**- achieved most of the things they would have liked to (T2->T3)**

◆ **People who ranked their condition as Less Serious were more likely to have had lower Self Esteem scores (T2->T3).**

◆ **People who reported problems and difficulties were more likely to have had:**

**- lower Self Esteem (T1->T2, T2->T3).**

**- higher HAD Depression scores (T1->T2).**

**- poorer wellbeing scores (T1->T3, T2->T3).**

◆ **People with more limitations were more likely to have had:**

**- lower Self Esteem (T2->T3).**

**- higher HAD Anxiety scores (T2->T3).**

**- higher HAD Depression scores (T1->T2, T1->T3, T2->T3).**

**- poorer Wellbeing scores (T1->T3, T2->T3).**

**- reported feeling Less Happy (T2->T3).**

**- wanted to change either some or many parts of their lives (T1->T2, T1->T3).**

◆ **People who believed in a cure were more likely to have had lower Self Esteem scores (T1->T2).**

◆ **People with little expectation of improvement were more likely to have reported having accomplished all the things they wanted to (T1->T3).**

### 6.4.4 Coping and evaluation of coping

**The relationship between coping and evaluation of coping will examined in three parts; concurrent, predictive and feedback relationships, Table 6.17 summarises the results.**

**Table 6.17: Relationships between coping and evaluation**

| | COPING | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | T1 | | | | | | | T2 | | | | | | | T3 | | | | | | |
| | Hlt | Prb | Inf | Lif | Act | Sn | Ss | Hlt | Prb | Inf | Lif | Act | Sn | Ss | Hlt | Prb | Inf | Lif | Act | Sn | Ss |
| EVALUATION | | | | | | | | | | | | | | | | | | | | | |
| T1 | . | . | . | . | . | .04 | .04 | . | . | . | . | . | .02 | . | . | . | . | . | . | .05 | .02 |
| T2 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |
| T3 | . | .03 | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . | . |

**There were no interactions between coping, evaluation of coping and time.**

**<u>Part 2. Concurrent relationships between coping and evaluation of coping.</u>**

- **People who felt they had managed Very Well had more social supports and were more satisfied with those supports (T1: F=5.95,df=2,p=.04;F=6.32,df=2,p=.04).**

**<u>Part 3. Predictive relationship between coping and evaluation of coping.</u>**

- **People taking action to manage specific problems and difficulties were more likely to evaluate themselves as having managed Very Well (T1->T3 Fishers Exact,p=.03).**

**<u>Part 4. Feedback relationship between evaluation of coping and coping.</u>**

- **People who evaluated themselves as having managed Less Well:**
  - **had had fewer social supports (T1->T2:F=3.53,df=2,p=.05).**
  - **had been less satisfied with those supports (T1->T3:F=3.64,df=2,p=.02).**

### 6.4.5 Coping and outcome

**The relationships between social support and outcome were examined using MANOVA's, as were the relationships between coping and HADS and Wellbeing. All other relationships were examined using Fishers Exact Test. There were no significant relationships between coping and disability.**

**Neither were there any predictive relationships between coping and outcome or any interactions between coping, outcome and time.**

**Part 2. Concurrent relationships between coping and outcome.**

◆ **People with fewer social supports were:**

**- more likely to report feeling negatively about themselves (T3:F=6.04,df=1,p=.03).**

**- Less Happy (T3:F=4.56,df=2,p=.05).**

◆ **People taking no actions to change their lifestyles had higher HAD Anxiety scores (T3:F=9.46,df=2,p=.007).**

**Part 4. Feedback relationships between emotional wellbeing and coping.**

◆ **People with negative feelings about themselves had had fewer social supports (T2->T3:F=6.04,df=2,p=.03).**

◆ **People who wanted to change either some or many parts of their lives were more likely to have sought information (T1->T3:p=.03).**

◆ **People with lower HAD Anxiety were more likely to have changed their lifestyles (T1->T3, T2->T3:F=7.43,df=2,p=.01).**

### 6.4.6 Evaluation of coping and outcome

**The relationships between evaluation of coping and outcome are summarise below (Table 6.18).**

**Table 6.18: Relationship between evaluation of coping and outcome.**

| | | EVALUATION OF COPING | | | STATISTICAL PROCEDURES |
|---|---|---|---|---|---|
| | | T1 | T2 | T3 | |
| T1:IMPACT ON SELF | Self | . | . | . | Fishers Exact Test |
| | Self Esteem | . | . | . | MANOVA + t Test |
| EMOTIONAL OUTCOMES | HAD Anxiety | . | . | .01 | MANOVA + t Test |
| | HAD Depression | . | .003 | .02 | MANOVA + t Test |
| | Wellbeing | . | .008 | . | MANOVA + t Test |
| | Happiness | . | . | . | Fisher's Exact test |
| | Change | . | . | . | " |
| | Accomplishment | . | . | . | " |
| T2:IMPACT ON SELF | Self | . | . | . | |
| | Self Esteem | . | .007 | . | |
| EMOTIONAL OUTCOMES | HAD Anxiety | . | . | .03 | As T1 |
| | HAD Depression | . | .001 | . | |
| | Wellbeing | . | . | . | |
| | Happiness | . | . | . | |
| | Change | . | . | . | |
| | Accomplishment | . | . | . | |
| T3:IMPACT ON SELF | Self | . | . | . | |
| | Self Esteem | . | .005 | .05 | |
| EMOTIONAL OUTCOMES | HAD Anxiety | . | . | .008 | As T1 |
| | HAD Depression | . | .002 | .02 | |
| | Wellbeing | . | .02 | .01 | |
| | Happiness | . | . | . | |
| | Change | . | . | . | |
| | Accomplishment | . | . | . | |

**There were no interactions between evaluation of coping, outcome and time.**

**Part 2.Concurrent relationships between evaluation of coping and outcome.**

♦ **People who had evaluated themselves as having managed Very Well had:**

- **higher Self Esteem scores (T2,T3).**
- **lower HAD Anxiety scores (T3)**
- **lower HAD Depression scores (T2,T3)**
- **better Wellbeing scores (T3).**

## Part 3. Predictive relationships between evaluation of coping and outcome.

◆ **People who had evaluated themselves as having managed Very Well had:**

**- higher Self Esteem(T2->T3).**

**- lower HAD Depression scores (T2->T3)**

**- better Wellbeing scores (T2->T3).**

## Part 4. Feedback relationships between evaluation of coping and outcome.

◆ **People who had evaluated themselves as having managed Very Well were more likely to have had:**

**- lower HAD Anxiety scores (T1->T3, T2->T3).**

**- lower HAD Depression scores (T1->T2, T1->T3).**

**- better Wellbeing scores (T1->T2).**

## 6.5 Discussion

This is a longitudinal study, and is the first attempt to examine the usefulness of Leventhal and colleagues (Leventhal et al,1984) model in a chronic, progressive neurological illness, where neither cure nor significant palliative treatment is available.

### 6.5.1 Support for the elements of the model at each time

Representations. Before coming into hospital almost half the people had, and maintained, the correct label and this increased over time. The majority of people reported symptoms at all times. Previous research (Nerenz 1970, Meyer et al 1985) found that being told one has an illness increased the symptomatology, however, neither having the correct label nor being told the diagnosis was associated with an increase in the number of symptoms at times 2 and 3; indeed, a reduction in symptoms was found from T1 to T3. Symptoms of multiple sclerosis, by the nature of the condition, pre-date diagnosis and are a reason for seeking medical advice; whereas conditions such as hypertension are asymptomatic, diagnosis frequently leading to reporting of symptoms. Approximately half the people attributed a cause, the nature of which remained relatively constant, while nearly everyone reported some consequences.

There was a positive relationship between the concrete representations of symptoms and limitations. Nerenz et al (1982) found that patients with lymphatic cancers used the perceived size of their lymph nodes to monitor effects of treatment. In the absence of treatment, people with multiple sclerosis may be using both symptoms and limitations to monitor their illness.

About half the people had some causal explanation for their condition at each time, half of whom attributed the cause to their own behaviour, the content of which remained relatively stable over time. The diagnosis of a chronic illness did not increase the likelihood of the psychological process of searching for a cause at times 2 and 3, it may be that this process had been undertaken before the diagnosis of multiple sclerosis. Findings from attribution theory (Turnquist et al, 1988), would suggest that a response to adverse events such as illness is the search for explanations about cause and outcomes were not supported by this study. From the work of

Meyer et al (1985), one would have predicted that the content of the causal attribution would have changed, however, this research found that the content of the attribution remained remarkably stable over time.

Everyone reported some consequence as a result of their symptoms/condition. About half either rated or ranked their condition as "More Serious" at each time, there being no significant change over time. However, people who ranked their condition as "More Serious" before diagnosis at T1 ranked their condition as "Less Serious" after diagnosis and at T3. Carver et al (1989) suggest that people may cope with chronic illness by changing the reference criteria. Previous research (Leventhal & Diefenbach,1991; Croyle & Jemmott,1991) support this contention, and suggest that providing the person with new reference criteria may alter their representations, in this study the experience of hospital and diagnosis may have provided these reference criteria.

At all times over half the sample reported specific problems & difficulties and some degree of limitation caused by their condition. In a progressive illness such as multiple sclerosis, a tendency for increasing limitations, problems and difficulties might have been expected. This absence may reflect successful re-attribution of what is and is not perceived to be a limitation or a problem or difficulty when provided with new reference criteria.

People's expectation of cure and timeline showed variability, but overall reflected a chronic timeline with decreasing belief in a cure and reducing expectations of improvement. This is possibly due to the medical information received and to personal experience of the condition.

The results provide support for the five components of illness representation, with the temporal pattern for cure and time-line being consistent with the medical representation of multiple sclerosis as being a condition of slow inexorable deterioration. In a condition with an insidious onset, it is perhaps unsurprising to find relatively well established illness schema before formal diagnosis. Previous research has emphasised the importance of symptoms in contributing to this schema, results from this study confirm this is also the case for chronic neurological illness and highlight the equal importance of consequences, in particular limitations which have a similar role to that of symptoms in monitoring the condition.

Coping. Nearly everyone had taken some action to manage their symptoms\condition. Two thirds of the people had undertaken some kind of activity, mainly exercise and diet, to keep themselves healthy generally. Most had taken action to deal with specific problems and difficulties, had sought information and had taken actions to change their lifestyles. The most frequent action people took overall, was that directed towards increasing understanding, with no one reporting that they had had "too much" information at any time. Significantly more people reported having "too little" rather than "enough" information before diagnosis, with significantly more people reporting having "enough" information after diagnosis. This may be accounted for by the information given during the stay in hospital and at the time of diagnosis, and also by the patients own efforts at information seeking. This lends support to the importance of information in the process of self-regulation.

Social support changed over time with the number of supports increasing. Information seeking did not increase over time, thus it is unlikely that seeking social support served a primarily information seeking function. It is possible that this increase in number and satisfaction with social support represented an increase in emotional support as the scale used primarily measures emotional support. The high correlation between the number of social support and satisfaction with social support is not surprising, Sarason et al (1983) reports that while conceptually distinct, the measures are frequently correlated.

The data lend support to Carver et al's (1989) hypothesis that people cope with illness by changing reference criteria and reducing the mismatch by perceiving the condition to be less serious following diagnosis and admission to hospital. Indeed, it is the more abstract representations of identity and consequences that are related to actions taken to cope. In multiple sclerosis, the perception of seriousness is potentially more susceptible to change than the more concrete symptoms and limitations.

Evaluation of coping. Most people evaluated their coping actions favourably, and this was not simply a biassed perception, as there was good agreement with that of the interviewers rating. However, an evaluation of "Less Well" at T1 predicted an evaluation of "Very Well" at T2. This is a similar pattern to that found with ranked seriousness, a possible explanation of which might be an attempt to reduce the mismatch following the establishment of new reference criteria. An alternative explanation might be that those who were critical of their coping efforts were motivated to do more and therefore evaluated their efforts more favourably later. However, this is not supported by the data as evaluation of coping does not predict subsequent coping.

Outcome. Most people reported feeling differently about themselves as a result of their symptoms\condition, with significantly more people feeling negatively about themselves. People who felt negatively about themselves had lower self esteem. Emotional outcomes did not indicate high rates of emotional disorder and a large proportion of people showed positive well-being on Bradburn's measure , and were satisfied with their lives. This supports other research (Cassileth et al 1984; Dakof & Mendelson,1986) reporting levels of distress among people with disability and chronic illness as being similar to that of the normal population. There was considerable concordance between people's response to the various measures of emotional wellbeing and measures of life satisfaction. There was also a strong predictive relationship between measures of emotional wellbeing and self esteem, with HAD Depression and Self Esteem strongly predicting HAD Depression, Wellbeing and Self Esteem. There were low levels of disability consistent with the early stages of a condition such as multiple sclerosis which has an insidious onset.

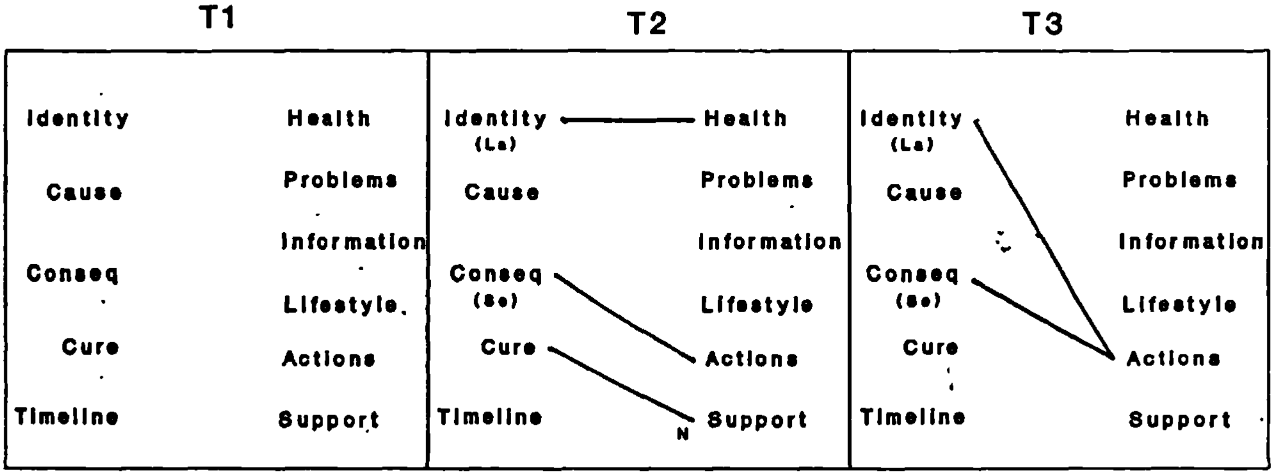
### 6.5.2 Relationship between the elements of the model

Self-regulation theory postulates concurrent, predictive and feedback relationships between elements of the model and gives priority to the direction of causality described in Fig 3.2.

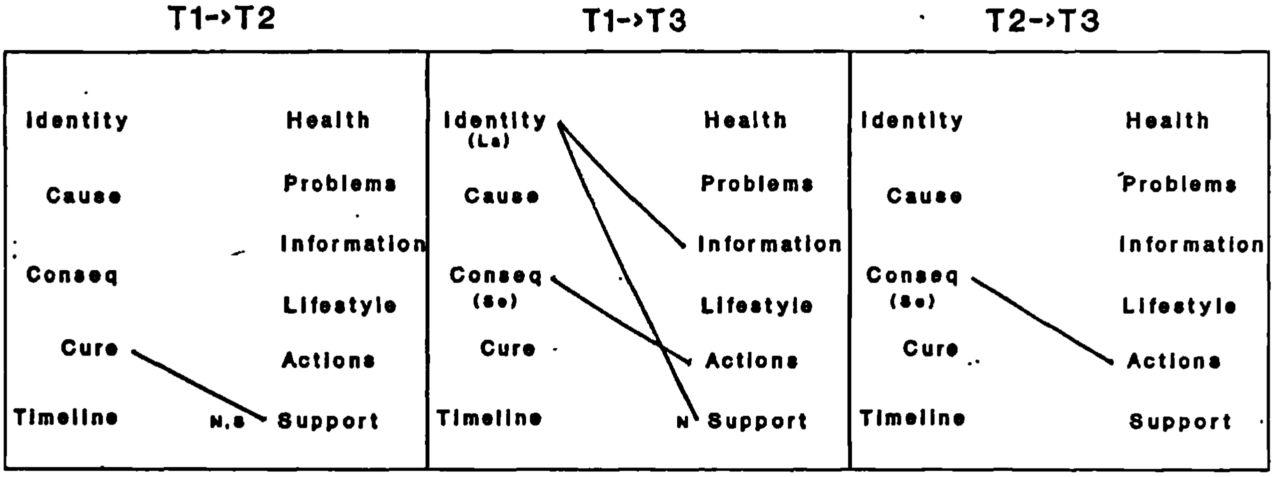
Representation and coping. Fig.6.16 summarises the relationships between representations and coping. Previous research (Love et al,1989; Meyer et al,1985; Gonder-Frederick & Cox,1991; Farmer & Good,1991) has demonstrated the importance of symptoms in guiding action, this study provides only weak support for the predictive nature of representations, with the more abstract

# Fig.6.16 Relationships between representations and coping

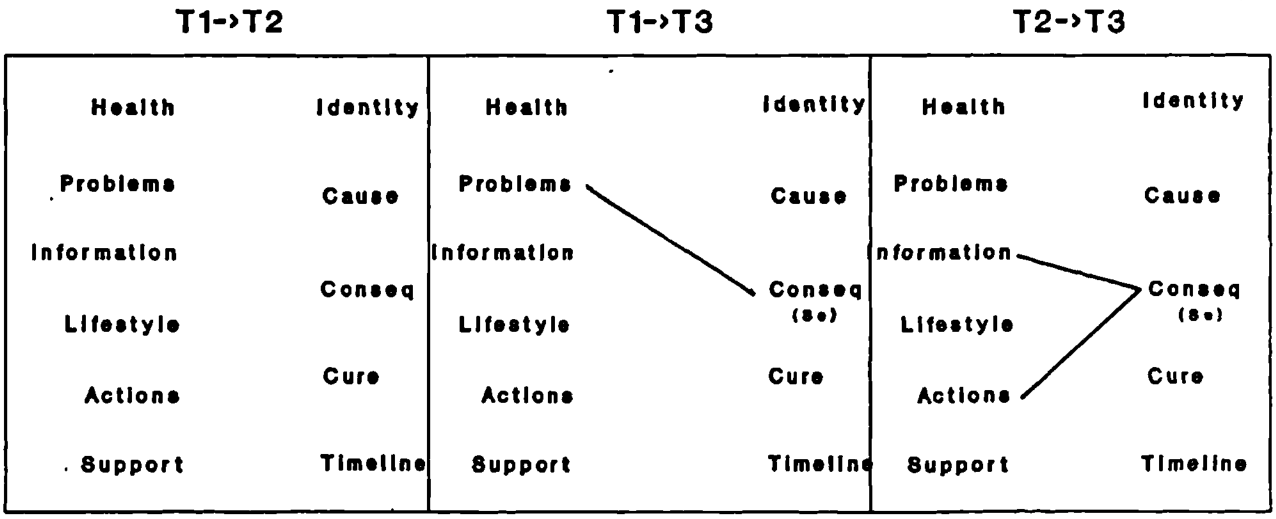
a) Concurrent



b) Predictive



c) Feedback



Key: La label
Se Seriousness
N Number of social supports
S Satisfaction with social supports

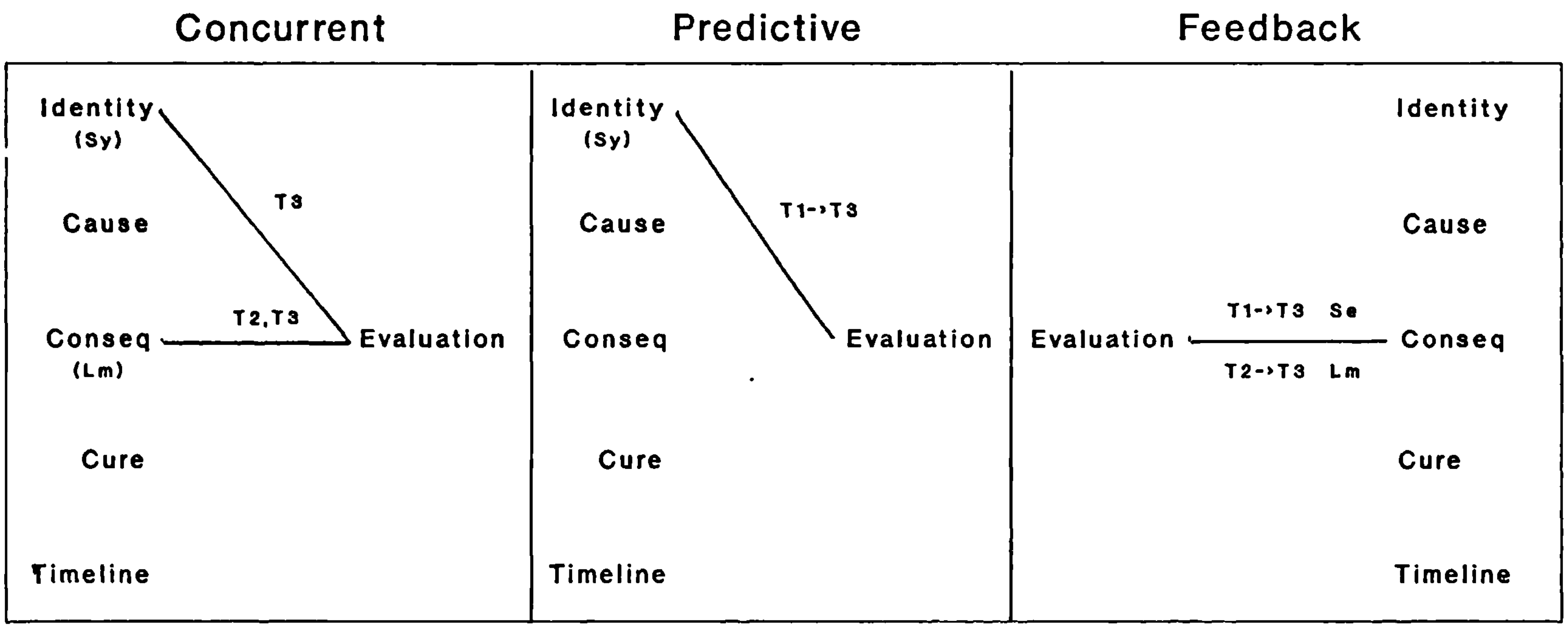
elements of illness representation - having a label (identity) and both rating and ranking the condition as "More Serious", (consequences) and belief in a cure predicting coping. In particular seeking information, the number of types of actions taken and social support. People who had the correct label increased both their number of and satisfaction with social support over time.

The concurrent relationships at T2 and T3 were similar in nature to the predictve relationships. There was minimal support for the feedback loop with people who had sought information and took more types of actions to be more likely to rate their condition as "More Serious". There were no relationships between cause, timeline, or the more concrete representations of symptoms, problems and difficulties or limitations and coping. It is possible that the coping action had already been taken place prior to the study in that the experience of symptoms and limitations had resulted in seeking advise from the doctor which led to admission to hospital for tests and investigations. This would be consistent with the medical representation of the condition which emphasises the unlikely success of any coping action in influencing symptoms or limitations and the patients own experience of the illness.

Representation and evaluation of coping. There were weak concurrent, predictive and feedback relationships between representation and evaluation of coping (Fig.6.17). However, there was a consistency of finding with the more concrete representations of identity and consequences being related to evaluation of coping. In particular, more symptoms and limitations being related to, predictive of and predicted by less favourable evaluations of coping.

Representation and outcome. There were concurrent, predictive, feedback and interactive relationships between representation and outcome (Fig.6.18). In particular, the more concrete components of representation, symptoms, specific problems & difficulties and limitations were consistently related to psychological outcome at all times, with the greatest number of these relationships being concurrently at T3. While there was support for the predictive nature of representations on outcome, there were more feedback relationships, with Self Esteem, mood and well-being predictive of symptoms and limutations later. Rating the condition as "More Serious" was related to lower satisfaction with life. At no time was cause related to outcome.

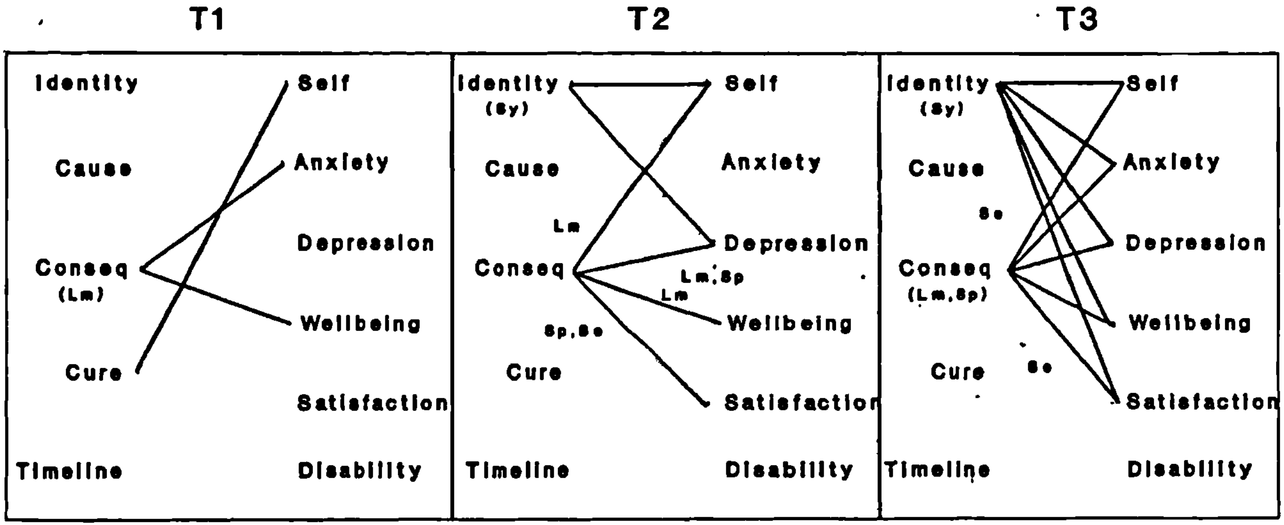
Fig.6.17 Relationship between representations and evaluation of coping



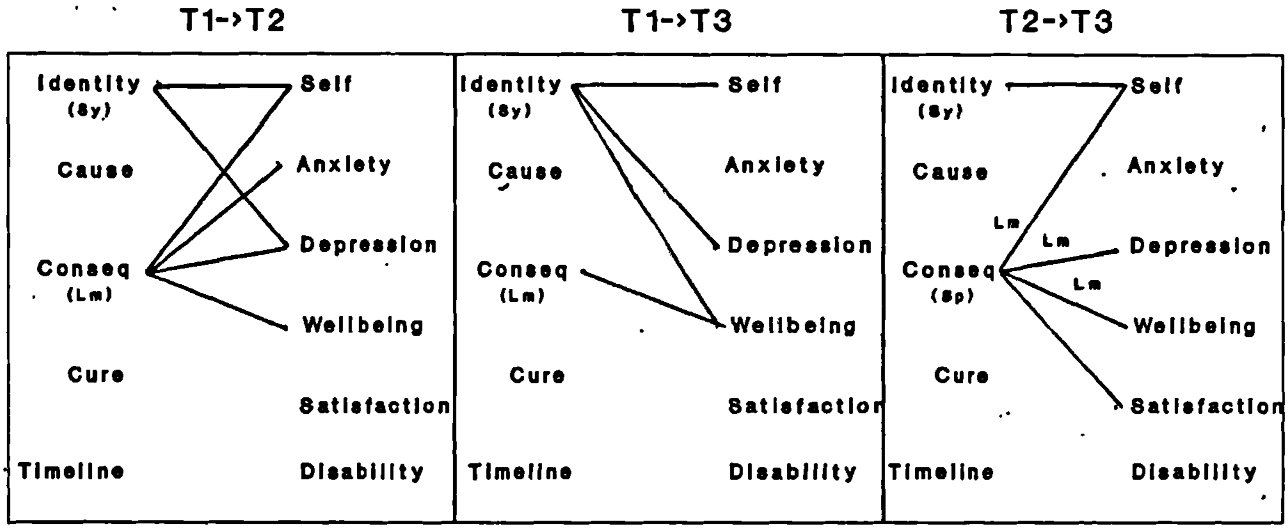
Key: Sy symptoms
Se seriousness
Lm limitations

Fig.6.19 Relationship between representations and outcome

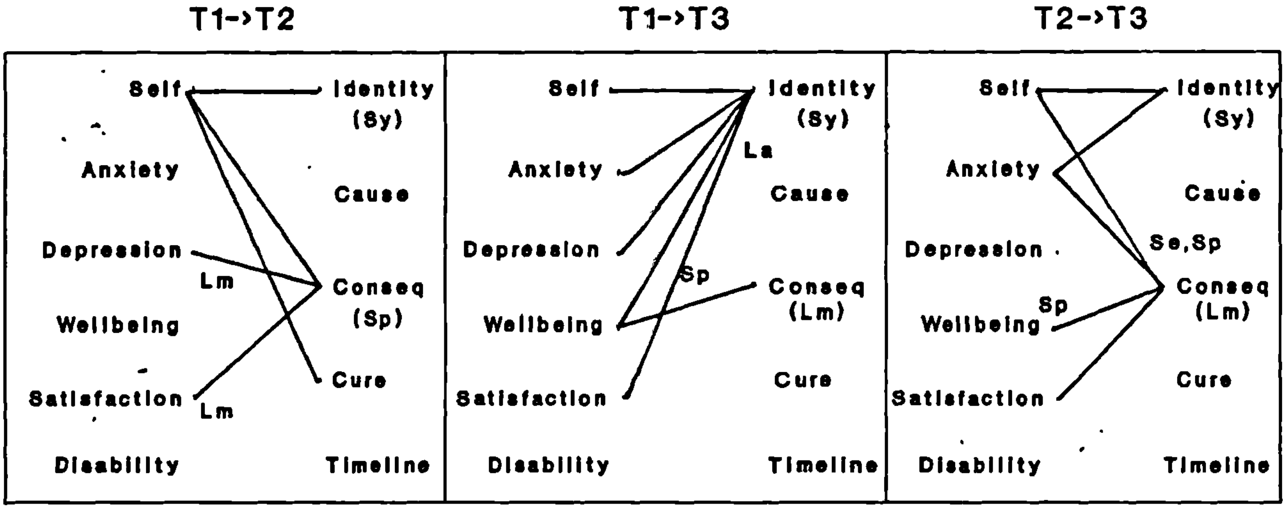
a) Concurrent



b) Predictive



c) Feedback



Key: Sy Symptoms
Lm Limitations
Sp Specific problems & difficulties
Se Seriousness

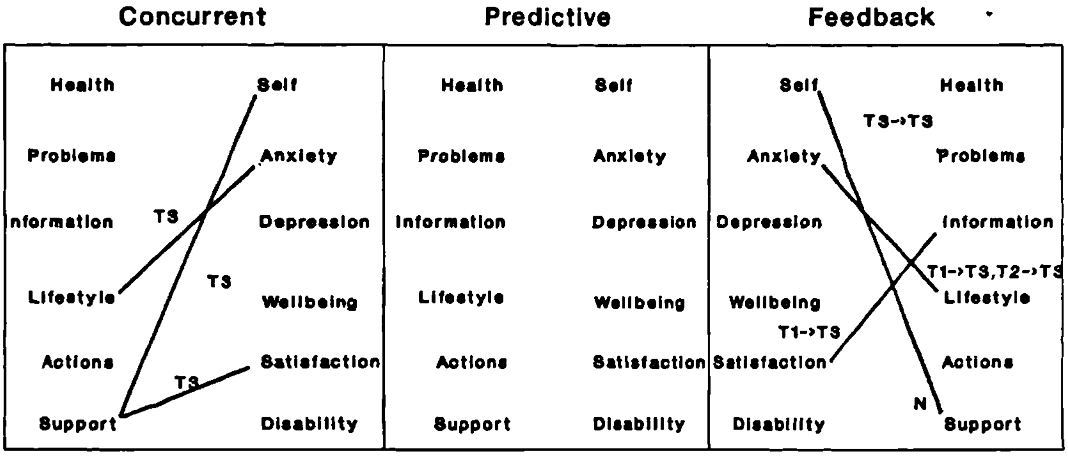
Watson & Pennebaker (1989) concluded that the relationship between mood or negative affectivity and complaints or symptoms is not adequately explained either by a psychosomatic model suggesting that the emotional state results in the symptoms, or by a disability model which suggests that symptoms result in negative moods. Instead they propose that much of this relationship can be explained by a disposition to report symptoms. Since symptoms were not related to mood at T1, it is unlikely that the dispositional explanation is adequate, although significant relationships were found at T2 and T3. The psychosomatic hypothesis is also supported as symptoms at T3 are predicted by mood at T1 and T2, but not for the prediction of symptoms at T2. These results offer some support for each of the explanatory hypothesis. Mood and limitations show a similar pattern of relationships, suggesting the possibility that they have an equally important role as symptoms in chronic illness schema.

Coping and evaluation of coping. The few relationships between coping and evaluation of coping that were found showed that more social supports and greater satisfaction with social supports were positively related to evaluation of coping.

Coping and outcome. The relationships between coping and outcome are summarised in Fig.6.19. The few relationships there were showed that taking action was associated with better psychological outcomes. Only at T3 were there any concurrent relationships between coping and emotional wellbeing, with a lack of action to change lifestyle being related to higher HAD Anxiety, and fewer social supports being related to feeling "Less Happy". While coping was not found to predict outcome, there was a weak feedback relationship between HAD Anxiety and actions taken to change lifestyle. It is possible that with respect to perceived control, taking action would result in better mood, and that better mood might result in improved self-efficacy. As all people were exposed to a stressor (admission to hospital for investigation of a chronic neurological illness), it is not possible to separate out main effects from the buffering effects of social support.

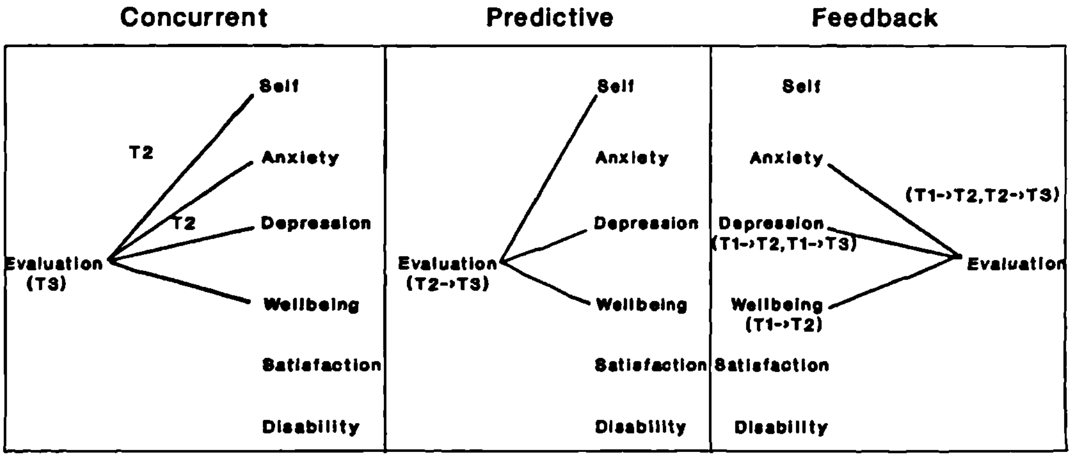
Evaluation of coping and outcome. The concurrent, predictive and feedback relationships between evaluation of coping and outcome are summarised in Fig.6.20. For all relationships at all times, positive evaluation of coping was related to better psychological mood and general Well-being; in particular, positive affect predicted a more positive evaluation of coping.

Fig.6.19 Relationships between coping and outcome



Key: N = Number of social supports

Fig.6.20 Relationship between evaluation of coping & outcome



In conclusion, results from this study provide new data that demonstrates the strong relationship between the concrete representations of symptoms and limitations and psychological well-being, with evidence to support the presence of a feedback loop, mood predicting  symptoms and limitations and vice versa, lending support to both the psychosomatic and disability model (Watson & Pennebaker,1989). In a deteriorating chronic illness where no coping actions have been identified as alleviating the effects of the condition, it is not perhaps surprising that the concrete representations are strongly associated with mood, and that this relationship is bi-directional. It may be that the crucial feature of multiple sclerosis is that it is an illness with neither cure nor palliation as opposed to an illness of chronic timeline. People may be coping by trying to develop more positive representations of the condition and more positive evaluations of the outcomes of their coping actions. This finding highlights the importance of focusing equally on both the physical sequelae of the condition and the person's illness representation.

# Chapter 7. Study 2: Self-regulation before diagnosis: results and discussion.

## 7.1 Introduction

This is a cross-sectional study which examines self-regulation before diagnosis. The illness representations, coping actions, evaluation of coping and outcomes of people being investigated for three potentially serious illnesses; multiple sclerosis (MS), motor neurone disease (MND) and liver disease (LV) were compared. Unless otherwise stated, the data has been handled in the same way as in the previous study. The central analyses of the study were concerned with two aspects, usefulness of the model before diagnosis, and secondly, the differences and interactions between the elements of the model for different diagnoses. In all cases, where results of the Chi square test are reported, Yates Correction has been applied, and where the results of a Oneway ANOVA are significant, the Scheffe test was used. This test is the most conservative in the sense that it is least likely to find significant differences between the groups. It is also exact for unequal numbers of subjects in the groups (Tabachnik & Fidell,1989). In addition, two way ANOVA,s and Multiple Regression Analysis (Stepwise) were used to examine the relationships between the elements of the model and diagnosis.

## 7.2 Demographic characteristics

The table below shows the mean ages for each group (table 7.1).

Table 7.1 Mean ages and sex for each group

| | | MS | MND | LV |
|---|---|---|---|---|
| Number : | Men | 5 | 6 | 15 |
| | Women | 15 | 5 | 7 |
| Age: | Mean | 35.8 | 57.2 | 44.5 |
| | SD | 6.6 | 14.2 | 15.6 |
| | F | 9.882 | | |
| | p | .0002 | | |

A Oneway ANOVA showed a significant age difference between the groups, the Scheffe test showed that the MND group were older than both the MS and LV groups. Overall, there were 27 men and 26 women. The LV group had significantly more men (Chi sq=6.2,df=2,p=.05). Marital status, living arrangements and employment status are shown below:

Table 7.2 Domestic arrangements for each group

| | MS | MND | LV |
|---|---|---|---|
| Marital status: | | | |
| Single | 5 | 1 | 4 |
| Married | 12 | 10 | 13 |
| Separated/divorced | 3 | 0 | 2 |
| Widowed | 0 | 0 | 2 |
| Living arrangements: | | | |
| Alone | 1 | 1 | 4 |
| With family | 19 | 10 | 18 |
| Employment Self: | | | |
| Paid employment | 17 | 6 | 14 |
| Housework | 1 | 0 | 0 |
| Not working/condition | 2 | 2 | 2 |
| Not working/other | 0 | 3 | 6 |

As can be seen from the above table, the majority of people were married, living with their families and in paid employment. A small number of people were not working because of their condition.

## 7.3 Description of the elements of the model for each group

### 7.3.1 Illness representation

The five components to illness representation, identity, cause, consequences, cure and timeline were assessed using the semi-structured interview. Table 7.3 summarises the illness representations for each of the groups.

Table 7.3: Illness representation for each group

| | MS | MND | LV |
|---|---|---|---|
| Number: | 20 | 11 | 22 |
| Identity: | | | |
| correct label | 8(40%) | 5(46%) | 14(64%) |
| reporting symptoms | 17(85%) | 11(100%) | 11(50%) |
| Cause: | 11(55%) | 6(54%) | 11(50%) |
| Consequences: | | | |
| rated as More Serious | 13(65%) | 9(82%) | 13(59%) |
| ("very serious" + "somewhat serious") | | | |
| ranked as More Serious | 8(40%) | 7(64%) | 14(64%) |
| (ranked 1-5) | | | |
| specific problems | 13(65%) | 10(91%) | 7(32%) |
| limitations | 14(70%) | 8(72%) | 10(45%) |
| Cure: | 12(60%) | 3(27%) | 7(32%) |
| Timeline: | | | |
| expect to be better: | 8(40%) | 2(18%) | 10(46%) |

### (a) Identity

There were no significant differences between the groups in terms of label (Chi sq=2.5,df=2,p=.29). A Oneway ANOVA was used to examine the differences between the groups in the number of symptoms reported. Table 7.4 shows the mean number of symptoms reported by each group.

Table 7.4 Number of symptoms reported by each group

| | N | Mean | SD | F | p |
|---|---|---|---|---|---|
| MS | 20 | 2.9 | 2.2 | 4.6 | .01 |
| MND | 11 | 3.1 | 1.8 | | |
| LV | 22 | 1.3 | 1.8 | | |

A Scheffe test showed that the LV group reported significantly fewer symptoms than did the MS group. Fig. 7.1 shows people's estimates of the time since their first symptom. Those being investigated for MND had a shorter estimate of time since onset than did the other groups (Chi sq=8.0,df=2,p=.02). Fig. 7.2 shows the types of symptoms reported by the three diagnostic groups. For each group, over half the symptoms were accounted for by abnormal sensations, with MND and LV reporting twice as many symptoms of tiredness and fatigue as the MS group.

### (b) Cause

There were no significant differences between the groups in attribution of cause (Chi sq=.12,df=2,p=.94), with approximately half attributing a cause to their condition.

### (c) Consequences

Seriousness. There were no significant differences in rated or ranked seriousness between the diagnostic groups. Neither was there a relationship between rated or ranked seriousness and

Fig.7.1 Identity: time since onset of first symptom for each group

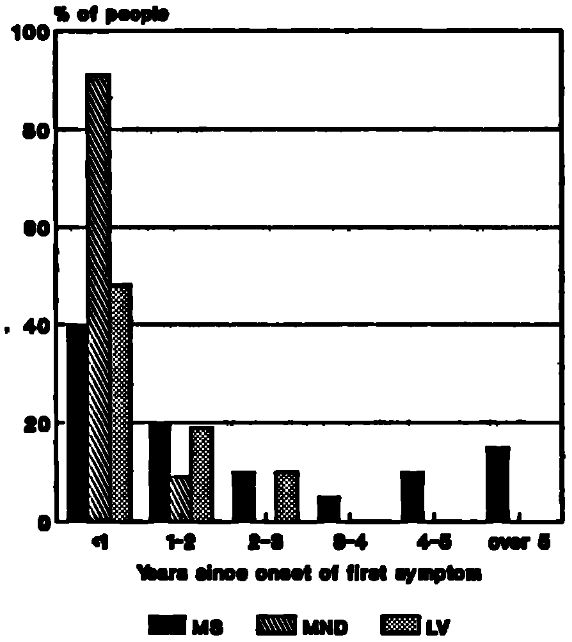
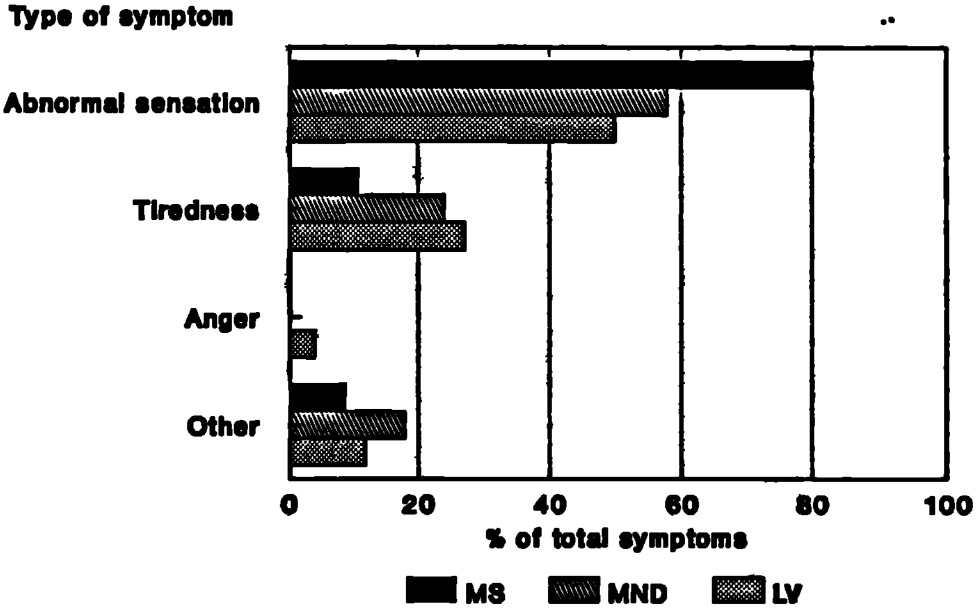


Fig.7.2 Identity: type of symptoms reported for each group



number of symptoms, either within each group or over all subjects.

Problems and difficulties. Fewer people in the LV group reported problems and difficulties (Chi sq=11.3,df=2,p=.003).

Limitations. There were no significant difference between the groups in the total number of limitations reported (Oneway ANOVA, F=.39,df=1,p=.68). Fig. 7.3 shows the types of limitations people reported for each of the groups. Overall there was a positive relationship between the number of symptoms reported and the total number of limitations (Pearson's R=.38, p=.005).

### (d) Cure

There were no significant differences between the groups in belief in a cure (Chi sq=4.6,df=2,p=.10).

### (e) Timeline

There was no significant difference between the groups in expectation of improvement (Chi sq=2.4,df=2,p=.30).

## 7.3.2 Coping

Five categories of action measuring coping were compared across groups:

(a) Actions taken to keep healthy generally

(b) Actions taken to manage specific problems and difficulties

(c) Actions taken to increase understanding

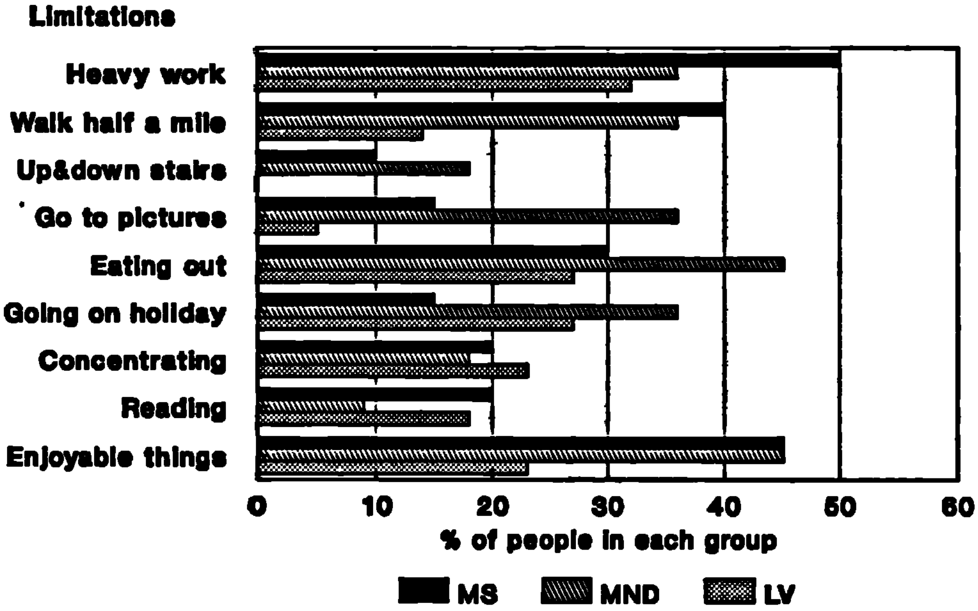
(d) Actions taken other than those advised by doctor

(e) Total number of types of actions taken

(f) In addition, social support as a coping resource was compared.

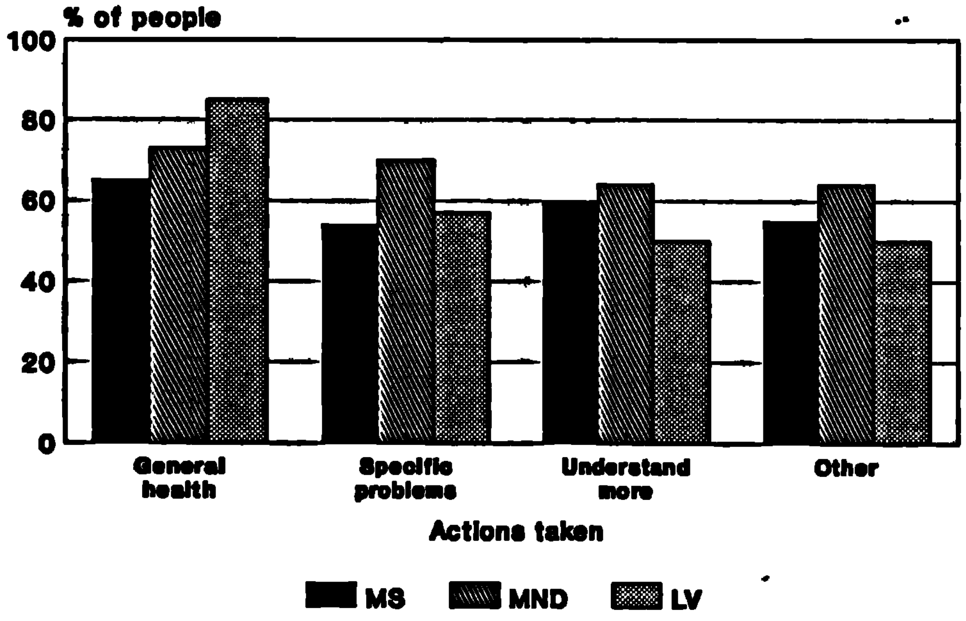
There were no significant differences between the groups on the types of actions taken, the number of types of actions taken or whether action was taken at all, with 87% taking some kind

## Fig 7.3 Consequences: type of limitation reported by each group



| Key: |  | MS | MND | LV |
|---|---|---|---|---|
|  | Mean | 2.5 | 2.6 | 1.7 |
|  | SD | 2.8 | 2.7 | 2.4 |

## Fig.7.4 Coping: actions taken to cope by each group



of action. Fig.7.4 shows the percentage of people taking actions to cope with their condition. No one reported having "too much" information, people in the MS and LV groups were more likely to report having "too little" information rather than "enough" (Binomial,MS p=.04, LV p=.000). There were no differences between the groups in either the number of social supports or satisfaction with those supports (Table 7.5).

Table 7.5: Social support for each group.

| | | Number | | | | Satisfaction | | | |
|---|---|---|---|---|---|---|---|---|---|
| | N | Mean | SD | F | p | Mean | SD | F | p |
| MS | 20 | 3.2 | 2.2 | .05 | .95 | 17.6 | 13.0 | .14 | .86 |
| MND | 11 | 3.2 | 1.2 | | | 19.0 | 7.2 | | |
| LV | 22 | 3.4 | 2.0 | | | 19.7 | 12.7 | | |

The mean number of supports for the group was 3.3 (SD 2.0, range 0 - 7.8), the mean satisfaction 18.8 (SD 11.7, range 3 - 46). Overall, there was a strong correlation between the number of social supports and satisfaction with those supports (Pearson's r=.99, p=.0001).

### 7.3.3 Evaluation of coping

There were no significant differences between the groups in evaluation of coping efforts. Over 90% of people in all groups felt that they had coped either "quite well" or "very well", with only one person in the MND group feeling that they had coped "very badly". For further analysis, data were collapsed into those who felt that they had managed Very Well ( "very well") and those who did not (Less Well). The overall difference in the number who evaluated their coping Very well rather than Less well was significant (Binomial test, p=.01).

### 7.3.4 Outcome

There were no significant differences between the groups on any of the outcome measures. Only 2 people in the overall sample were rated as disabled on the OPCS, the groups were not therefore compared on this measure.

The perceived changes in feelings about self are shown in Fig.7.5. The Binomial test showed that overall, of the 33 people who felt differently about themselves, significantly more people felt negatively rather than positively as a result of their symptoms (p=.0001). The scores for the groups on the standardised outcome measures of Self Esteem and emotional wellbeing were compared using a Oneway ANOVA (Table 7.6), no significant differences were found.

Table 7.6 Self Esteem and emotional wellbeing for each group

| | MS | | MND | | LV | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | F | p |
| Self Esteem | 35.5 | 7.1 | 37.2 | 4.6 | 38.6 | 5.8 | 1.4 | .26 |
| HAD Anxiety | 7.6 | 3.2 | 8.8 | 3.9 | 7.5 | 4.4 | .43 | .65 |
| HAD Depression | 5.3 | 3.7 | 5.6 | 3.7 | 4.1 | 3.2 | .86 | .43 |
| Bradburn Wellbeing | 2.8 | 5.5 | 1.3 | 6.0 | 4.9 | 4.8 | 1.8 | .18 |

Less than 20% in each group scored over 10 on the HAD Anxiety, considered to be indicative of clinical anxiety, and less than 10% over 10 on the HAD Depression scale, considered to be indicative of clinical depression. Table 7.7 shows the relationships between the standardised outcome measures for all groups, with significant correlations being found between each pair of measures.

Fig.7.5 Impact on self: feelings about self for each group

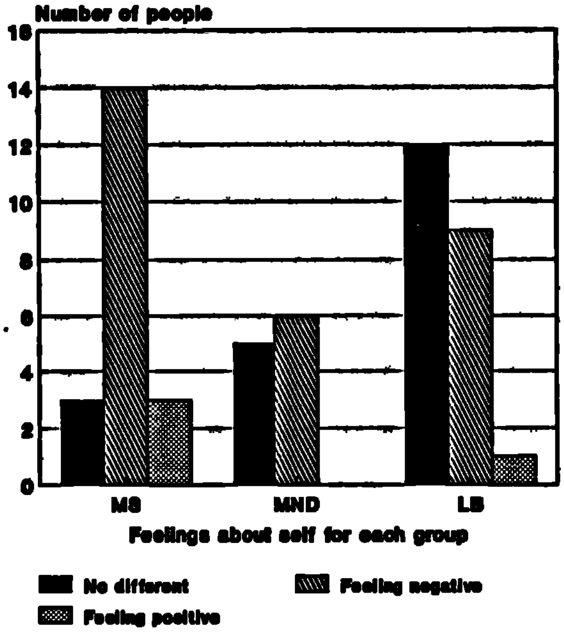


Fig.7.6 Emotional wellbeing: life satisfaction for each group

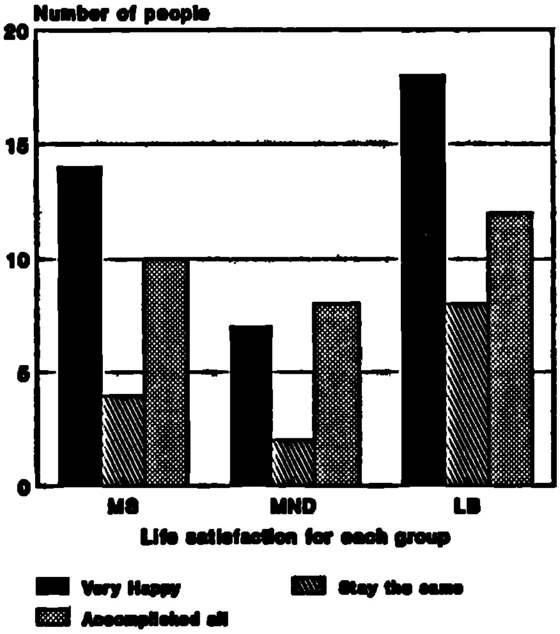


**Table 7.7 Relationship between standardised outcome measures**

| | HAD Anxiety | | HAD Depression | | Bradburn Wellbeing | |
|---|---|---|---|---|---|---|
| | r | p | r | p | r | p |
| Measures: | | | | | | |
| Self Esteem | -.55 | .0001 | -.67 | .0001 | .64 | .0001 |
| HAD Anxiety | | | .68 | .0001 | -.58 | .0001 |
| HAD Depression | | | | | -.70 | .0001 |

**Fig.7.6 shows the pattern of responses for all groups on life satisfaction. The relationship between Life Satisfaction, Self Esteem and emotional wellbeing were higher for the more satisfied people (Table 7.8). Being More Happy and wanting to continue in the same way were significantly and consistently associated with better emotional outcomes.**

**Table 7.8 Relationship between Life Satisfaction, Self Esteem and emotional wellbeing**

| | Self Esteem | HAD Anxiety | HAD Depression | Bradburn Wellbeing |
|---|---|---|---|---|
| Happiness: | | | | |
| (More Happy - Less Happy) | 5.8** | -5.0*** | -5.3*** | 7.1*** |
| Change: | | | | |
| (stay the same - change) | 6.5*** | -2.4* | -3.6*** | 5.9*** |
| Accomplishment: | | | | |
| (yes - no) | 4.1* | -1.8 | -1.2 | 1.7 |

**Unpaired t-Test *p= <.05, **p= <.01, ***p= <.001**

**A Oneway ANOVA (F=2.42,df=2,p=.10) showed no significant differences between the groups on interviewer rating of coping (Table 7.9).**

Table 7.9 Interviewers evaluation of coping

| | GAIS | | | |
|---|---|---|---|---|
| | N | Mean | SD | Range |
| MS | 19 | 80.5 | 11.6 | 53 - 95 |
| MND | 11 | 83.5 | 9.6 | 65 - 95 |
| LV | 22 | 87.9 | 2.3 | 60 - 98 |
| Total | 52 | 84.3 | 11.1 | 53 - 98 |

The relationship between the interviewers evaluation of people's adjustment and standardised outcome measures was examined (Table 7.10), and found overall to be significantly positively correlated.

Table 7.10 Relationship between interviewers evaluation and standardised measures.

| | Interviewers evaluation of coping | | |
|---|---|---|---|
| Measures: | n | r | p |
| Self Esteem | 51 | .35 | .01 |
| HAD Anxiety | 50 | -.37 | .01 |
| HAD Depression | 50 | -.29 | .04 |
| Bradburn Wellbeing | 50 | .42 | .003 |

## 7.4 Relationship between elements of the model

The relationships between the elements of the model will be examined for the whole group. The relationships between the elements for individual groups will only be examined where statistically significant differences were reported in the previous section. 2-way ANOVA's and Chi sq have been used to examine the following relationships:

(a) Representations and coping

(b) Representations and evaluation of coping

(c) Representations and outcome

(d) Coping and evaluation of coping

(e) Coping and outcome

(f) Evaluation of coping and outcome

Graph's of significant ANOVA's are shown in Appendix C with F and p values. Interactions are reported where significant.

### 7.4.1 Representation and coping

Of the 30 people who had reported specific problems and difficulties, taking action to manage those difficulties was significantly related to attributing a cause (Chi sq=4.69,df=2,p=.03), with 13 out of 16 people who attributed a cause taking some action.

### 7.4.2 Representation and evaluation of coping

There were no significant relationships between representation and evaluation of coping for any of the groups.

### 7.4.3 Representation and outcome

♦ People with more symptoms had higher HAD Depression scores

♦ People who rated their condition as More Serious were more likely to report feeling negatively about themselves (Chi sq=6.42,df=2,p=.01).

♦ People with fewer limitations:

- had higher Self Esteem
- had lower HAD Depression scores
- had better Wellbeing scores
- were more likely to report feeling Very Happy (Ch sq=7.36,df=2,p=.007).

### 7.4.4 Coping and evaluation of coping

There was a significant interaction between coping and evaluation of coping with diagnosis (Fig.7.7). People with MS and LV who evaluated their coping efforts Very Well had more social supports and were more satisfied with their supports.

### 7.4.5 Coping and outcome

◆ People who had accomplished all the things they wanted to were less likely to have sought information (Chi Sq=4.96,df=2,p=.03).

### 7.4.6 Evaluation of coping and outcome

◆ People who evaluated themselves has having managed Very Well had:

- higher Self Esteem scores
- lower HAD Anxiety scores
- lower HAD Depression scores
- better Wellbeing scores

## 7.5 Discussion

### 7.5.1 Support for the elements of the model before diagnosis

Support for the elements of the model was examined for the whole group and differences between the groups were investigated. While the MND group were older, significant differences between the groups for illness representation were in identity (LV reported less symptoms) and consequences (LV reported fewer limitations and problems & difficulties), no significant differences between the groups for coping, evaluation of coping and outcome were found. Thus, despite differences between the conditions both in terms of the physiological system affected and the medical treatment, there was little difference in what people did or felt about the conditions and it is reasonable to consider the experience of the total group.

People's representations of their condition were varied, overall about half had the correct label. Over 85% of people being investigated for MS and MND reported symptoms, while those being investigated for liver disease had significantly fewer symptoms (50%). About half attributed a cause for their condition. Most people perceived their condition to be More Serious and reported limitations. People being investigated for liver disease reported significantly fewer limitations and problems & difficulties. Just less than half the overall group believed in a cure or expected to be better. There was a positive relationship between symptoms and limitations.

Nearly all the group had taken some action to manage their symptoms/condition. No one reported having "too much" information, although people being investigated for MND were less likely to report having "too little" information. This supports previous work indicating that patients wish to be informed (Ley,1989). Overall there was a strong correlation between the number of social supports and satisfaction with those supports. Nearly everyone evaluated themselves as having managed either "quite well" or "very well".

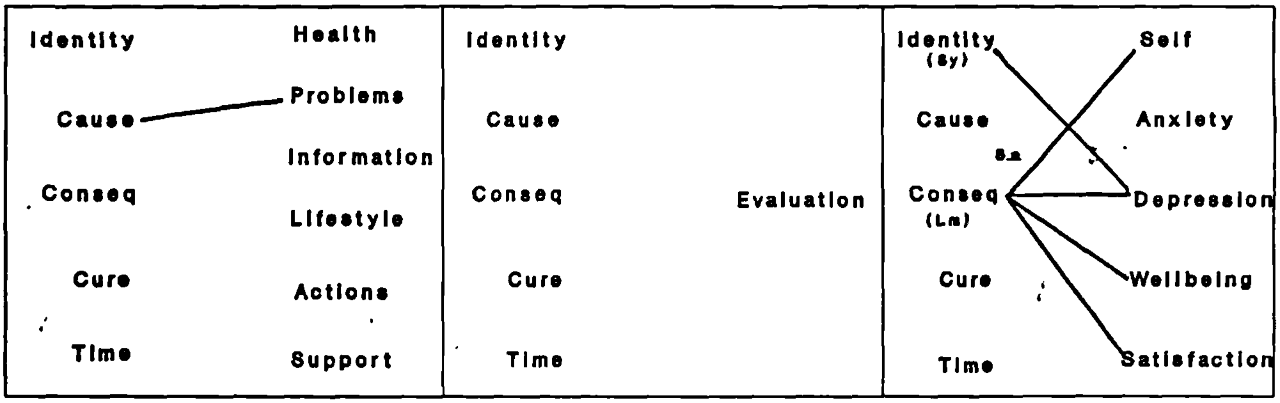
While significantly more people reported feeling negatively about themselves as a result of their symptoms/condition, results from the standardised outcome measures did not indicate high levels of emotional distress or low self esteem.

### 7.5.2 Relationship between the elements of the model

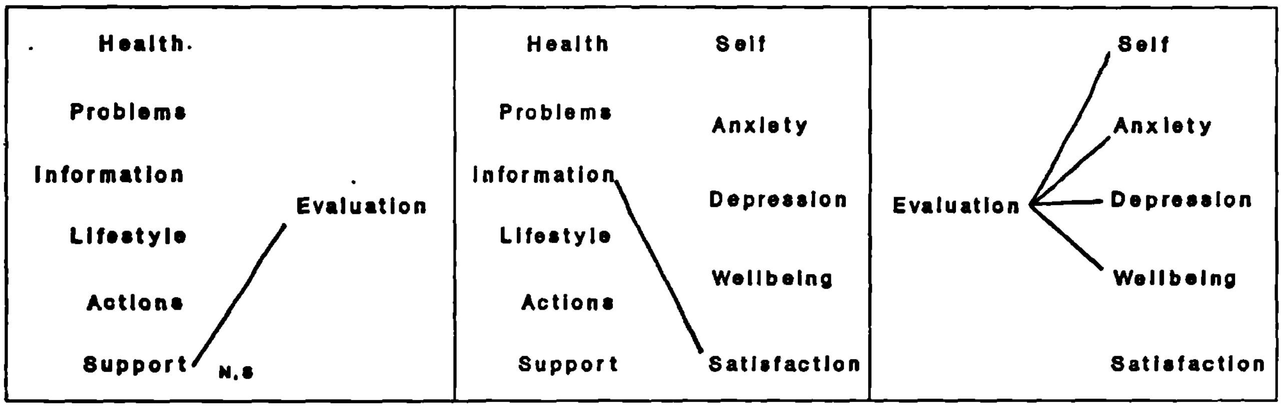
Fig. 7.8 summarises the relationships between the elements of the model. This study provides support for the model in that representations and coping, rather than illness per se, are important elements in determining emotional outcomes. Outcomes were determined by representations of the condition (number of symptoms, limitations and seriousness), coping (information) and evaluation of coping, and not by differences between conditions. People who attributed a cause were more likely to be taking action to deal with specific problems and difficulties. Perhaps attribution implies controllability, other models of illness representation consider controllability

Fig.7.8 Relationships between the elements of the model

a) Representations & coping      Representations & evaluation      Representations & outcome



b) Coping and evaluation      Coping and outcome      Evaluation and outcome



Key: N = Number, S = Satisfaction
Lm = Limitations, Se = Seriousness

important (Turk, Rudy & Salovey,1986). There was minimal impact of representations on coping, perhaps because they were engaged in the diagnostic process having taken the action of seeking medical advice.

The greatest number of relationships were between representations and outcome, with reporting more symptoms and limitations being associated with poorer emotional outcomes. Rating of the condition as More Serious was also associated with a negative impact on the self. There were very few relationships between coping and evaluation, and coping and outcome. Evaluation and coping were related only via social support. It appears that, rather than social support implying they are not coping well and need things doing, social support may have a more important role in confirming that they are coping well. Alternately, Sarason et al (1983) has suggested that social support is a disposition and it may reflect a general positive outlook. This compares to Watson & Pennebakers (1989) ideas on "positive affectivity" or Carver and Scheier's (1989) "dispositional optimism". People who had more social supports and were more satisfied with those supports were more likely to have evaluated themselves as having managed Very Well. People who had accomplished all the things they wanted to were less likely to have sought information.
People who had evaluated their coping as Very Well had higher Self Esteem and better emotional wellbeing.

This study is limited in its value in that being of cross-sectional design, one cannot examine direction of causality. In addition, these people were at a key stage of the diagnostic process, waiting for admission to hospital for tests and investigations, with uncertainty, and the impending stress of medical intervention and diagnosis.

# Chapter 8. Study 3: Self-regulation at different stages of the illness following diagnosis: results and discussion.

## 8.1 Introduction

This was a pseudo-longitudinal study which examined self-regulation following the diagnosis of multiple sclerosis. The illness representations, coping actions, evaluation of coping and outcomes of people who have received a diagnosis of multiple sclerosis 6 months (MS1), 2 years (MS2) and over 7 years (MS3) previously were compared. The central analysis of the study were concerned with the elements of the model at different stages of the illness, and the interactions between the elements of the model and stage of illness. Unless otherwise stated the data were handled in the same way as the previous studies, the statistical procedures used were similar to those used in the cross-sectional study.

## 8.2 Demographic characteristics

The age differences between the groups was examined (Table 8.1).

Table 8.1 Age at different stages of the illness

| | | MS1 | MS2 | MS3 |
|---|---|---|---|---|
| Number: | Men | 5 | 5 | 8 |
| | Women | 15 | 14 | 17 |
| Age: | Mean | 35.8 | 43.4 | 40.5 |
| | SD | 6.6 | 11.8 | 8.6 |
| | F | 3.0343 | | |
| | p | .0554 | | |

A Oneway ANOVA and Scheffe test showed a tendency for the MS1 group to be younger. Overall there were 46 women and 18 men a similar ratio of men to women in each group.

**Table 8.2 Domestic arrangements at different stages of the illness**

| | MS1 | MS2 | MS3 |
|---|---|---|---|
| **Marital status:** | | | |
| Single | 5 | 2 | 1 |
| Married | 12 | 16 | 19 |
| Separated/divorced | 3 | 0 | 3 |
| Widowed | 0 | 1 | 2 |
| **Living arrangements:** | | | |
| Alone | 1 | 0 | 4 |
| With family | 19 | 19 | 21 |
| **Employment:** | | | |
| Paid employment | 17 | 11 | 10 |
| Housework | 1 | 0 | 0 |
| Not working/condition | 2 | 7 | 12 |
| Not working/other | 0 | 1 | 3 |

The majority of people were married and living with their families. Significantly more people in the MS1 group were in paid employment (Chi sq=8.6,df=2,p=.01).

Table 8.3: Illness representation at different stages of the illness

| | MS1 | MS2 | MS3 |
|---|---|---|---|
| **Identity:** | | | |
| correct label | 16(80%) | 18(95%) | 25(100%) |
| reporting symptoms | 13(65%) | 16(84%) | 24(96%) |
| **Cause:** | 9(45%) | 15(79%) | 12(48%) |
| **Consequences:** | | | |
| rated as More Serious ("very serious" + "somewhat serious") | 11(55%) | 12(63%) | 23(92%) |
| ranked as More Serious (ranked 1-5) | 6(30%) | 14(74%) | 23(96%) |
| specific problems | 10(50%) | 13(68%) | 18(72%) |
| limitations | 12(60%) | 17(89%) | 25(100%) |
| **Cure:** | 3(15%) | 3(16%) | 0 |
| **Timeline:** | | | |
| expect to be better: | 4(20%) | 4(21%) | 4(16%) |

### (a) Identity

Holding the correct label and the number of symptoms increased over time. People in the earliest stage of the illness, MS1, were significantly less likely to have the correct label (Chi sq= 6.4,df=2, p=.04), while and ANOVA an Scheffe test showed that MS3 reported significantly more symptoms than did MS1, with over half the symptoms reported accounted for by abnormal sensations (Fig.8.1)

Fig. 8.1 Identity: type of symptoms reported at different stages of illness

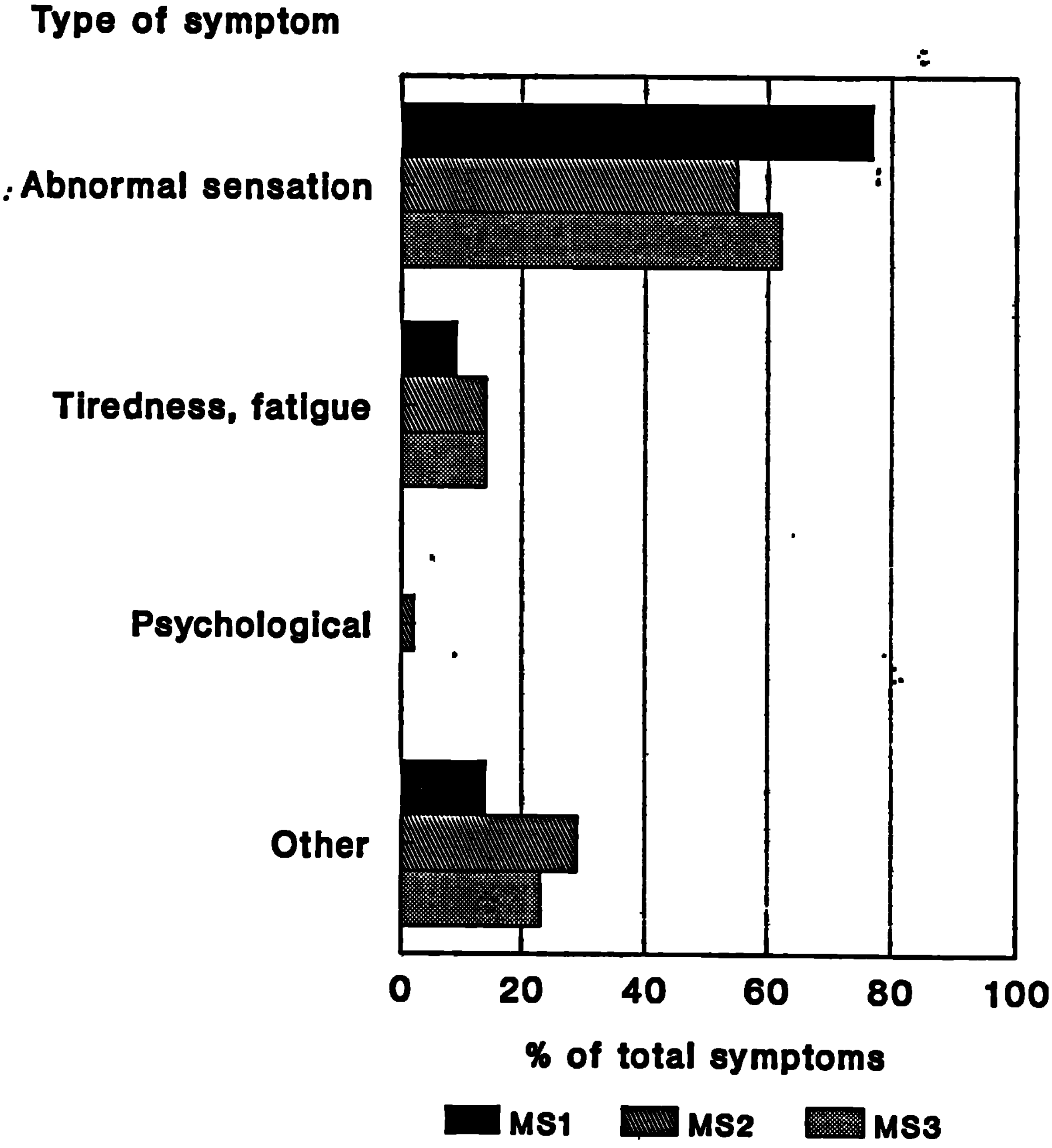


Table 8.4 Symptom reporting at different stages of the illness

| | Mean | SD | F | p |
|---|---|---|---|---|
| MS1 | 1.8 | 1.7 | 8.2 | .0007 |
| MS2 | 2.6 | 1.8 | | |
| MS3 | 3.9 | 1.9 | | |

(c) Cause

While the groups did not differ significantly in terms of whether or not they attributed a cause, of those people who did attribute a cause, significantly more of MS2 attributed the cause to their own behaviour (Chi sq=7.2,df=2, p=.03) (Fig.8.2).

(c) Consequences

<u>Seriousness</u>. Rated and ranked seriousness increased over time (Fig.8.3). MS3 were significantly more likely to rate their condition as More Serious (Chi sq= 8.5,df=2, p=.01), and MS1 to rank their condition less seriously (Oneway ANOVA and Scheffe test (Table 8.5).

Table 8.5 Ranking of seriousness at different stages of the illness

| | Ranking of seriousness | | | |
|---|---|---|---|---|
| | Mean | SD | F | p |
| MS1 | 5.7 | 2.5 | 8.0 | .0009 |
| MS2 | 3.8 | 1.9 | | |
| MS3 | 3.3 | 1.6 | | |

For MS1, ranking the illness as Less Serious was associated with reporting more symptoms (Pearson's r=.44, p=.05) while for MS3, having more symptoms was positively correlated with seriousness of ranking (Pearson's r=-.51,p=.01).

Fig. 8.2 Cause: attribution of cause at different stages of the illness

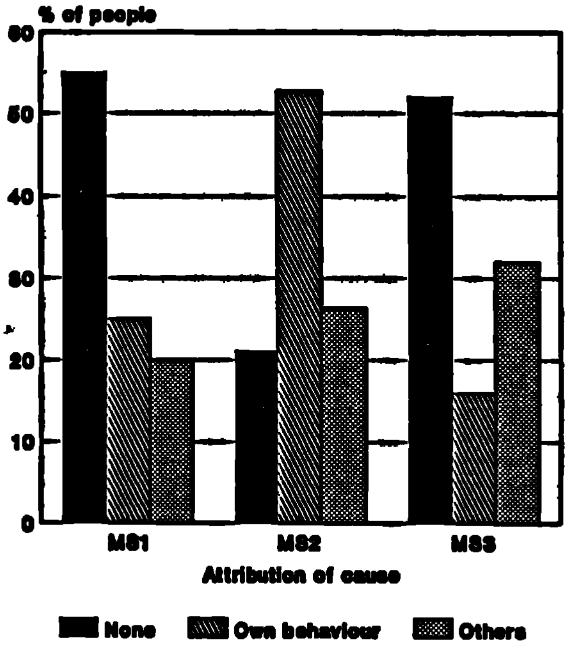
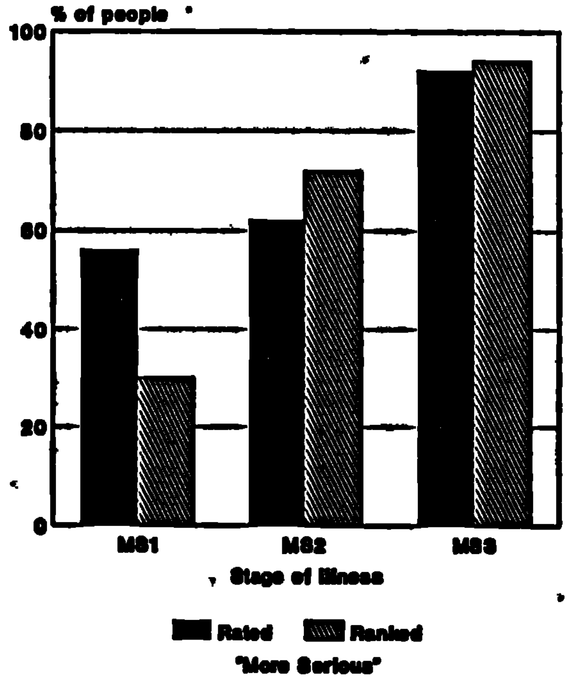


Fig. 8.3 Consequences: rated & ranked seriousness at different illness stages



Problems and difficulties. The number of specific problems and difficulties reported did not increase significantly with the stage of illness.

Limitations. The number of limitations reported increased over time, MS3 reporting significantly more limitations than either MS1 or MS2 (Oneway ANOVA + Scheffe) (Table 8.6)

Table 8.6 Total number of limitations reported at different stages of the illness

| | Number of limitations reported | | | |
|---|---|---|---|---|
| | Mean | SD | F | p |
| MS1 | 2.0 | 2.4 | 12.6 | .0001 |
| MS2 | 3.6 | 2.3 | | |
| MS3 | 5.7 | 1.6 | | |

Fig.8.4 shows the types of limitations people reported for each of the groups, the increase in % showing limitations over the stages being apparent for each of the limitations. Overall there was a positive relationship between limitations and number of symptoms (Pearson's r=.59, p=.0001) and between limitations and the ranking of seriousness (Pearson's r=-.31, p=.01).

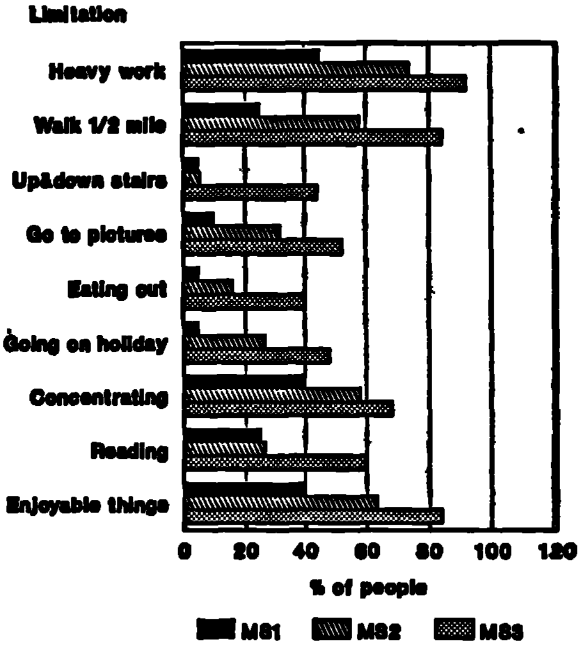
### (d) Cure and timeline

There were no significant differences between the groups in belief in a cure (Chi sq=4.3,df=2, p=.12) or in the expectation of improvement (Chi sq=.21,df=2, p=.90).

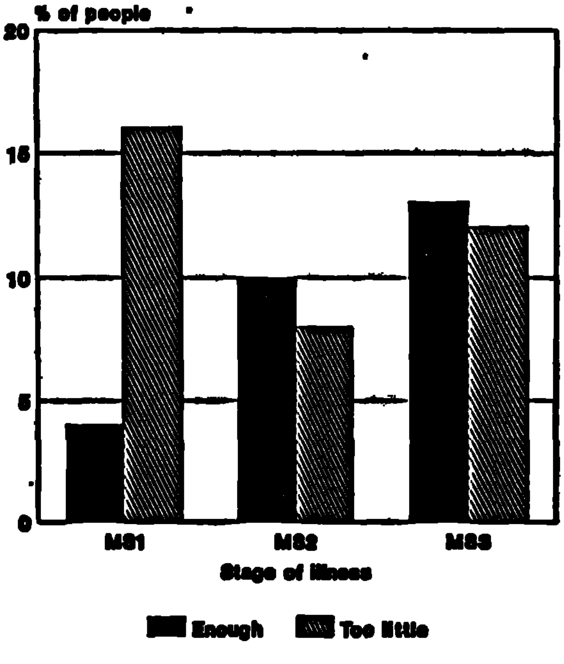
### 8.3.2 Coping

There were no significant differences over time in the type, number or amount of action taken, with over 85% taking some kind of action. Only one person in MS2 reported having "too much" information, with significantly more people in MS1 reporting that they had "too little" information (Chi sq=5.9,df=2,p=.05)(Fig.8.5). There were no significant differences between the groups in

### Fig. 8.4 Consequences: limitations reported at different illness stages



### Fig.8.5 Coping: satisfaction with information at each time



Satisfaction with information

either the number of social supports or satisfaction with those supports. The mean number of social supports for the group was 4.2 (SD 2.6, range .2-14.0), the mean satisfaction 22.3(SD 13.5, range 3.5-54). Overall, there was a strong correlation between the number of social supports and satisfaction with those supports (Pearson's r=.90, p=.0001).

### 8.3.3 Evaluation of coping

There were no significant differences over time in how people evaluated their coping efforts. Overall, 90% of people felt that they had coped either "quite well" or "very well", with no one reporting that they had coped badly.

### 8.3.4 Outcome

Outcome was examined in three broad areas; impact on self, emotional wellbeing and disability.

#### a) Impact on self

Overall, people reported significantly more negative than positive feelings about themselves (Binomial test, p=.004), and a Oneway ANOVA + Sheffe test showed no significant difference between the groups in Self Esteem although it tended to be lower in MS3 (Table 8.7).

#### (b) Emotional wellbeing

A Oneway ANOVA showed no significant differences in emotional wellbeing (Table 8.7), although there was a tendency for those who had had the condition the longest to have lower Self Esteem scores.

Table 8.7 Self Esteem and emotional wellbeing at different stages of the illness

| | MS1 | | MS2 | | MS3 | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | Mean | SD | F | p |
| Self Esteem | 37.3 | 8.2 | 36.2 | 9.2 | 31.9 | 7.6 | 2.6 | .08 |
| HAD Anxiety | 7.0 | 3.4 | 8.1 | 4.3 | 8.4 | 3.8 | .86 | .43 |
| HAD Depression | 5.2 | 4.2 | 5.1 | 4.2 | 5.7 | 3.7 | .16 | .85 |
| Bradburn Wellbeing | 3.9 | 5.8 | 3.6 | 6.0 | 2.5 | 5.9 | .35 | .70 |

22% of the sample overall had HAD Anxiety scores greater than 10, indicative of clinical anxiety, only 8% of people had scores greater than 10 on the HAD Depression scale, indicative of clinical depression. Over 65% had positive wellbeing scores on the Bradburn scale. There were no interactions with age or sex. The relationships between the standardised outcome measures for all groups are shown below:

Table 8.8 Relationship between standardised outcome measures

| | HAD Anxiety | | HAD Depression | | Bradburn Wellbeing | |
|---|---|---|---|---|---|---|
| | r | p | r | p | r | p |
| Measures: | | | | | | |
| Self Esteem | -.56 | .0001 | -.75 | .0001 | .76 | .0001 |
| HAD Anxiety | | | .59 | .0001 | -.49 | .0001 |
| HAD Depression | | | | | -.71 | .0001 |

Fig 8.6 shows the percentage of people reporting feeling Very Happy, wanting to "stay the same" and those reporting that they had accomplished all the things they wanted to "up to this point" in their lives. There were no significant differences between the groups.

Being More Happy, wanting to continue in the same way, and feeling that you had achieved all you wanted to were significantly and consistently correlated with higher Self Esteem and better emotional wellbeing (Table 8.9).

# Fig.8.6 Emotional wellbeing: life satisfaction at different illness stages

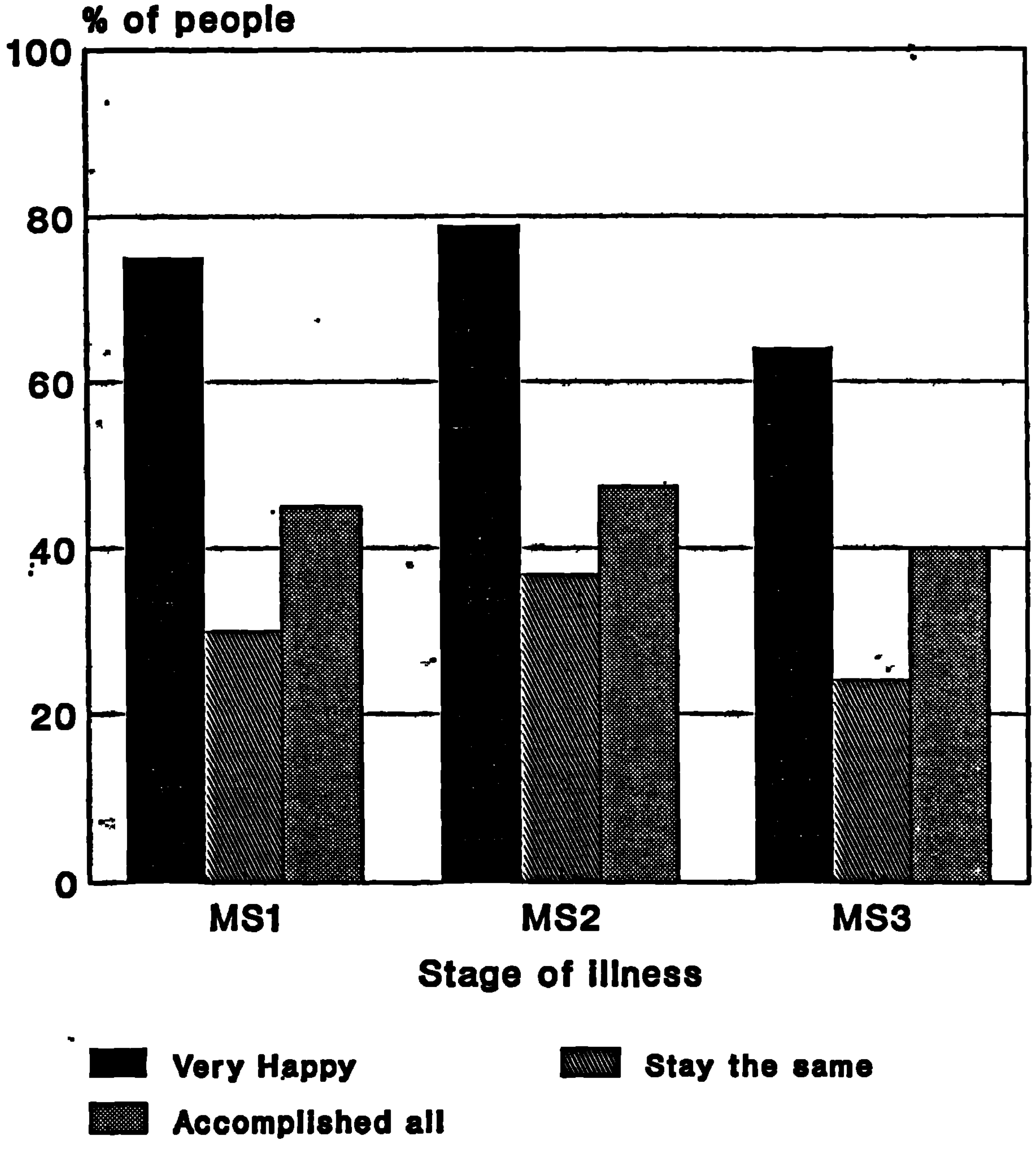


**Table 8.9 Relationship between life satisfaction, Self Esteem and emotional wellbeing**

| | Self Esteem | HAD Anxiety | HAD Depression | Bradburn Wellbeing |
|---|---|---|---|---|
| **Happiness:** | | | | |
| **(More Happy - Less Happy)** | **9.2*** ** | **-2.9** ** | **-5.1*** ** | **7.3*** ** |
| **Change:** | | | | |
| **(stay the same - change)** | **10.3*** ** | **-3.8*** ** | **-3.3*** ** | **6.0*** ** |
| **Accomplishment:** | | | | |
| **(yes - no)** | **6.9*** ** | **-1.3** | **-2.1* ** | **3.7** ** |

**Unpaired t-Test *p=<.05, **p=<.01, ***p=<.001**

**A Oneway ANOVA showed no significant differences between the groups on interviewer rating of coping. An overall comparison of the interviewers evaluation of people's adjustment and standardised outcome measures was examined using Pearson's Product Moment correlation and showed a significant correlation, r=.52,.47,-.54,-.68 (p=.0001 in each case) for Wellbeing, Self Esteem, HAD Anxiety and HAD Depression respectively.**

**(c) Severity of disability**

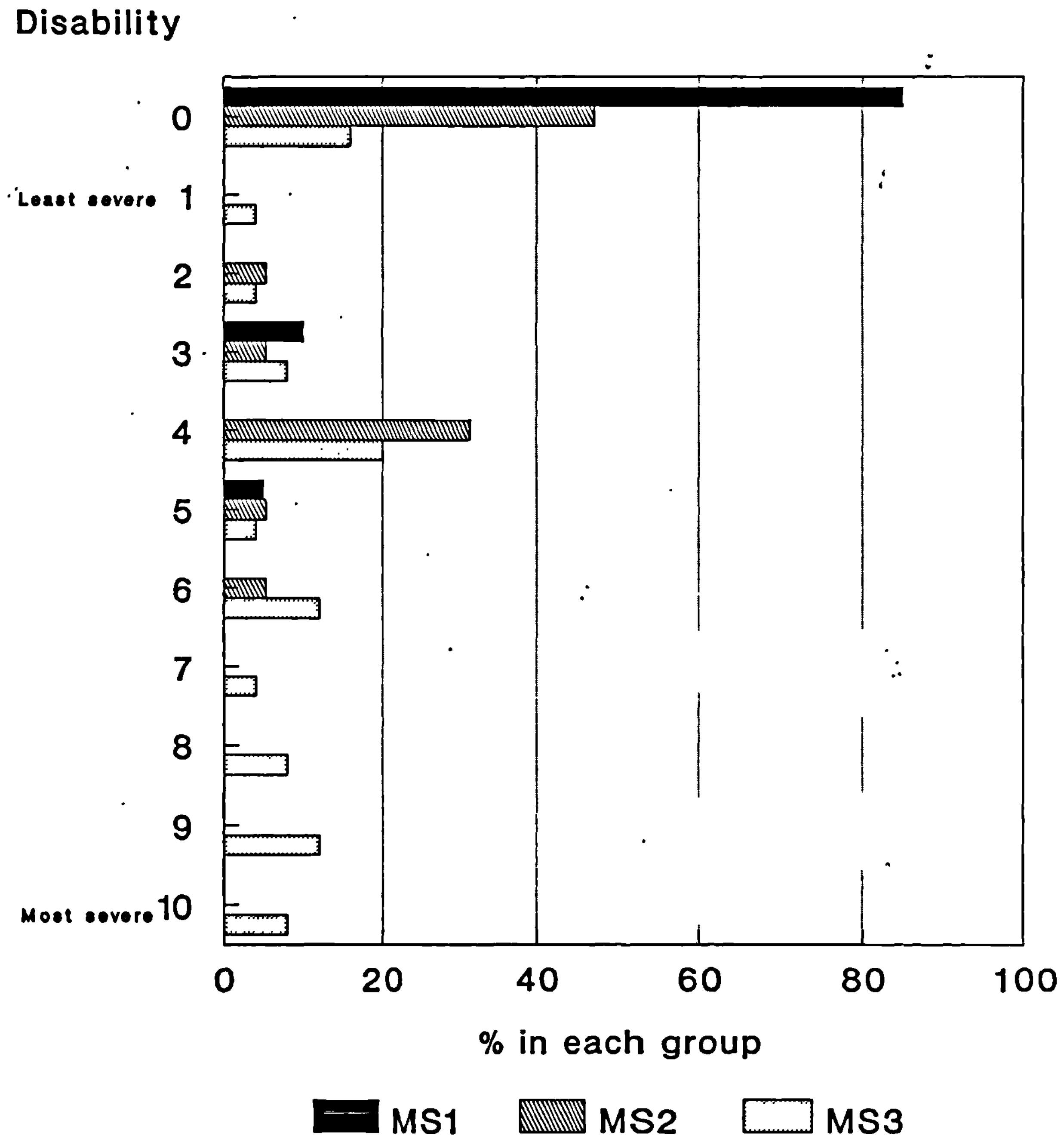
**Fig. 8.7 shows the distribution of severity scores on the OPCS for each group.**

**Table 8.10 Severity of disability at different stages of the illness**

| | Mean | SD | F | p |
|---|---|---|---|---|
| **MS1** | **.55** | **1.4** | **17.2** | **.0001** |
| **MS2** | **2.1** | **2.2** | | |
| **MS3** | **4.9** | **3.3** | | |

**A Oneway ANOVA showed a significant difference between the groups in severity of disability**

## Fig.8.7 Severity of disability at different stages of the illness



(Table 8.10). A Scheffe test shows that MS3 had significantly higher levels of disability than either MS1 or MS2.

There was no significant relationship between age and disability (Pearson's r=.07, p=.56) or sex and disability (Unpaired t test, F=1.16, p=.87). The relationship between severity of disability, Self Esteem and emotional wellbeing was examined (Table 8.11).

Table 8.11 Relationship between disability, Self Esteem and emotional wellbeing

| | Self Esteem | HAD Anxiety | HAD Depression | Wellbeing |
|---|---|---|---|---|
| Severity of disability: | | | | |
| MS1 | -.33 | .63** | .42 | -.36 |
| MS2 | -.40 | .20 | .41 | -.33 |
| MS3 | -.69*** | .42* | .66*** | -.43* |
| Total | -.55*** | .42*** | .32** | -.39*** |

A Pearson's r showed that for MS3 and the total group severity of disability was positively correlated with poorer outcomes, with severity of disability and HAD Anxiety being positively correlated for MS1, and no significant relationships being found at MS2.

Severity of disability was related to Life Satisfaction (Table 8.12). Overall, and for MS3 and for "change" at MS2, overall more severe disability was associated with less satisfaction with life.

Table 8.12 Relationship between disability and life satisfaction

| | Severity of disability | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | MS1 | | MS2 | | MS3 | | Total | |
| | mean | F | mean | F | mean | F | mean | F |
| Happiness: | | | | | | | | |
| (More - Less Happy) | -1.4 | 8.8 | 0.2 | 2.2 | -2.8 | 1.3* | -2.2 | 1.8** |
| Change: | | | | | | | | |
| (same - change) | -0.8 | - | -2.0 | 2.1* | -4.2 | 2.1** | -2.7 | 1.8** |
| Accomplishment: | | | | | | | | |
| (yes - no) | -.04 | 2.8 | -0.8 | 1.0 | -3.1 | 1.7* | -1.7 | 1.5* |

*p=<.05, **p=<.01, ***p=<.001

## 8.4 Relationship between elements of the model

The results will be reported in two parts, firstly the interactions between the stages of illness and the elements of the model and secondly, where there are no interaction effects, the relationships between the elements of the model are reported. The elements "label" and "cure" have been excluded from all analysis due to lack of variance. The following relationships were examined using two-way ANOVA's and Chi square:

(a) Representations and coping

(b) Representations and evaluation of coping

(c) Representations and outcome

(d) Coping and evaluation of coping

(e) Coping and outcome

(f) Evaluation of coping and outcome

Graph's of significant ANOVA's are shown in Appendix D with F and p values.

### 8.4.1 Relationship between representation, coping and stage of illness

**Part 1 : Interactions between representations, coping and stage of illness.**

- **People making changes to their lifestyles at MS2 and MS3 had more symptoms. At MS1 the reverse was true.**
- **Those taking actions to keep healthy generally at MS2 and MS3 ranked their condition more seriously except at MS1 where the reverse was true.**
- **People who did not expect to be better had significantly more social supports at MS1, but this support was lower at MS2 and MS3 where those expecting some improvement showed fewer supports and there was a significant difference between those with different expectations.**

**Part 2: Relationship between representation and coping**

- **People with more symptoms :**

**- had fewer social supports**

**- were less satisfied with those supports**

- **People who attributed a cause :**

**- were more likely to be taking actions to change their lifestyles (Chi sq=4.2,df=1,p=.04).**

**- were taking more kinds of actions overall**

- **People who rated their condition as More Serious were more likely to be taking actions to change their lifestyle (Chi sq=3.7,df=1, p=.05).**
- **People who ranked their condition more seriously had fewer social supports and were less satisfied with those supports**
- **People with specific problems and difficulties were less satisfied with their social supports**

### 8.4.2 Relationship between representation, evaluation of coping and stage of illness

- **People with more symptoms evaluated their coping Less Well.**
- **For those who evaluated their coping Very Well, the number of limitations increased less over time.**

### 8.4.3 Relationship between representations, outcome and stage of illness

Part 1: Interaction between representations, outcome and stage of illness

The only component to interact with outcome and stage of illness was ranking of seriousness.

- For people who ranked their condition as Less Serious, Wellbeing improved over time, whereas for people who ranked their condition as More Serious, Wellbeing decreased over time.
- For MS2 and MS3, feeling Less Happy was associated with a more serious ranking, the reverse was found for MS1.
- For MS2 and MS3, wanting to stay the same was associated with less serious ranking, whereas for MS1 the reverse was found.
- For MS2 and MS3, having achieved all they wanted to was associated with less serious ranking of their condition, whereas for MS1 the reverse was found.
- People rating their condition as More Serious were more disabled at each stage.

Part 2 : Representations and outcome

- People with more symptoms:
  - had lower Self Esteem scores
  - had higher HAD Anxiety scores
  - had higher HAD Depression scores
  - had poorer Wellbeing scores
  - were Less Happy
  - wanted to stay the same
  - were less likely to report having achieved all they wanted to
  - were more severely disabled
- People who rated their condition as More Serious:
  - had higher HAD Anxiety scores
  - had higher HAD Depression scores
  - were more likely to report feeling Less Happy (Chi sq = 6.32,df=1, p=.04)
  - were more likely to want to change parts of their lives (Chi sq=14.0,df=1, p=.0002)
  - were less likely to report having achieved all they wanted to (Chi sq=4.1,df=1, p=.04)

◆ People with specific problems and difficulties:

- had higher HAD Anxiety scores
- had higher HAD Depression scores
- were more likely to want to change their lives (Chi sq=10.5,df=1, p=.001).
- were more severely disabled

◆ People with more limitations:

- had lower Self Esteem scores
- had higher HAD Anxiety scores
- had higher HAD Depression scores
- had poorer Wellbeing scores
- were Less Happy
- wanted to change parts of their lives
- were more severely disabled

### 8.4.4 Relationship between coping, evaluation of coping and stage of illness

There were no significant relationships or interactions between coping, evaluation of coping and stage of illness.

### 8.4.5 Relationship between coping, outcome and stage of illness

◆ For people who were Very Happy the number of social supports reduced over time, whereas for people who were Less Happy, the number increased over time.

◆ People who had more social supports had:

- lower HAD Anxiety (F=6.2, p=.02)
- lower HAD Depression (F=12.8, p=.0007)
- better Wellbeing (F=5.7, p=.02)

◆ People who were more satisfied with their social supports:

- had higher Self Esteem (F=8.6, p=.01).
- had lower HAD Anxiety (F=6.8, p=.01)

- had lower HAD Depression (F=11.6, p=.001)
- had better Wellbeing (F=7.6, p=.008)
- were more likely to be Very Happy

♦ At MS1 and MS2, significantly more people were "Very Happy".

### 8.4.6 Evaluation of coping and outcome

♦ For people who evaluated their coping as "Very Well", severity of disability increased less over time. At MS3, people who evaluated their coping as "Less Well" were significantly more disabled.

♦ People who evaluated their coping Very Well:

- had higher Self Esteem scores
- had lower HAD Anxiety scores
- had lower HAD Depression scores
- had better Wellbeing scores
- were more likely to be Very Happy (Chi sq=7.7, p=.02)

## 8.5 Discussion

### 8.5.1 Support for the elements of the model at different stages of the illness

There were very few differences between the stages of illness in either representation or outcome, and no differences in the actions people took to manage their condition or in how they evaluated their efforts.

There was a tendency for people at the earliest stages of the illness, MS1, to be younger and for more to be in paid employment. Having the correct label, number of symptoms and limitations, rated and ranked seriousness increased over time. Thus there was a general trend for a worse representation of the illness to develop with time and, presumably, as the illness progressed. About half the group attributed a cause for their condition, with those people in MS2 being more likely to attribute that cause to their own behaviour. Belief in a cure and expectation of improvement did not differ at different stages of the illness, with less than 25% expecting either.

As in the previous study, there was a positive association between symptoms and limitations.

There were no differences in actions taken to manage the condition, or evaluation of those efforts at different stages of the illness. Over 85% of people had taken some kind of action, in contrast to previous studies, one person at MS2 reporting having "too much" information. Thus it would seem that people are actively coping at all stages. Overall there was a strong correlation between number of social supports and satisfaction with those supports. There were no significant differences in evaluation of coping at different stages, with over 90% reporting that they had managed "Very Well", despite increasing limitations, symptoms and disability.

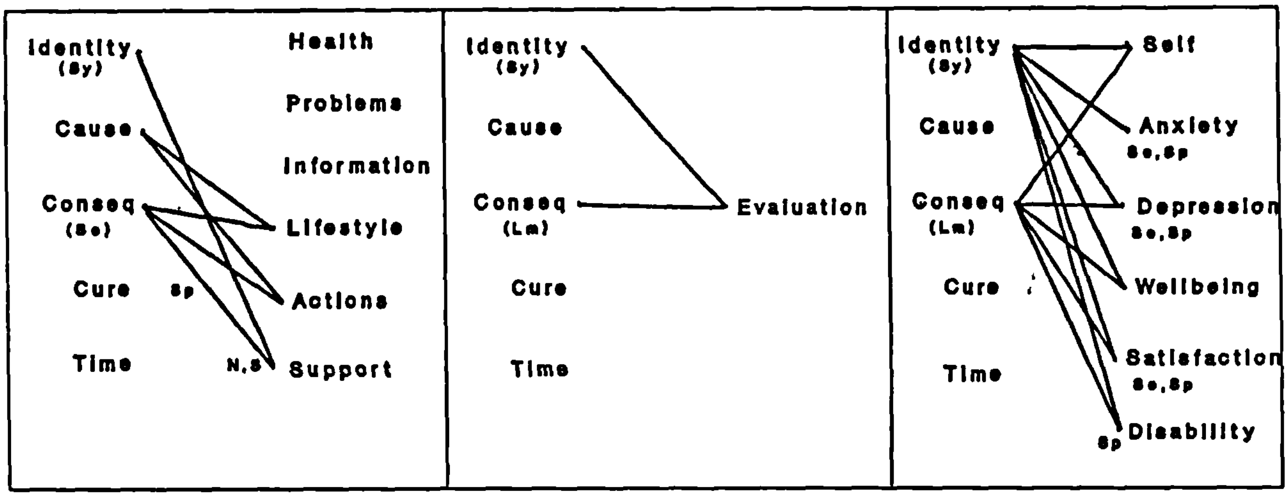
There were no differences between the groups on any of the measures of emotional wellbeing, despite increasing levels of disability. A simple explanation of distress in terms of disability clearly cannot account for these findings. As in the previous studies, more people reported feeling negatively about themselves as a result of their symptoms/condition. Similarly, results from standardised outcome measures of self esteem, mood, general wellbeing and life satisfaction did not indicate high rates of psychological distress. Twenty two percent of the overall group could be classified as clinically anxious, and 8% as clinically depressed, with 65% having positive wellbeing scores. There was a strong correlation between the measures of emotional wellbeing, and between those and the interviewers evaluation of coping. Severity of disability increased over time, with severity being associated with poorer emotional outcomes, this could be interpreted as providing some support for Watson and Pennebaker's(1989) disability model, distress being associated with greater levels of disability.

### 8.5.2 Relationships between the elements of the model and stage of illness (Fig.8.8).

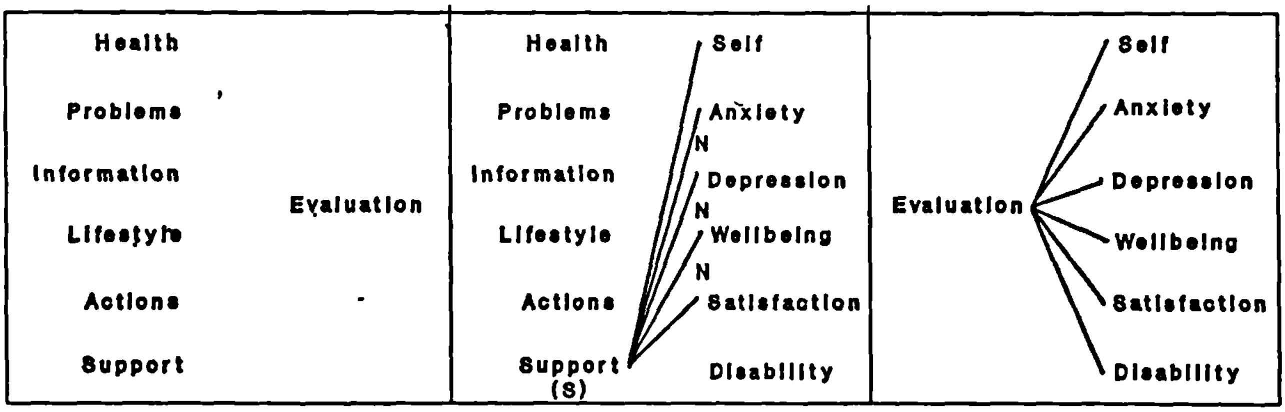
Fewer symptoms, ranking the condition more seriously and reporting no specific problems or difficulties were associated with more social supports and more satisfaction with those supports, thus supporting the role of social support as a coping resource. Attributing a cause and rating the condition as More Serious was associated with taking more actions to change lifestyle and taking

Fig.8.8 Relationships between elements of the model

a) Representations & coping     Representations & evaluation     Representations & outcome



b) Coping and evaluation     Coping and outcome     Evaluation and outcome



Key: Lm limitations
Sp specific problems & difficulties
Se seriousness
N number of social supports
S satisfaction with social support

**more types of actions overall. Fewer symptoms were also associated with a better evaluation of coping.**

**The greatest number of relationships were between representation and outcome. In particular, reporting more symptoms and limitations, and rating the condition as More Serious were associated with lower Self Esteem, higher HAD Anxiety and Depression, poorer Wellbeing, less Life Satisfaction and increased severity of disability.**

**While there were no relationships between coping and evaluation of coping at any stage of the illness, there were consistent and significant relationships between both coping and outcome and evaluation of coping and outcome. More social supports and more satisfaction with social support was associated with higher Self Esteem and better emotional wellbeing. People who evaluated their coping "Very Well" had better outcomes; higher Self Esteem, better emotional wellbeing and less severe disability.**

**The relationships between the elements of the model were not always similar at each stage, the main differences were between people at the earliest stage of the illness, MS1, and later stages at MS2 and MS3. There were differences in outcomes associated with ranking the condition as serious at each stage: for MS1, ranking the condition as More Serious was associated with good emotional outcomes, whereas the reverse was true for the later stages of the illness. One possibility is that perceiving the condition to be More Serious is an approach strategy that is effective at MS1, however, avoidance, perceiving the condition to be Less Serious, maybe more effective at MS2 and MS3 (Suls & Fletcher,1985). Perhaps people are coping with different things at different stages, dealing with the diagnosis at MS1 and with every day living at MS2 and MS3.**

**People at MS2 and MS3 who had more symptoms and ranked their condition more seriously were more likely to be making changes to their lifestyle and taking action to keep healthy generally, respectively. The reverse was true for MS1. A possible explanation is that people at MS1 are making the types of changes that will reduce the mismatch by changing the reference criteria; changing lifestyle at an early stage might make it easier to manage the consequences of**

progressive illness. Taking action to improve ones health generally may well serve the purpose of establishing a new acheivable goal unlike for example controlling the illness. People at MS1 who did not "expect to be better" had significantly more social supports, but this support was lower at MS2 and MS3.

There were no significant relationships or interactions between coping, evaluation of coping and stage of illness. Having more social supports and being more satisfied with social support was consistently and strongly associated with higher Self Esteem and better emotional wellbeing. There was a difference between the groups in that the number of social supports for people who were Less Happy increased over time.

A similar association was found between evaluation of coping and outcome, with people who evaluated their coping efforts Very Well having higher Self Esteem, better emotional wellbeing and less severe disability. People at MS3 with more severe disability were more likely to evaluate their coping as "Less Well".

# Chapter 9. Summary and discussion of findings

**9.1 Summary**

**9.2 Theoretical issues**

- **9.2.1 Support for the elements of the model**
- **9.2.2 Change over time**
- **9.2.3 Relationships between the elements of the model**
- **9.2.4 Relationship of findings to other theoretical frameworks**

**9.3 Methodological issues**

**9.4 Clinical implications**

**9.5 Conclusions**

## 9.1 Summary

The results of these studies show that overall Leventhal's model provides a useful framework to explore and understand how people with a chronic, progressive incurable neurological illness represent, cope with and evaluate those coping efforts. There was some support for the elements of the model in all studies. Most people held a representation of their condition, took actions to manage, made evaluations of their coping efforts and showed varying outcomes. Illness representation and not diagnosis was related to outcome, and there was variation over time at the different stages of illness. Leventhal's premise that representations guides coping received only limited support. The presence of a feedback loop for some elements of the model, was supported by these results.

## 9.2 Theoretical issues

### 9.2.1 Support for the elements of the model

#### (i) Representations

In all studies, people responded positively to questions about representations and held representations of their condition. In addition to providing support for previous research in confirming the importance of identity (Leventhal & Nerenz,1985), this study suggests that consequences appear to serve a similar function in chronic illness to that served by symptoms, with nearly everyone in all studies reporting some consequence. Over half the people in all studies attributed a cause, with fewer believing in a cure or any improvement.

The finding that between 40%-64% of people had accurate disease labels before coming into hospital for tests and investigations for all conditions supports Shober & Lacroix's (1991) statement that people are capable of making informed diagnostic judgments. Results from this study also suggest that limitations, or restrictions in daily activities, provide additional information upon which people base their diagnostic judgments. Over half the people in all the studies described symptoms, being told one had an illness did not appear to increase symptomatology (study 1) as found by Pennebaker (1984). In all studies and at all times there was a positive relationship between the number of symptoms and the number of limitations, with a similar increase in limitations to that reported for symptoms being found in the later stages of the illness (study 3).

Approximately half the people in all studies attributed a cause, which remained relatively constant over time (study 1). This finding is interesting as the diagnosis of a chronic illness did not set in motion the psychological process of searching for a cause as proposed by Timko & Janoff-Bulman (1985), as this search clearly pre-dated diagnosis for a large number of respondents. As yet lifestyle has not been implicated as a cause in any of the major neurological illnesses, and in the case of MS and MND, the aetiology of the diseases are still largely unknown. Despite this a substantial proportion of people had postulated a cause.

All reported some consequence, either perceiving their condition to be serious, or resulting in some degree of limitation or specific problems and difficulties. In all studies there was a positive relationship between the number of symptoms and the number of limitations reported, one possible explanation for this could be that for chronic, progressive illness, limitations, in addition to symptoms, provide continual and readily available information for monitoring and evaluating the impact of the illness.

Few people believed in a cure or the likelihood of any improvement occurring. Cure has been a more uncertain element in the representations and does not feature in Leventhal's (1984) model, but was introduced by Lau & Hartman (1983) who did not study chronic conditions but conditions people recovered from. They have suggested that cure may be a representation of people who have recovered, or for whom recovery is a possibility, and therefore less applicable in chronic illness, this study supports this contention.

### (ii) Coping

Nearly everyone was taking some kind of action to manage their condition, the most frequent in the early stages (study 1) being to increase understanding, with only one person at the later stage of the illness (study 3,MS2) reporting having "too much" information. This lends support to the importance of information in the process of self-regulation. There has been considerable discussion in the coping literature about which forms of coping are adaptive (Felton & Revenson,1984). This study was consistent with Earll et al (1993) in a study of patients with MND in finding no evidence of some coping styles being associated with better emotional outcomes than others. The number and variability of coping actions at all times in this study showed very few people to be using avoidant coping. The results may reflect effective coping with a long-term stressor, as postulated by Suls & Fletcher (1985) and this interpretation would be borne out by the relatively low scores on emotional distress in this population engaged in long-term coping.

While coping actions were varied and numerous, social support became more frequent as a coping resource at the later stages of illness (study 3), both greater numbers and satisfaction with social support was associated with better psychological outcomes, though not better physical outcomes. Perhaps this is not surprising as social support can be seen as emotion focussed coping (Payne & Jones, 1987) which tends to predominate when people feel that the stressor is something to be endured, while problem focussed coping predominates when people feel that something constructive can be done (Folkman & Lazarus,1985). The correlation between number and satisfaction is consistently high and Sarason et al (1983) suggest that while the two components are conceptually separate, they are frequently correlated. Based on the data from this thesis, it may be that in these diseases people who offer support offer high quality support.

### (iii) Evaluation of coping

Nearly everyone evaluated their coping efforts positively, over 90% of people in all studies evaluated themselves as having managed "Very Well". One possible explanation is that, with no standard against which to evaluate that coping, these assessments were simply inaccurate. A bias towards positive evaluations would serve to bolster self-esteem and possibly enhance coping. However, although this may explain some bias, there is evidence that these evaluations did relate to objective assessments as there was good agreement in all studies between subjective evaluation of coping and the interviewers evaluation on the GAIS. Other evidence of the meaningfulness of the discriminations made in the evaluation of coping lies in its prediction of outcomes.

Bias to positive evaluations occurs in other types of measures, most notably satisfaction with medical care. It is not clear whether such evaluations imply comparison with some other standard, eg. coping with MS was good compared with coping with other life events, or whether the results are due to social desirability bias. It is also possible that evaluating coping positively is a coping response.

### (iv) Outcome

While the majority of people in all studies reported feeling negatively about themselves as a result of their condition, emotional outcomes did not indicate high levels of emotional disorder, the percentage of people classified as clinically anxious and depressed for all studies being less than that expected in a medical outpatient population (Zigmond & Snaith,1983). Results from study 3 are consistent with earlier research showing increased severity of disability to be associated with poorer psychological outcomes (Counte et al,1983).

### 9.2.2 Change over time

There is a contrast between studies 1 and 3 in that Study 1 spans the period of time in which the diagnosis is formally given, and Study 3 covers a period of tme following formal diagnosis. The greatest variability in representations was in study 3 between the earlier stage of the illness, MS1 and the later stages, MS2 and MS3. The proportion of people having the correct label increased from 40% before coming into hospital for tests and investigation to the later stages, where at MS3 in study 3, 100% had the correct label. Thus while the formal diagnostic process undoubtedly contributed to the possession of a correct label, time also increased the likelihood of the correct label being held. The number of symptoms increased significantly over the later stages of the illness (study 3).

Perceived seriousness increased over the later stages of the illness (study 3). In study 1 there was an interesting interaction between ranked seriousness and time. People who ranked their condition as "More Serious" before admission to hospital and before diagnosis, all changed their ranking to "Less Serious" following discharge from hospital and after diagnosis. This is not consistent with research showing that avoidant coping is a commonly used strategy in the early stages (Folkman et al,1986). Carver et l (1989) suggest that people may cope with chronic illness by changing the reference criteria, in the current studies the experience of hospital and diagnosis may have provided these reference criteria, and thus account for these findings.

The number of people believing in a cure or expecting any improvement decreased over time (study 1 & study 3). This is consistent with information about the condition acquired through either informal networks, formal medical communication, and their own experience over time.

Overall there were no changes over time in the evaluation of coping, however, in study 1, an evaluation of "Less Well" before admission to hospital for tests and investigations predicted an evaluation of "Very Well" following discharge and diagnosis at T3. This is a similar pattern to that seen for ranked seriousness and may be similar in reflecting an attempt to reduce the mismatch following the establishment of new reference criteria provided by medical diagnosis and the hospital experience. The possibility that this could be accounted for by improved coping is not supported by the data, as evaluation of coping did not change over time. Alternatively, approach coping rather than avoidant coping may have resulted in collecting more relevant information (Suls & Fletcher, 1985).

In contrast to earlier research which showed psychological disturbance to be generally greater at the earlier stages of illness (Meyerowitz,1980; Cassileth et al,1984), results from these studies showed no changes in any of the psychological outcome measures over time.

### 9.2.3 Relationships between the elements of the model

Representations and coping. Leventhal's premise that representations guide coping was only partially supported. Of the few predictive relationships that occurred (study 1) these were between identity, consequences and coping. The predictive effect of perceived seriousness on behaviour supports previous research (Schwarzer,1992). In addition, people who held the correct label before coming into hospital for tests and investigations for multiple sclerosis (study 1) increased the number and satisfaction with social supports they had over time. By contrast at the later stages of the illness (study 3) less favourable representations were associated with an increased number and satisfaction with social support. There was no association between attribution of cause to self and poorer psychological outcome as would have been predicted by reformulated learned helplessness theory (Abrahamson et al 1978).

Representations and evaluation of coping. The few relationships between representations and evaluation of coping in studies 1 and 3 showed that less favourable representations, in particular reporting more symptoms and limitations, were associated with a less favourable evaluation of coping.

Representations and outcome. The greatest number of relationships over time and between conditions was between representation and outcome. The concrete representations of symptoms and limitations being both associated with and predictive of poorer outcomes of all types, and provide support for Watson & Pennebakers (1992) disability hypothesis. Whilst the more concrete representations, symptoms and limitations, were predictive of poorer outcome in study 1, perceived seriousness was associated with poorer emotional outcomes at the later stages of the illness (study 3). It is possible that within Leventhal's model, for chronic illness with no cure or palliative treatment, consequences have the same if not greater impact on coping and outcome as identity did for people undergoing treatment for lymphoma (Nerenz, Leventhal & Love,1982). Nerenz et al (1982) found high levels of distress in those patients whose tumours shrank rapidly and who had difficulty coping with the inconsistency between the absence of concrete symptoms and the continuation of treatment.

Coping and evaluation of coping. There were no significant relationships between coping and evaluation in the later stages of the illness (study 3), the few relationships there were in studies 1 and 2 were between the coping resource of social support and evaluation of coping. A greater number of and satisfaction with social support was both associated with (study 1 and study2) and predictive of (study 1) better evaluation of coping. In addition, a better evaluation of coping predicted a greater number of social supports at later times.

Coping and outcome. Perhaps not surprisingly, before being admitted to hospital for tests and investigations (study 2) there were negligible relationships between coping and outcome. It may be that at this stage, people are in the planning phase of active coping, and exercising "restraint coping" (Carver et al ,1989) before taking any further actions which might influence outcome. For study 1, taking action was associated with better psychological outcomes. While coping was not predictive of outcomes, there was support for a feedback loop with negative feelings about self predicting fewer social supports. In the later stages of MS (study 3), a greater number and satisfaction with social supports was consistently and strongly associated with better psychological, though not physical, outcomes. This supports previous research with the SSQ which has indicated that the instrument is related to the experience of anxiety and depression (Sarason & Sarason,1984), and that people high in social support seem to experience more positive events in their lives, have higher self esteem and take a more optimistic view of life.

Peoples' strategies for coping with chronic progressive illness did not lead to maladaptive outcomes as assessed in this study - in fact they appeared to be little related to outcomes at all.

Representations were more predictive of outcome than the actions people took to manage, the latter failing entirely to predict outcome. In a condition where there have as yet not been any actions identified as influencing the course or the outcome of the illness, such a finding is perhaps not surprising. It may be that the major function of coping in this study, (seeking information, changing lifestyle and seeking social support), was to influence the representations by establishing new goals, eg. to try and keep healthy generally "inspite of" the multiple sclerosis. As nearly everyone was taking some form of coping action, it is not possible to see if taking no action would have been predictive of depression. Even so, the low level of psychological distress found in all studies suggests that while no particular coping actions are predictive of outcome, it may be that taking some type of action in a situation where there is nothing the medical profession can do is sufficiently motivating to minimise depression.

Evaluation of coping and outcome. In all studies, better evaluation of coping was associated with better outcomes and in study 3 this included less severe disability. In study 1 better evaluation of coping was predictive of better emotional wellbeing. Also the converse was found, better emotional wellbeing was predictive of more positive evaluation of coping.

### 9.2.4 *Relationship between findings and other theoretical models*

ICIDH and self-regulation. The International Classification of Impairment, Disability and Handicap (WHO,1980) offers an alternative to the classification of symptoms and limitations. In this classification symptoms would be similar to 'impairment', which refers to parts of the body that do not work and is defined as "any loss or abnormality of psychological, physiological or anatomical structure and function"; and limitations with both 'disability' which refers to the things people cannot do, eg. walking up a flight of stairs, and 'handicap', defined as "a disadvantage for a given individual, resulting from an impairment or disability, eg. not being able to go to the cinema. However, current studies do not classify symptoms in such a way as to be comparable to these definitions, being based on people's perceptions of limitations, only some of which would be classified as 'disability', eg."difficulty walking". Similarly, limitations as used in these studies could be classified as either disabilities or handicaps.

Johnston (1994) proposes a relationship (marked by red lines) between Self-regulation model and WHO model whereby coping with the objective features mediates the impact of impairment on disability and handicap which in turn feedback into the perception stage and influences the evaluation of the objective impact of the condition (Fig.9.1). The evidence from this thesis suggests that rather than coping mediating the impact of the illness, it is peoples representations of their condition (Fig.9.2) which mediates the WHO model (relationships marked in red), which in turn feed back into the perception of the condition and influences the evaluation of the objective

Fig.9.1 Relationship between Self-regulation model (Leventhal et al,1984) and WHO model as proposed by Johnston (1994)

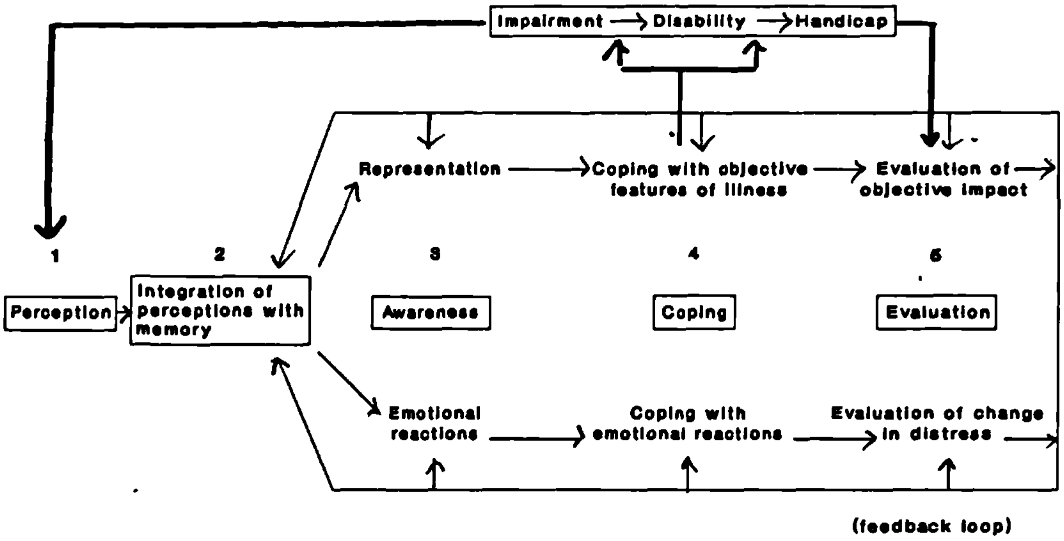
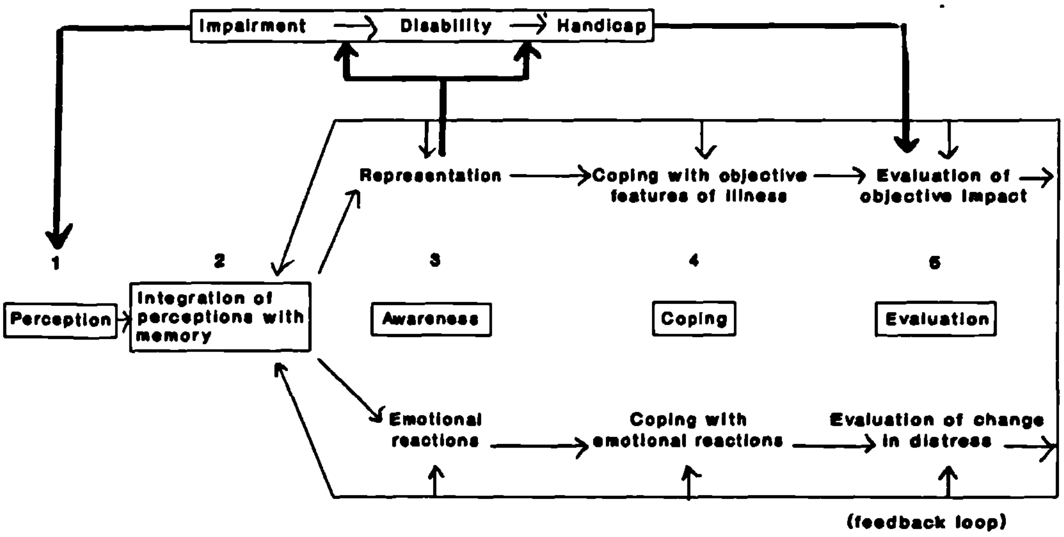


Fig.9.2 Relationship between Self-regulation model (Leventhal et al,1984) and WHO model based on the evidence of this thesis



impact of the condition. Rather than offering alternatives to the medical model, these modifications both attempt to combine a medical and psychological approach.

Reformulated learned helplessness model and self-regulation. The lack of relationship between cure cognitions and outcome might be understood in terms of Abrahamson et al's (1978) reformulation of the learned helpless model. They postulate that people who believe their inability to control important outcomes is due to their own incompetence will have low levels of self esteem, while those who believe their inability to control a stressful event is due to something that no one is able to control, will not show a lowered level of self esteem, however, the Abrahamson et al's model does not take account of events that can be controlled by other people. Study 1 showed that people who believed in a cure, ie. that someone could control it, were less likely to have negative feelings about themselves. Suffering from multiple sclerosis, where the medical representation and available information is of a chronic, progressive incurable illness with no palliative treatments available, might result in a "sadness" but not lowered self esteem. This would be consistent with the finding that most people felt negatively about themselves as a result of their condition, but did not have lowered Self Esteem.

Stress and coping. Lazarus & Folkman (1984) defined coping as the person's cognitive and behavioural efforts to manage, and focus not only on what the person does but also on what they think. In this study representations can be construed as cognitive acts, a "positive reinterpretation of events". This study showed that information seeking was a common coping action, which would serve to inform the representations, particularly in the early stages (study 1). In all studies, most people were taking some form of coping action and it may be that this served a useful function as part of the appraisal process, thus helping to shape the representations, with the emphasis on information seeking before diagnosis and social support at the later stages. The emphasis on these emotion-focused coping strategies tends to support Lazarus & Folkmans (1984) thesis that emotion-focused coping tends to predominate when nothing constructive can be done and the stressor, ie chronic illness, is something that must be endured.

**Social support and self-regulation.** Within Leventhal's model (Leventhal et al, 1984) social support is seen as a coping resource, results from these studies suggest that this relationship is complex.

◆ Social support as a buffer. If one considers the mechanisms for the buffering effect of social support, it may serve to alter the assessment of threat, or one's assessment of ones ability to cope by the provision of information. Thus social support may help to redefine the representation as being less threatening. Pearlin & Schooler (1979) argue that comparison is only a successful coping strategy when it allows people to judge their condition to be less severe, or no more severe than that faced by others, this is supported by results from study 1 where following admission to hospital for tests and investigations, people who had perceived their condition to be serious, altered that representation to less serious.

◆ Social support and self-efficacy. It is possible that in addition to social support being a coping resource, it may also serve as confirming self-efficacy. Individuals may acquire their sense of self-efficacy from their assessment of the outcomes of their own behaviour (Bandura,1986). Cobb (1976) argued that increasing ones feelings of self-efficacy through social support may elevate ones level of self-esteem by either praise of relevant others or through positive social comparison with similar others, certainly in Study 1 people with fewer social supports were more likely to report feeling negatively.

◆ Social support as emotion-regulation. When faced with a progressive incurable illness, social support may be serving as an adaptive emotion-regulating function, effective in enhancing self-esteem (Mechanic,1974). This is supported by the finding of a strong relationship between social support and emotional response in the later stages of the illness (study 3). The finding of high social support and positive evaluation of coping also lends support to the role of social support as an emotional support mechanism.

### 9.2.4 Methodological issues

While the samples in each study were small, there was remarkable consistency of findings across all samples and groups. There were a total of one hundred and thirty seven interviews of one and a half hours long, a total of 205 hours. In addition, an equal amount of time was taken in transcribing and analysing the free text. Thus, despite the small sample size, over 400 hours was spent examining people's representations of their illness, the actions they took to manage, their evaluation of those efforts and the impact on their psychological and physical wellbeing.

The methodology chosen for these studies was designed to access peoples representations of illness, and not to measure disease, "disease reflects pathological changes in the body, whereas an illness represents the experienced suffering of the patient" (Barondess, 1979). Self-report measures were used to directly access the subjective experience of the individual. These had face validity and appeared to be compatible with people's way of thinking about their condition, the interviewer intuitively felt that the framework allowed for a fluid interview during which people were able to express most of what they wanted to about their condition. Questionnaires compatible with Leventhal et al's model had not been developed at the start of this study, indeed, Leventhal and colleagues recommend that the model serve as a framework to increase understanding. However, this poses a problem as it is difficult to compare people using only qualitative data until converted to numerical format as here. To address this issue a measure is being developed by Weinman & Petrie (In press), which assess the main components of the model.

This study poses questions as to how best to measure the elements of the model, for example the representation of 'consequences'. Leventhal defines this as "perceived" consequences. While measures of seriousness are compatible with this definition, "limitations" are people's reports of what they are unable to do or need help in doing. It may be that while "limitations" is compatible with Leventhal's definition of representation of consequences, they could equally well be classed as an "outcome" along with "disability" in the modified model.

Most existing questionnaires of coping are based within the theoretical framework of stress and coping, which was not the model being used in this thesis. Self-report measures were therefore used in order that the actions people took to manage their condition might be documented to increase understanding as to the nature of these actions and change over time. This is particularly important for studies of chronic or life threatening illnesses as both the disease changes as well as people's perceptions. Indeed, there is no basis to say that existing standardised measures of for example coping apply to chronic neurological illness, and a lack of information about what people with these conditions actually do. However, using non-standardised measures (with the exception of social support) had problems of reliability and validity.

The original intention of coding the free text into possible existing categories identified in previous research quickly became untenable, as there was insufficient information to interpret any given action, eg. visiting a friend could serve numerous ends, such as seeking information, distraction or emotional support. The questions asked discriminated between responses in terms of their purpose but did not discriminate between the nature of the activities, so for example the same answer could be given to different coping questions, eg. changing diet was frequently given as an action taken to keep healthy generally, deal with specific problems and difficulties and as an action taken in addition to that recommended by the doctor. There was no association between the type of action and the reason for its implementation.

An additional issue in this research surrounds the possibility of Type 1 and Type 11 errors. With the large number of variables, and the even larger number of possible associations between those variables, the concern is that more Type 1 errors will occur, ie, that significant relationships are found when in fact there are no differences. However, while caution has to be exercised in interpreting the results, there is a degree of consistency across all three studies reducing the likelihood of them occurring due to a Type 1 error alone. For each analysis, the most powerful statistical tests compatible with the data have been used in order to avoid Type 11 error.

There was also the problem of comparing categorical or nominal data with ordinal or interval data, thus frequently limiting the use of more powerful statistical techniques. This variation in statistical analysis does beg the question of the reliability of the whole picture, when different elements are being analysed by different methods. Bryman & Cramer (1992), discuss some of the issues relating to the use of parametric versus non-parametric tests. They question the need to meet the three conditions for using parametric tests: that the level or scale or measurement is more than ordinal, the distribution of the population scores is normal, and that the variances of both variables are equal or homogeneous. They argue that parametric tests can also be used with ordinal variables since tests apply to numbers and not to what those numbers signify. Despite the fact that many psychological variables such as some attitude measures are basically ordinal in nature, parametric tests are routinely applied to such variables. With respect to the second and third conditions, a number of studies have been carried out where the values of the statistics used to analyse samples drawn from populations which have been artificially set up to violate these conditions have been found not to differ greatly from those for samples which have been drawn from populations which do not violate these conditions. Therefore the most powerful tests were chosen as recommended by Bryman & Cramer.

With regard to the elements of illness representation, the design of the study did not allow for the inclusion of any possible additional elements of representation outside Leventhal's model. However, there was adequate opportunity for people to express their views, and no consistent views were expressed to lead the interviewer to feel that the model did not adequately take account of the representations of people with chronic neurological illness. While evidence of both feedback and predictive relationships were found, the extent to which they could be accounted for by concurrent relationships could not be tested by statistics such as path analysis due to the limitations of both the numbers and the type of data.

A further limitation of the study was the use of one group of patients in all three studies. However, they were a cohort of patients and as such were considered to be representative, allowing for comparability over three studies and containing appropriate elements of the data in each.

## 9.3 Clinical implications

The results of these studies together with other studies of self-regulation and illness representation have implications for the approach to the management of people with chronic neurological illnesses as well as other chronic illnesses. The results also have implications for the training of health professionals. The best predictor of peoples' emotional wellbeing was their representation of their condition and their own evaluation of how well they have managed. This suggests that an essential task for health care professionals is therefore to assess peoples' own representations of their condition. Whilst most health professionals would perceive both MS and certainly MND to be very serious, this was not a representation which was shared by all patients. Furthermore, results from study 1 would suggest that people who are "ready to face the worst" and perceive their condition to be very serious, will, following the diagnosis and hospital stay evaluate their condition as less serious. Preparing people "for the worst" or at least allowing people to voice their worst fears may be of benefit.

A frequently expressed fear and concern of health professionals working with people with chronic progressive neurological illness is their inability to meet the patients expectations of cure or even significant palliative care. From before diagnosis, peoples expectations of cure and improvement were minimal, and reduced further as the illness progressed, yet this did not predict less favourable psychological outcomes, neither was it associated with taking no action to manage. Many people addressed the issue of cure in terms of the maintenance of their current health status, and minimising the impact of the condition on their lives and the lives of those around them: "modify my lifestyle, be aware of what makes it worse, keep out of the heat, diet, deal with tension and take exercise." These are areas where health professionals have a role to play in both providing support for this approach and in the provision of aids and adaptations to facilitate patients and their families achieving the aim of minimising the impact of the condition.

If one looks at the actions people take to manage their condition, in the early stages of the illness (study 1) these activities are focussed on seeking information, a role health professionals are well placed to fulfil. Indeed, out of 137 interviews, only 1 person reported having "too much" information. This finding may well offer some explanation for the popularity and success of self help groups, who provide a wide range of information both on the disease, how to manage it, people's reactions to being told the diagnosis and accounts of how people live with the illness. As well as providing information directly, health professionals are in a position to promote the benefits of self help groups. In the later stages the role of social support became increasingly important, and this an entirely valid aspect of the role of the health professional. The value of self-help groups is also relevant in this area.

Leventhal et al's (1984) premise that the role of representations is to guide coping received some support, although representations did not predict the type of action people took. Comments suggested that being told the diagnosis started the process of setting new goals for coping within realistic boundaries, but did not necessarily define the specific coping actions: "Hopefully get my mind ticking over and think about what I can do - employment"; "No more uncertainty, able to get it clear in my mind, know what the best and worst things are, can now try to do positive things to alleviate it, feel more in control."; "Something firm to fix my mind on so I can plan my life". It is important for health professionals to be aware that one of the most important tasks facing a person following the diagnosis of such a condition is what they are going to do with the rest of their lives. The setting of new life goals runs alongside dealing with the more concrete consequences of the condition, problems with activities of daily living. The health professional is well placed to advise and inform in this area, particularly as all those people who reported specific problems and difficulties were taking actions to manage them.

Despite the obvious role that health professionals can have in assisting people in activities of daily living, enlisting their support was rarely mentioned as a coping action. This might reflect not only a lack of information about these services, but health professional lack of confidence in their ability to offer anything in the light of illnesses with such poor prognosis. Results show that the more limitations people have (study 3) the poorer their psychological wellbeing, therefore any success by health professionals in practical efforts to manage or minimise these limitations more effectively should lead to better psychological outcomes.

None of the wide range of actions taken to manage their condition were strongly associated with outcome. Many health professionals discourage actions by patients such as "embrocations", "craniology", "live yogurt", "tablets from the herb shop", "faith healing", and "chiropractice", due to the lack of scientific support for such actions. The assumption is frequently made that taking these actions reflects unrealistic aspirations on the part of the patient and infer unhealthy coping strategies such as "denial", and will interfere with the far more healthy strategy of "accepting" ones' lot and being "realistic". There is no evidence to support these assumptions, and as such the role of the health professional might be to provide or encourage appropriate social support.

People who evaluated their coping positively had better psychological outcomes. It may be that health professionals can enhance people's positive evaluation of their efforts by providing them with reference criteria against which to judge themselves successful and by reinforcing and encouraging positive self-evaluative attitudes and beliefs.

Despite the fact that the majority of people reported feeling negatively about themselves as a result of their condition, most were able to identify positive aspects out of their experience, in particular relationships became more important: "people are very friendly.."; "brought family together.."; "closer to parents and immediate family". In view of the importance of social support in coping with these conditions, these positive feelings can be discussed and reinforced by health professionals.

## 9.4. Conclusions

Leventhal's model provided a useful framework within which to investigate and understand how people with a chronic, progressive neurological illness represent their illness, cope with and evaluate those coping efforts. There was support for the elements of the model for all studies, with minimal differences between different diagnostic groups or between the different samples. Differences were more marked over time since diagnosis. The actions people took to manage their condition were only partially associated with or predicted by their representations of the condition. Future research needs to investigate whether this finding is specific to neurological illness, or to conditions with no cure or palliative intervention.

In these conditions where the aetiology is still largely unknown, and where there is neither cure nor significant palliative treatment, representations were associated with and important predictors of psychological wellbeing. While previous research has highlighted the important role of symptoms in providing an easily accessible and "low cost" monitoring method, the current studies examined the role of perceived consequences in chronic illness, and pointed to their equal importance both in this monitoring process and, in the case of perceived seriousness, it's role within the control theory framework of reducing the mismatch via the feedback loop.

Prior to this research, intervention would have focussed on the actions people took to manage their condition. These findings suggest that interventions aimed at changing representations and enhancing people's own evaluations of how well they have managed may well be a more appropriate target and have more influence on outcome.

While Leventhal's model has proved useful in investigating and understanding chronic neurological illness, research into the role of representations and their relationship to outcomes is needed, and the precise nature of the function of social support investigated.

# Appendices

**Appendix A All studies**

- **A1 Semi-structured interview**
- **A2 Letter inviting people to participate in study 1 & 2**
- **A3 Letter inviting people to participate in study 3**

**Appendix B Figures for study 1**

**Appendix C Figures for study 2**

**Appendix D Figures for study 3**

# Appendix A

## Studies 1, 2 & 3

**Study no/Interview no.**

---

## PERSONAL

1. NAME......................

2. DOB..............

3. SEX    Male 1    Female 2

4. MARITAL STATUS: Single 1  Married 2  Separated/divorced 3 Widowed 4

5. RELIGION: C of E 1  Catholic 2  Jewish 3  Muslim 4  Other 5  None 6

---

## ACCOMMODATION

6. Who lives in your household?

| | |
|---|---|
| Living alone 1 | Brother/sister 4 |
| With spouse/partner 2 | With children 5 |
| With parents 3 | Other 6 |

7. What sort of housing do you live in?

Council 1 Owner occupier 2 Private rent 3 Other 4

---

## EDUCATION

8. What sort of education have you had?

Left school with minimum qualifications (CSE's, O's) 1
Left school with A's 2
Left school with qualifications plus tech.course 3
Higher education 4

---

## EMPLOYMENT

9. Do you have a paid job at present

| | |
|---|---|
| Full time 1 | Not working choice 6 |
| P/T choice 2 | Not working retired 7 |
| P/T retired 3 | Not working unemployed 8 |
| P/T unemployed 4 | Not working condition 9 |
| P/T condition 5 | Housework 1 |

10. Does your partner have a paid job at present

Code as above

**11. What kind of work do you do?**

________________________________________

**Professional 1**
**Intermediate 2**
**Skilled 3**
**Partly skilled 4**
**Unskilled 5**

**12. What kind of work does your partner do?**

**Code as above**

---

**GENERAL HEALTH**

**13. Are there things you do to keep yourself healthy?**

____________________________________

____________________________________

**Nothing 0**
**Exercise 1**
**Diet 2**
**Exercise and diet 3**
**Other activity 4**

---

**CURRENT SYMPTOMS**

**I would like to ask you about the symptoms you have had over the past week?**

**14. What symptoms have you had over the past week?**

| | |
|---|---|
| ________________ | ____________________ |
| ________________ | ____________________ |
| ________________ | ____________________ |
| ________________ | ____________________ |
| ________________ | ____________________ |

**15. How do you think your symptoms will be in 6 months time, compared to how they are are now?**

**No symptoms at all 5 better 4 about the same 3 worse 2 don't know 1**

---

## PAST EXPERIENCE OF ILLNESS

**16.Have you, or anyone you know, ever had symptoms like these before?**

**No 0**
**Yes, self 1**
**Yes, other 2**
**Yes, self & other 3**

**17.In the past, have you or anyone you know had any serious illness?**

**No 0**
**Yes, self 1**
**Yes, other-same condition 2**
**Yes, other-not same condition 3**
**Yes, self & other-same condition 4**
**Yes, self & other-not same condition 5**

---

## HISTORY OF CONDITION

**18.What was the very first symptom that made you think something was wrong?**

____________________________________________

**19.When was that?**

**Less than 1 month 1**
**1-3 months 2**
**3-6 months 3**
**6-9 months 4**
**9-12 months 5**
**1-2 years 6**
**2-3 years 7**
**3-4 years 8**
**4-5 years ago 9**
**5+ years 10**

---

## CAUSE OF SYMPTOMS/CONDITION

**20. Most people have some ideas about how they got their condition, what ideas do you have?**

____________________________________________

____________________________________________

**21.Do you think there is anything that can be done to cure your condition?**

**IF YES: WHAT?**

____________________________________________

____________________________________________

## EFFECTS OF SYMPTOMS/CONDITION

**I would like to ask you about the effects your symptoms/condition has had on you and your life.**

**22. Overall, how serious do you think the consequences of your symptoms/condition are?**

**Very serious** 3 **Somewhat serious** 2 **Not very serious** 1

**23. What problems or difficulties have your symptoms/condition caused you over the past week?**

________________________________________

________________________________________

**24. What have you done about them?**

________________________________________

________________________________________

**25. Have your symptoms/condition made you think or feel differently about yourself?**

________________________________________

________________________________________

**26. People with symptoms/condition often say they have "gained" something. What do you feel you have gained?**

________________________________________

________________________________________

**27. People also way they loose alot from having symptoms/condition. What have you lost?**

________________________________________

________________________________________

**28. Which of the following things are you well enough to be able to do without help?**

**Yes$_2$ No$_1$**

**a.Heavy work, like washing floors, carrying shopping, digging in the garden?**
**b. Walk half a mile?**
**c. Walk up and down stairs to bedroom(or equivalent)**
**d. Go out to the pictures, a meeting or visit friends?**

**29.Does your symptoms/condition interfere or prevent you from doing any of the following things?**

**Yes$_2$ No$_1$**

**a. Eating out at a restaurant/pub?**
**b. Going on holiday?**
**c. Concentrating on things?**
**d. Reading?**
**e. Doing the things you enjoy?**

SERIOUSNESS OF ILLNESS

**Moving away from your particular symptoms/condition. I would like to ask you about illness generally.**

**30.Here are some cards with illnesses written on them. They are not in any particular order. Which of these illnesses, in your opinion, do you think is the most serious from your point of view, which next etc.**

**headache $_1$**
**cancer $_2$**
**bad circulation $_3$**
**heart attack $_4$**
**diabetes $_5$**
**mental illness $_6$**
**arthritis $_7$**
**stroke $_8$**
**influenza $_9$**
**bronchitis $_{10}$**

**31.Many, if not all people, have their own ideas about what might be wrong with them. In your opinion, what do you think is wrong with you and why?**

____________________________________________

____________________________________________

**32.Where would you place your condition amongst the list of illnesses, and why?**

____________________________________________

____________________________________________

## ACTION TAKEN TO MANAGE

**I would like to ask you about the sorts of things you have done about your symptoms/condition; including what you have tried to do to make sense of, or try and understand.**

**33. What have you done to try and make sense of, or try to understand your symptoms/condition?**

**34.Do you feel you have as much information as you need?**

**Enough $_1$ Too much $_2$ Too little $_3$**

**35. Most people, as well as going to their own GP try other treatments or home remedies. What have you tried, and did it help?**

## APPRAISAL

**36.Overall, how well do you feel you have managed?**

**Very well $_5$ Quite well $_4$ Not sure $_3$ Not very well $_2$ Very badly $_1$**

## LETTER SENT TO PEOPLE COMING INTO HOSPITAL FOR TESTS AND INVESTIGATIONS : STUDY 1 & 2

---

Dear

We are trying to interview as many people as possible who are coming into hospital for tests and investigations.

The purpose of the interview is to understand the sorts of symptoms and difficulties that people have been experiencing before coming into hospital and what people expect from their stay.

I would like to visit you at home on:

--------------------------------before your admission to the ward. If you feel you can help, then I shall be pleased to call and see you at this time.

Please be assured that any information will be treated as being strictly confidential

Yours Sincerely

Louise Earll
Principle Psychologist

LETTER SENT TO CROSS SECTIONAL STUDY: NO. 3

**Dear,**

**We are carrying out a survey designed to improve the service to people referred to the neurology department.**

**In order to do this I am contacting a sample of people who were seen by the service in the past.**

**If you are willing to take part in the survey, then I would like to visit you at home to discuss your views and to ask you questions about how you have managed.**

**All information will be used to improve the service offered in the future and treated in the strictest confidence.**

**Please complete and return the printed slip below letting me knoe whether you will be willing to help me. A stamped addressed envelope is provided.**

**Thank you,**

**Yours faithfully,**

**Louise Earll**
**Principal Psychologist**

---

**Please complete and return in the SAE before 14th August 1989**

**Name-------------------------- Tel no.(home)---------------**

**(work)----------**

**Address------------------------------------------------------**

**------------------------------------------------------**

**Tick as appropriate:**

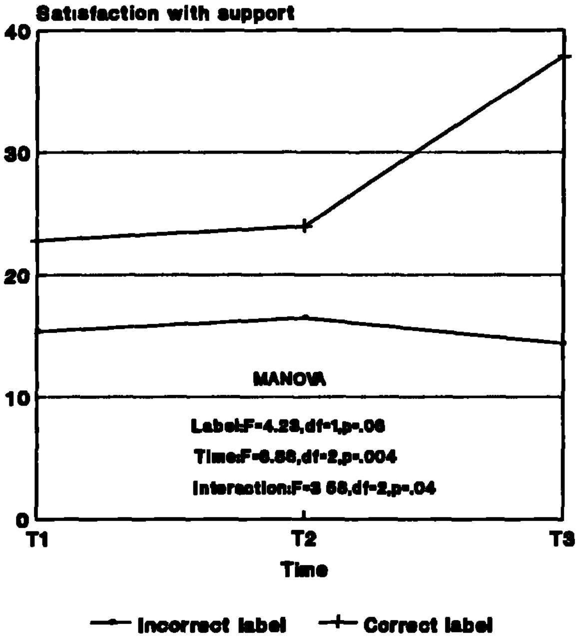
**I will be happy to take part in the survey______**

**I do not wish to take part in the survey_____**

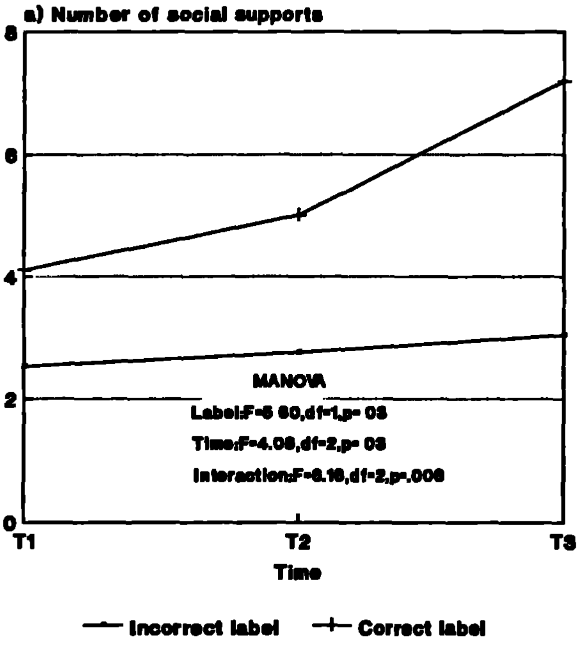
# Appendix B

## Study 1 : Figures

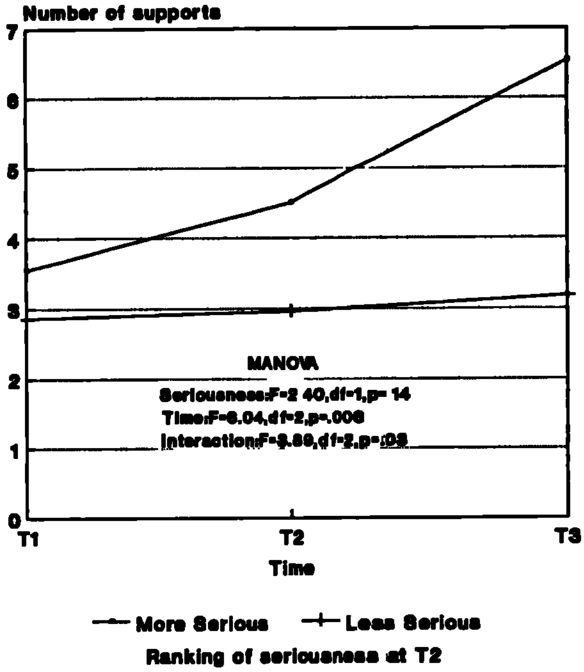
**B1.Interaction between representation, coping & time label(T1), Social Support(S) & time**



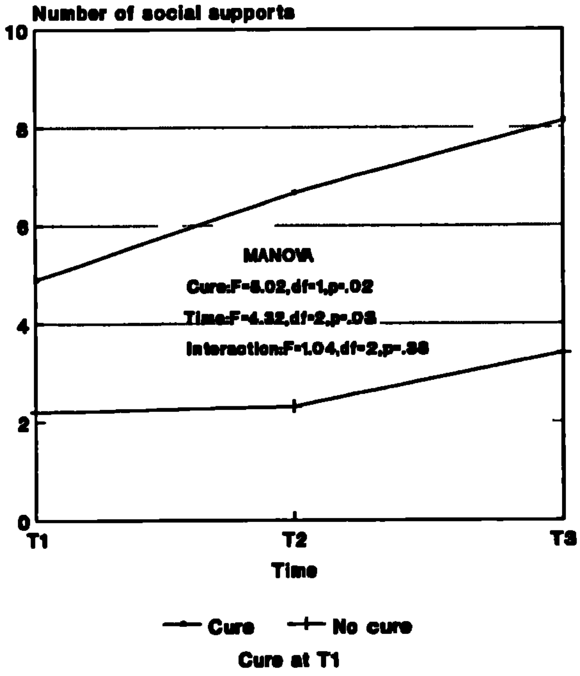
**B2.Interaction between representation, coping and time label(T1), Social Support(N) & time**



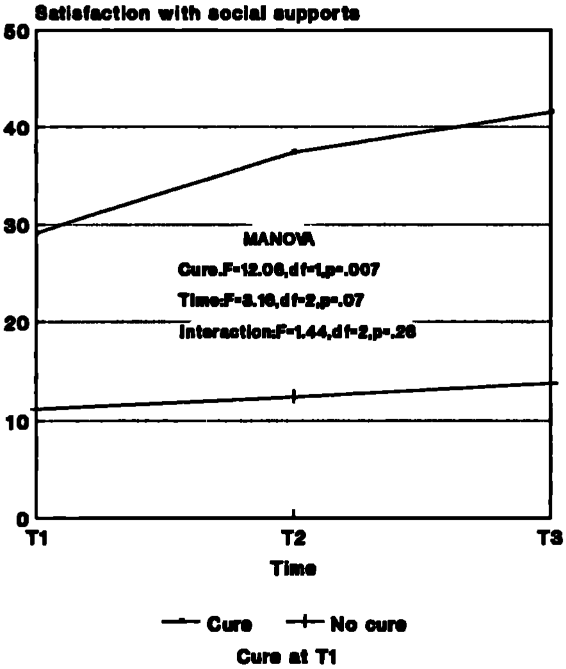
B3.Interaction between representation, coping & time seriousness, Social Support(N) & time



B4 Relationship between representation & coping- cure(T1) & Social Support(N)

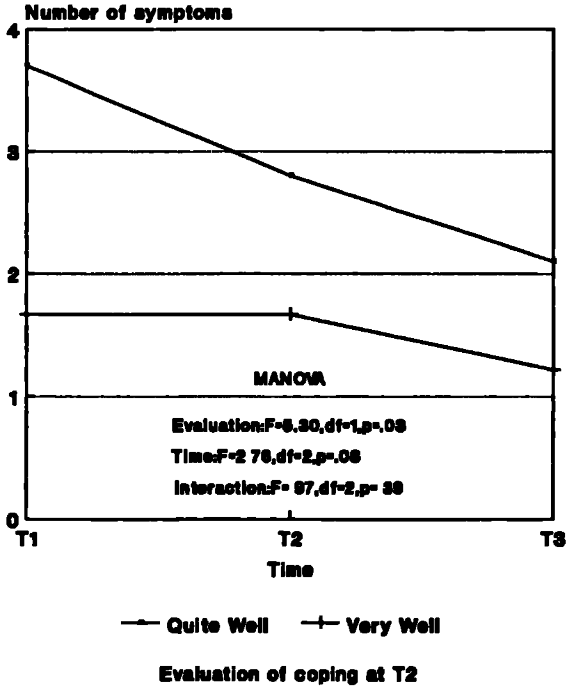


**B5 Relationship between representation & coping cure(T1) & social support(S)**



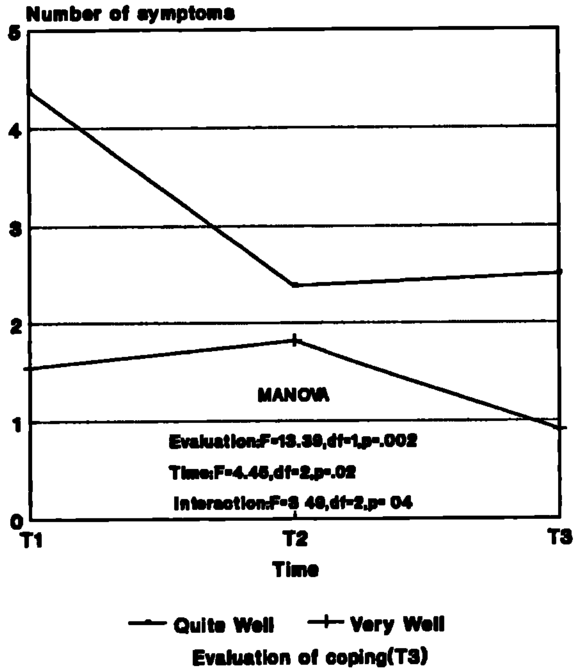
**B6.Relationship between representation & evaluation of coping**

**symptoms & evaluation(T2)**

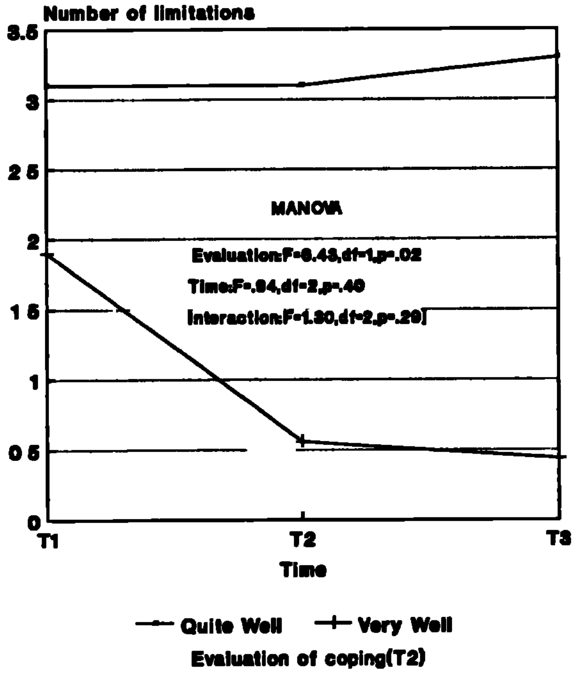


**B7.Relationship between representation & evaluation of coping**

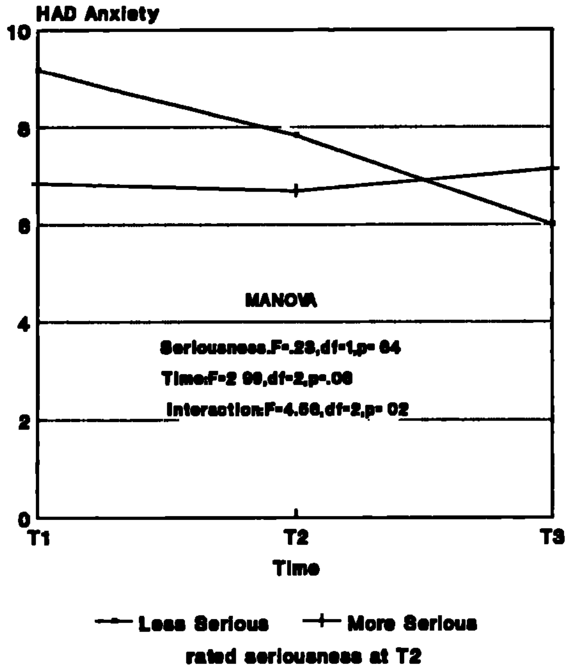
**symptoms & evaluation(T3)**



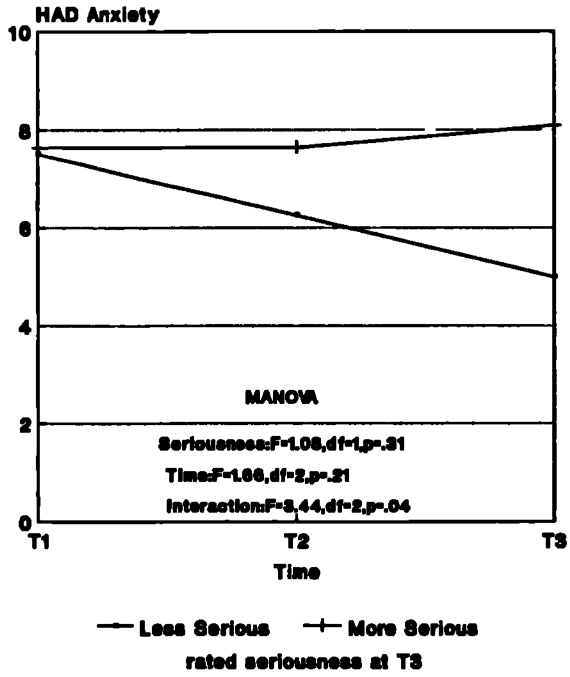
**B8 Relationship between representation & evalution of coping: limitations & evaluation of coping(T2)**



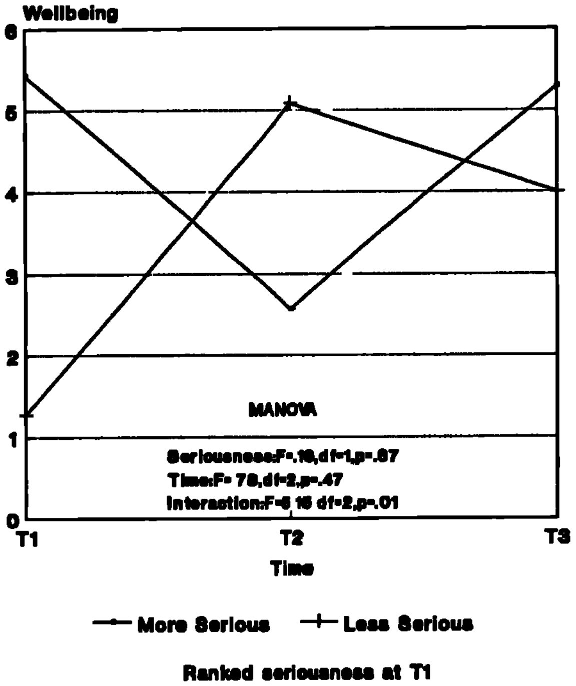
B9 Interaction between representation, Emotional Wellbeing and time rated seriousness(T2) & HAD Anxiety



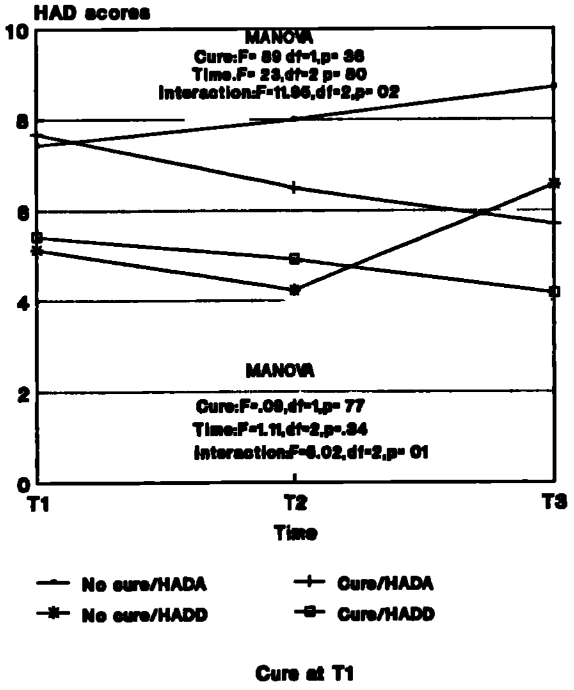
B10.Interaction between representation, Emotional Wellbeing and time-rated seriousness(T3) & HAD Anxiety



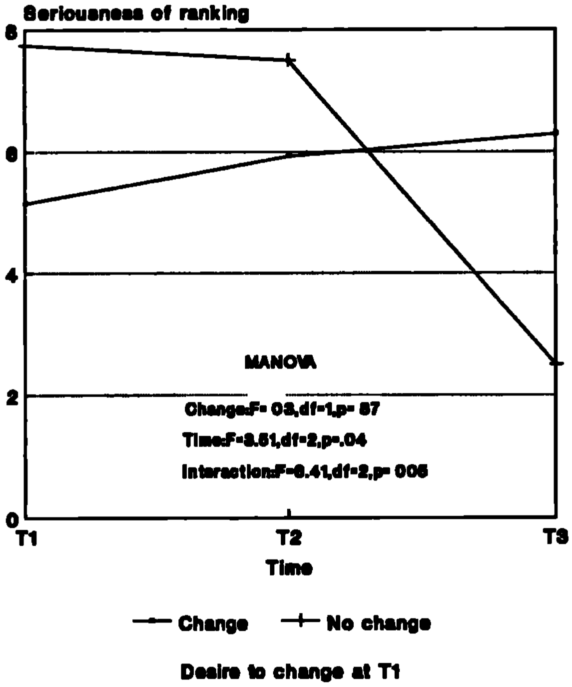
B11.Interaction between representation,
Emotional Wellbeing and time
ranked seriousness(T1) & Wellbeing



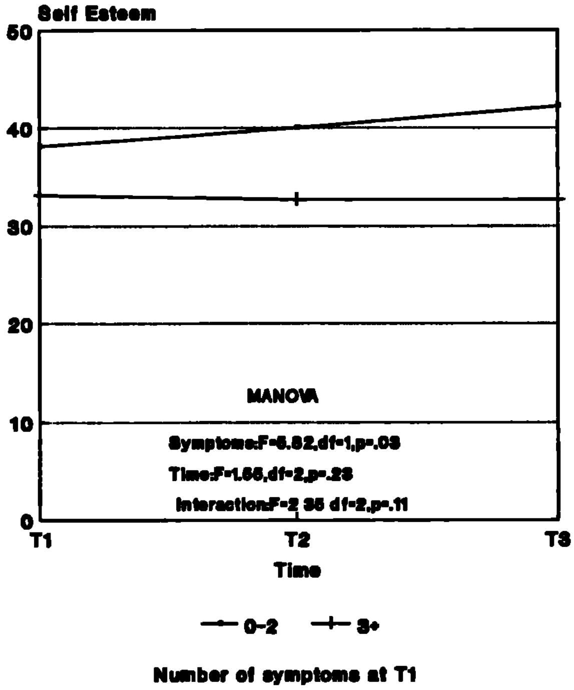
B12.Interaction between representation,
Emotional Wellbeing and time



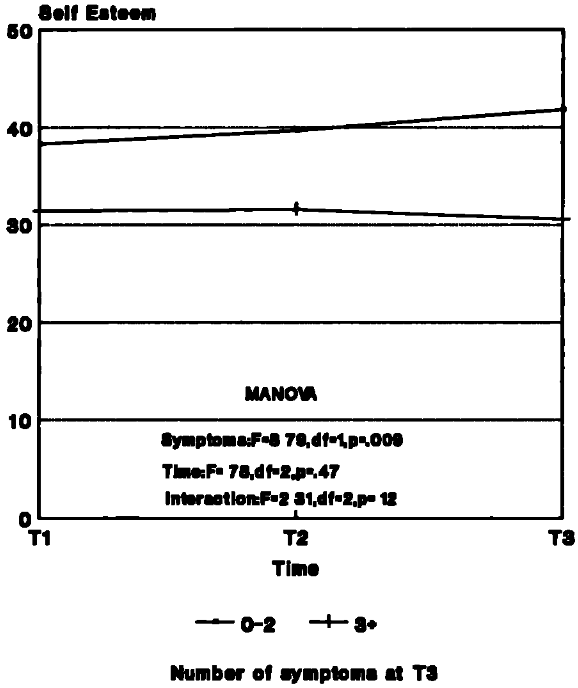
**B13 Interaction between representation,
Emotional Wellbeing and time
ranked seriousness & desire to change(T1)**



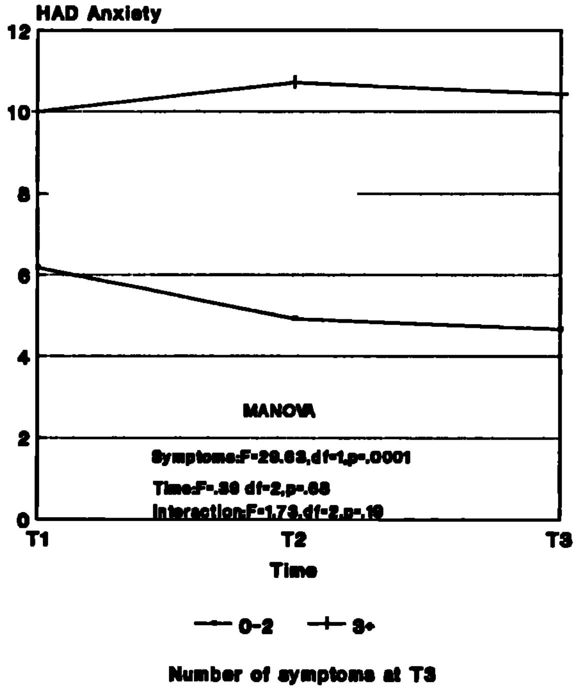
**B14 Relationship between representation
& Impact on Self
symtoms(T1) & Self Esteem**



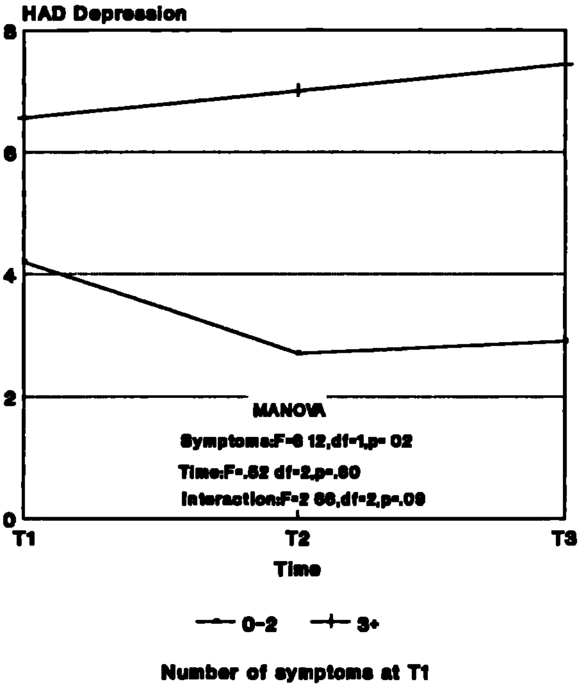
B15.Relationship between representation
& Impact on Self
symptoms(T3) & Self Esteem



B16.Relationship between representation
& Emotional Wellbeing:
symptoms(T3) & HAD Anxiety

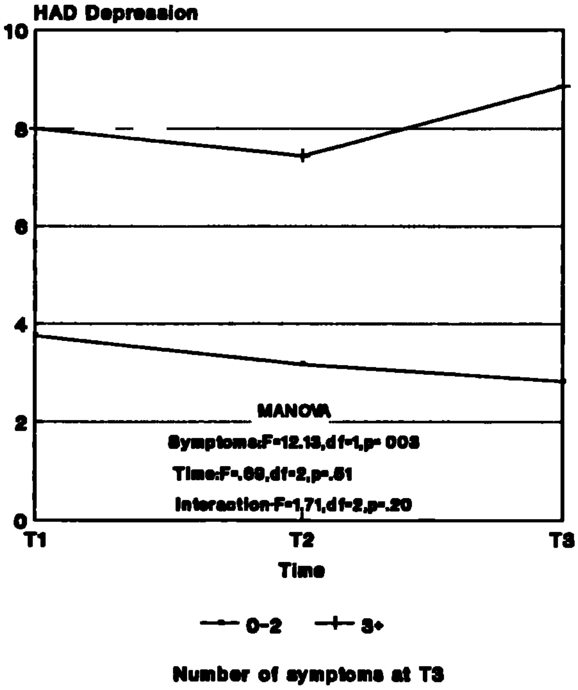


B17 Relationship between representation
& Emotional Wellbeing:
symptoms(T1) & HAD Depression



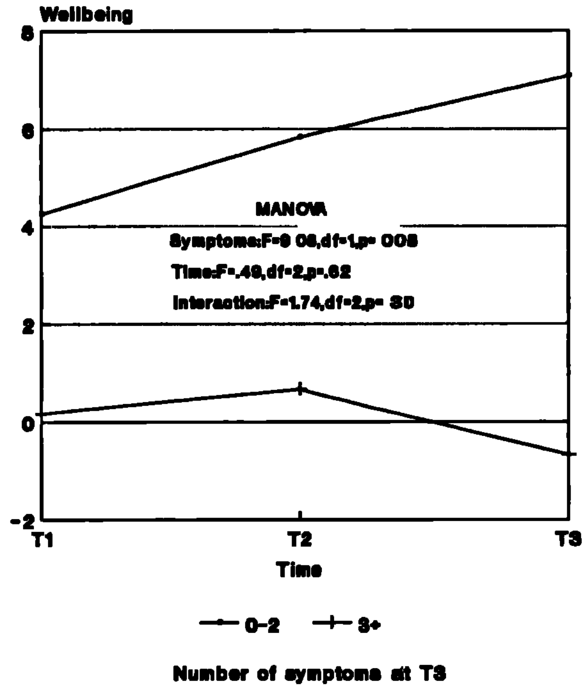
MANOVA
Symptoms:F=6 12,df=1,p= 02
Time:F=.52 df=2,p=.60
Interaction:F=2 66,df=2,p=.09

B18 Relationship between representation
& Emotional Wellbeing.
symptoms(T3) & HAD Depression

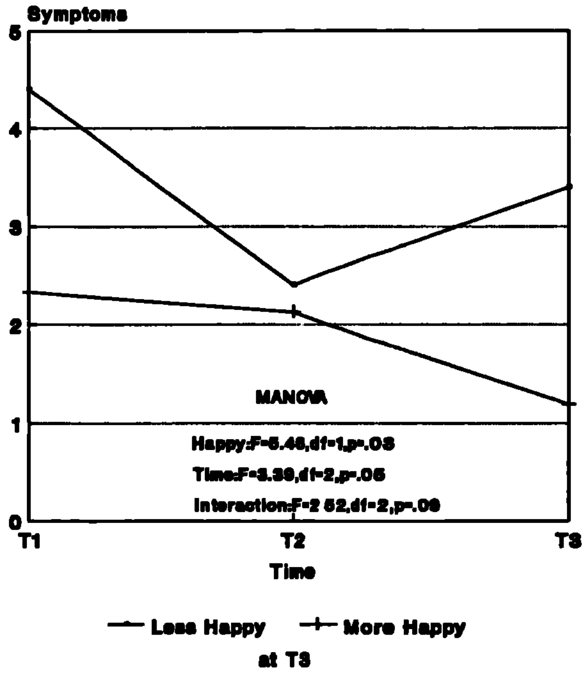


MANOVA
Symptoms:F=12.13,df=1,p= 003
Time:F=.69,df=2,p=.51
Interaction-F=1,71,df=2,p=.20

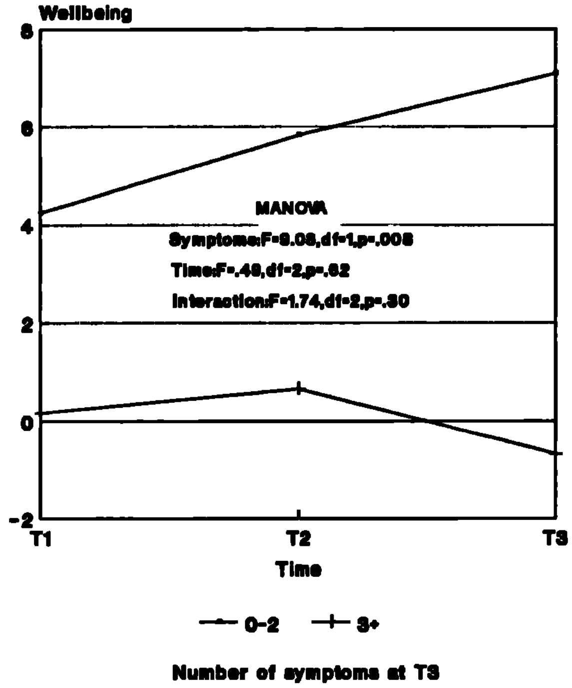
B19.Relationship between representation
& Emotional Wellbeing:
symptoms(T3) & Wellbeing



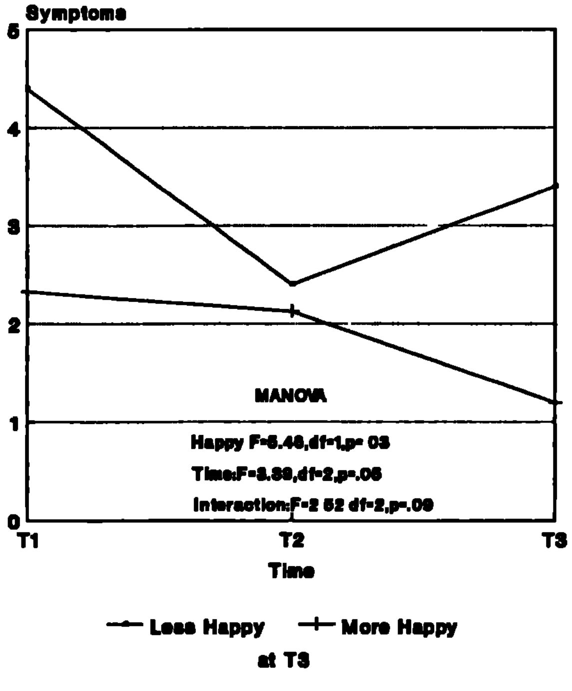
B20.Relationship between representation
& Emotional Wellbeing:
symptoms & Happiness(T3)



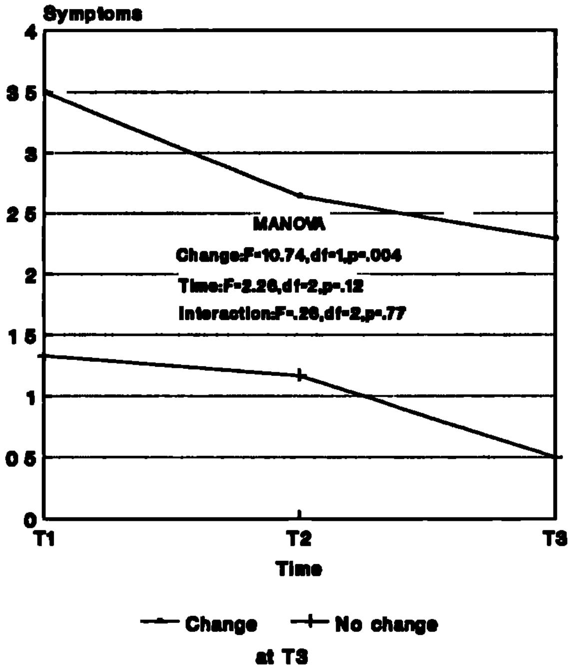
B19.Relationship between representation
& Emotional Wellbeing
symptoms(T3) & Wellbeing



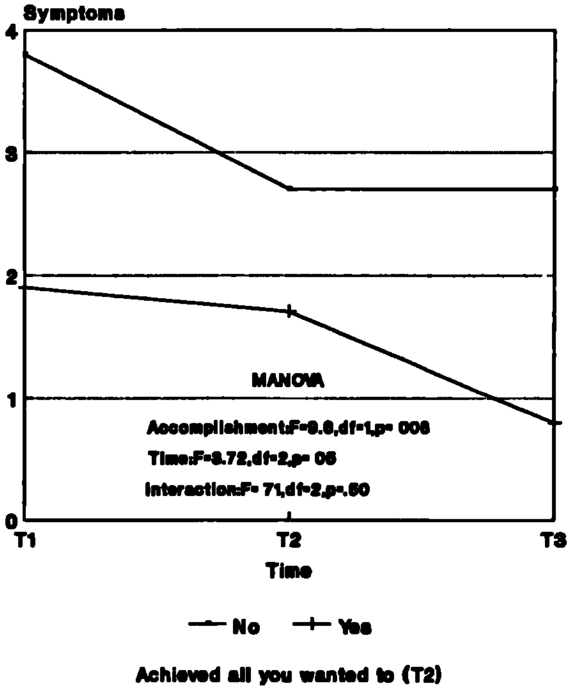
B20 Relationship between representation
& Emotional Wellbeing-
symptoms & Happiness(T3)



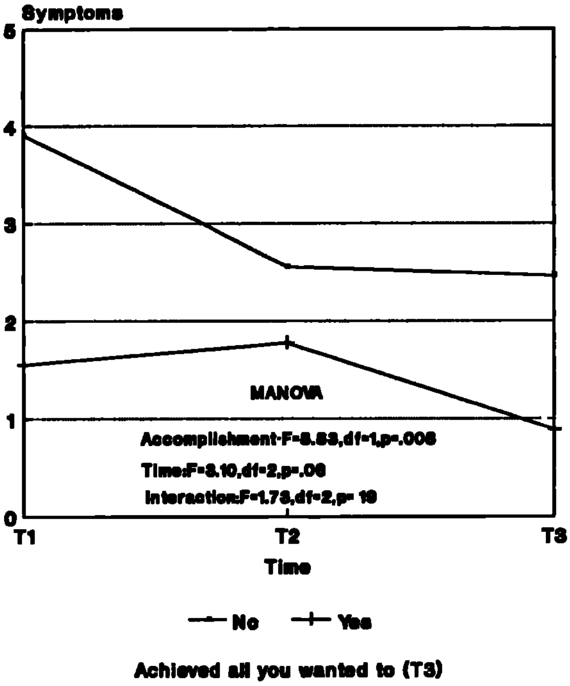
B21.Relationship between representation & Emotional Wellbeing symptoms & desire to change(T3)



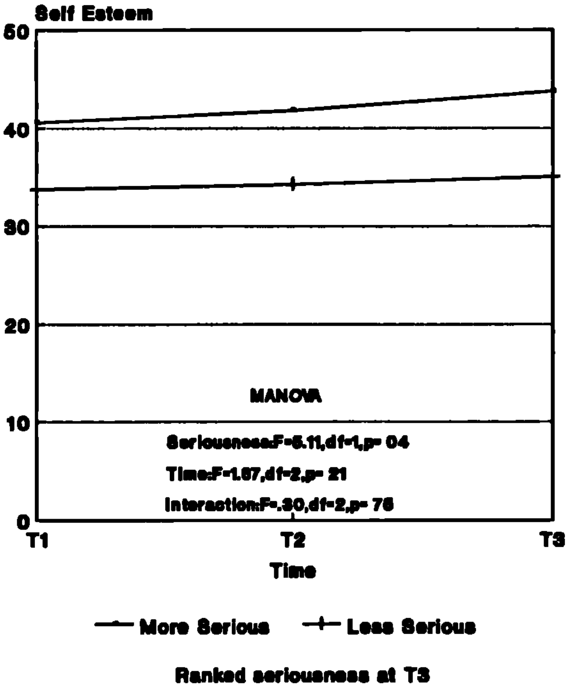
B22 Relationship between representation & Emotional Wellbeing: symptoms & accomplishment(T2)



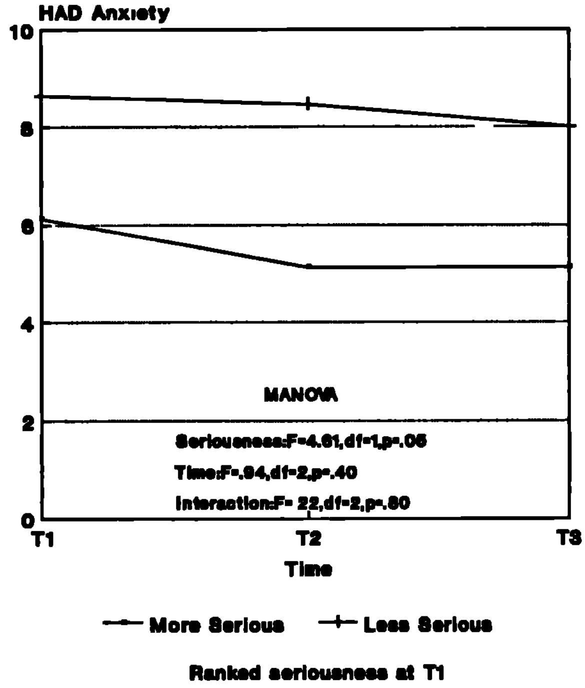
B23.Relationship between representation
& Emotional Wellbeing:
symptoms & accomplishment(T3)



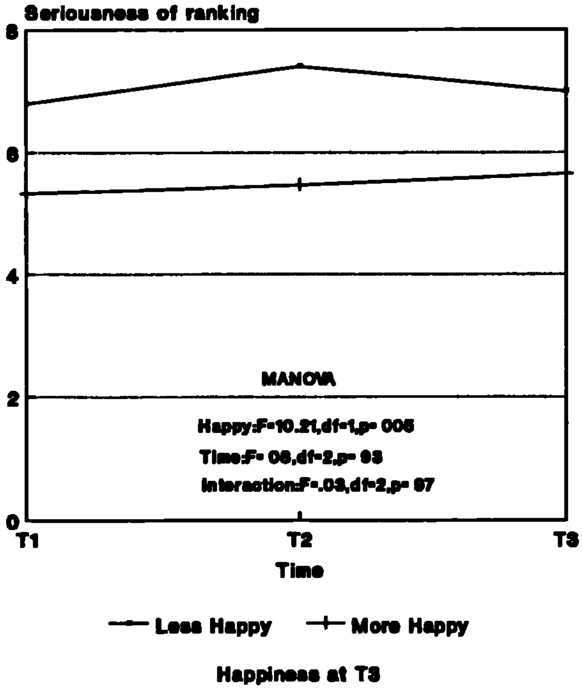
B24.Relationship between representation
& Impact on Self
seriousness(T3) & Self Esteem



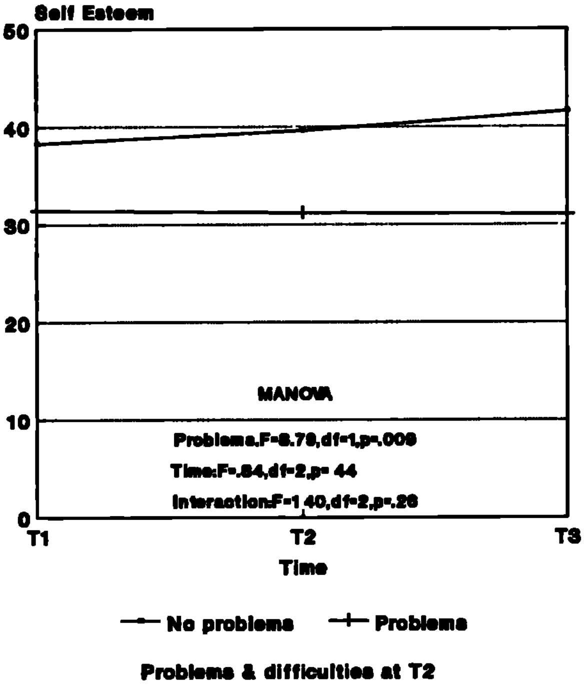
B25 Relationship between representation
& Emotional Wellbeing:
seriousness(T1) & HAD Anxiety



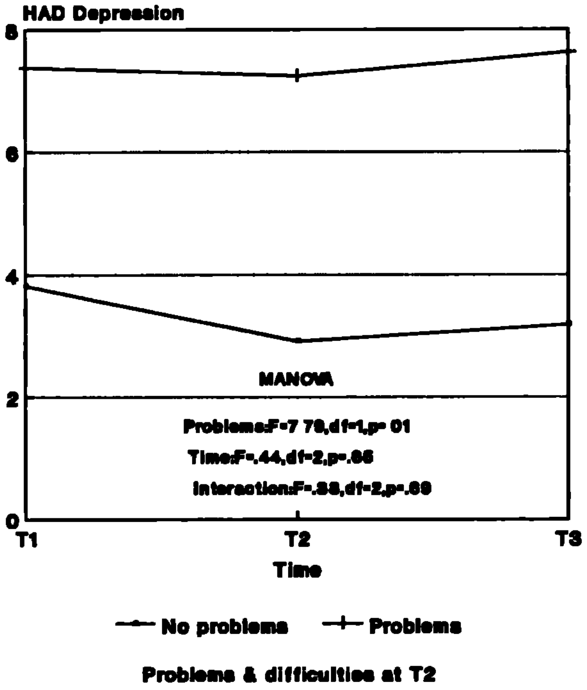
B26 Relationship between representation
& Emotional Wellbeing:
ranked seriousness & Happiness(T3)



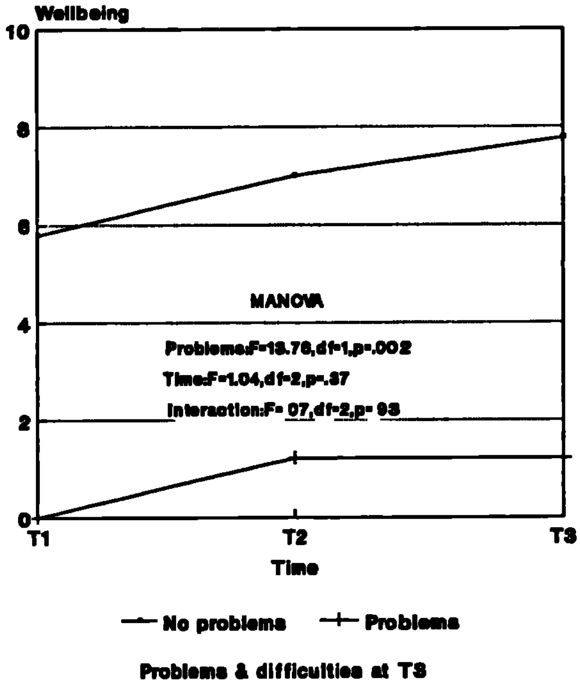
**B27.Relationship between representation & Impact on Self: Problems & Difficulties(T2) & Self Esteem**



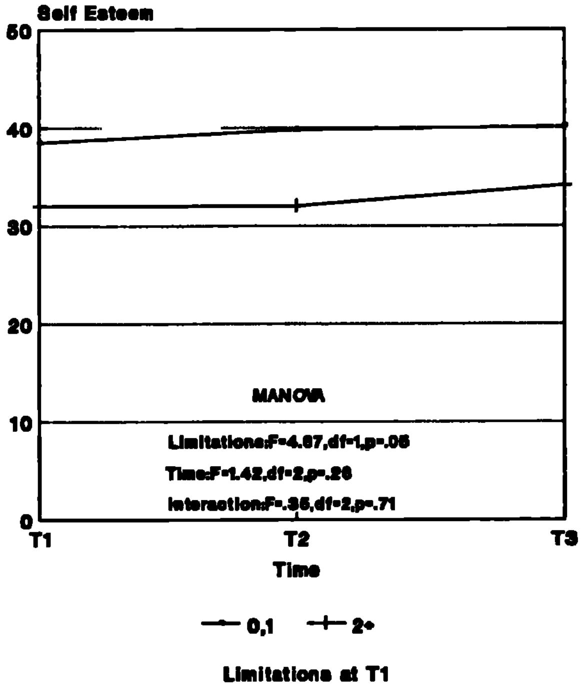
**B28.Relationship between representation & Emotional Wellbeing: Problems & Difficulties(T2) & HAD Depression**



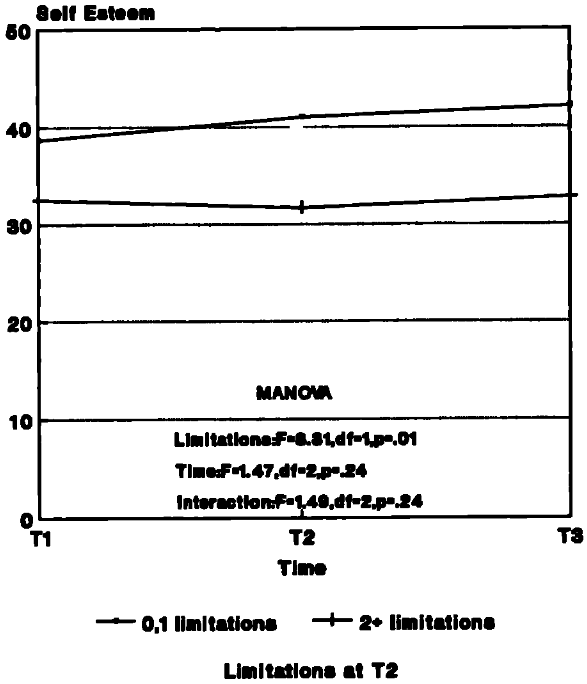
**B29 Relationship between representation & Emotional Wellbeing: Problems & Difficulties(T3) & Wellbeing**



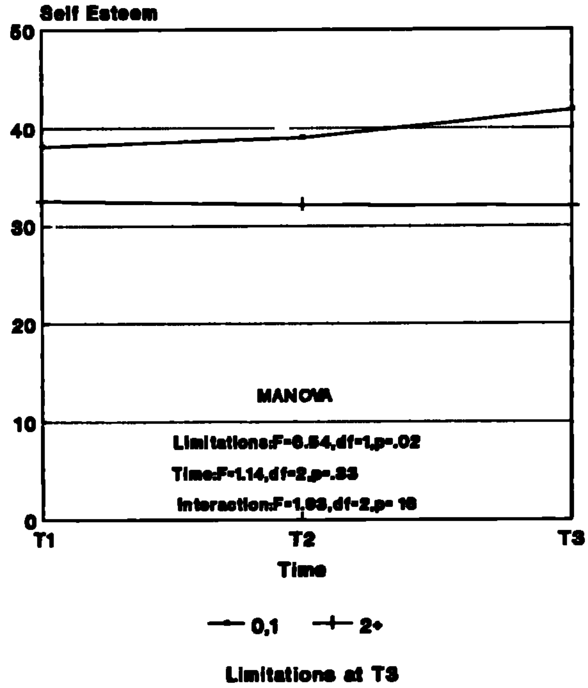
**B30 Relationship between representation & Impact on Self: limitation(T1) & Self Esteem**



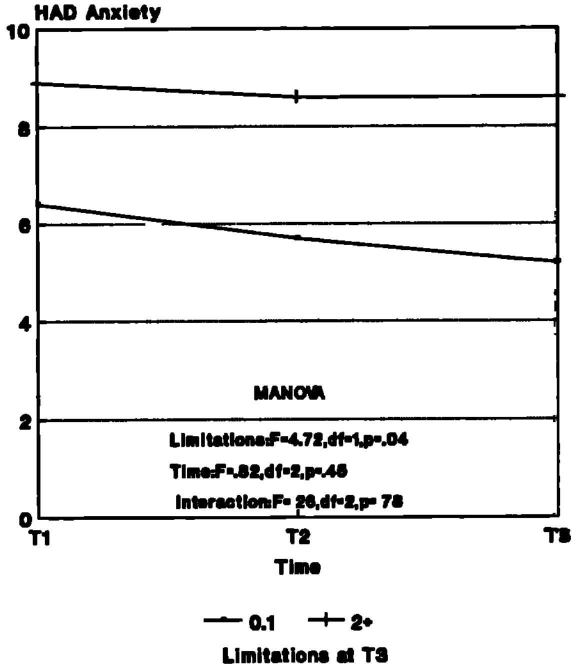
B31 Relationship between representation & Impact on Self limitation(T2) & Self Esteem



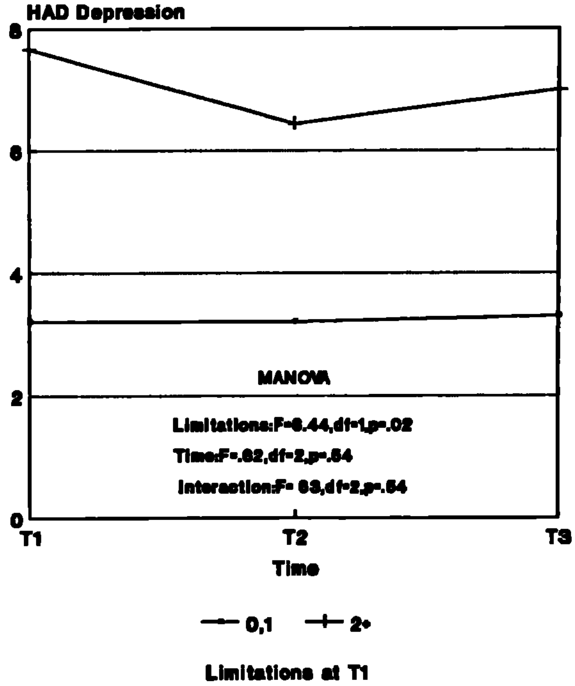
B32 Relationship between representation & Impact on Self: limitation(T3) & Self Esteem



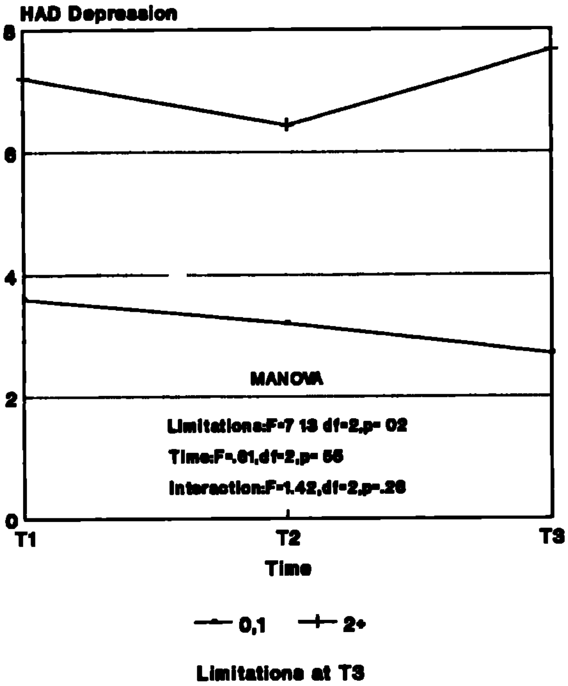
B33 Relationship between representation
& Emotional Wellbeing
limitations(T3) & HAD Anxiety



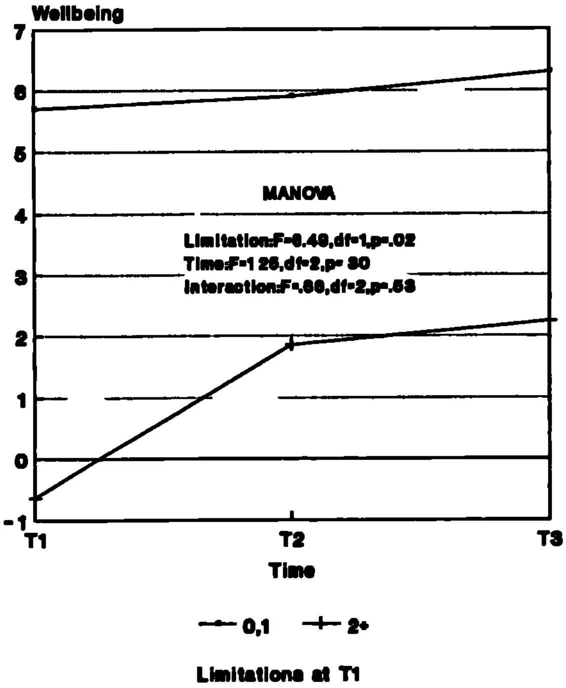
B34 Relationship between representation
& Emotional Wellbeing
limitation(T1) & HAD Depression



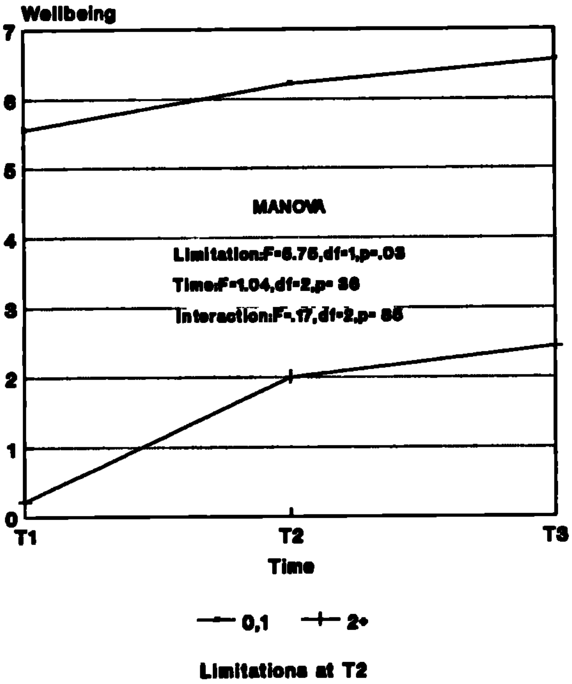
B35 Relationship between representation
& Emotional Wellbeing:
limitation(T3) & HAD Depression



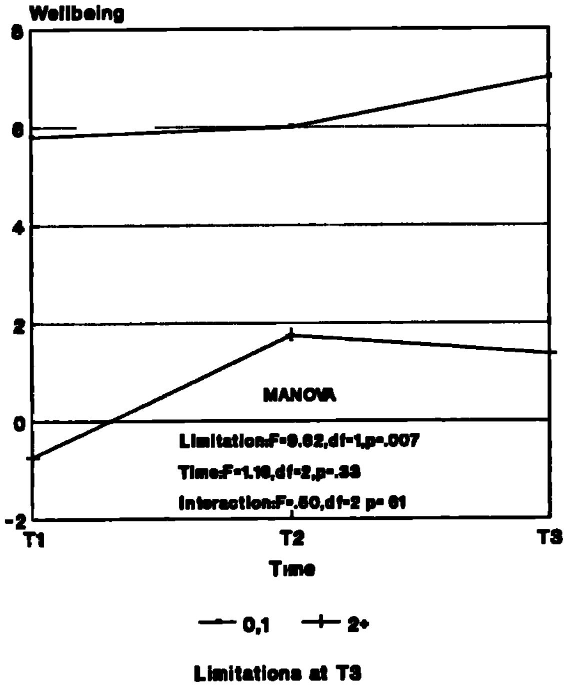
B36.Relationship between representation
& Emotional Wellbeing:
limitation(T1) & Wellbeing



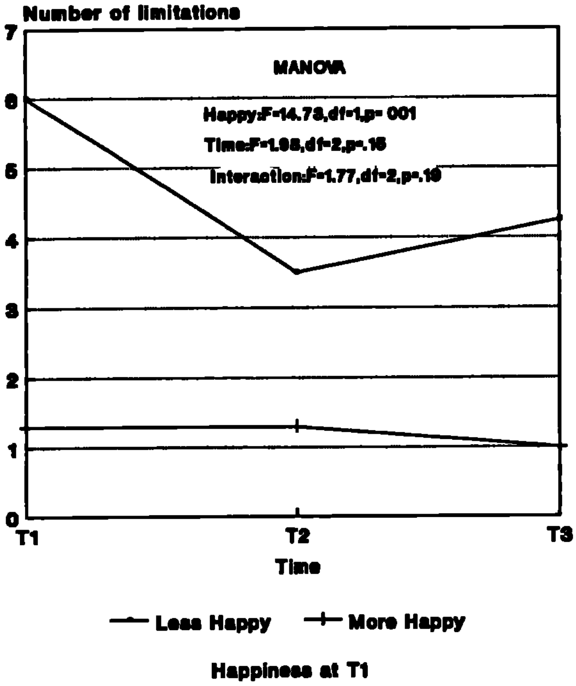
**B37.Relationship between representation & Emotional Wellbeing-limitation(T2) & Wellbeing**



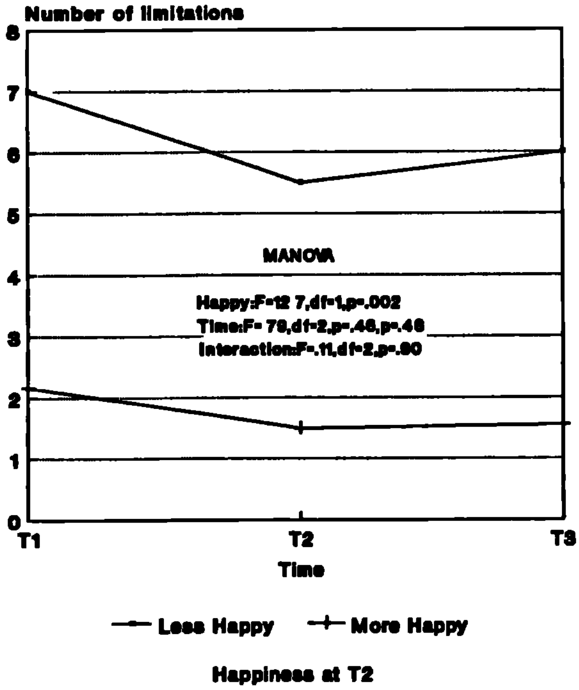
**B38 Relationship between representation & Emotional Wellbeing: limitation(T3) & Wellbeing**



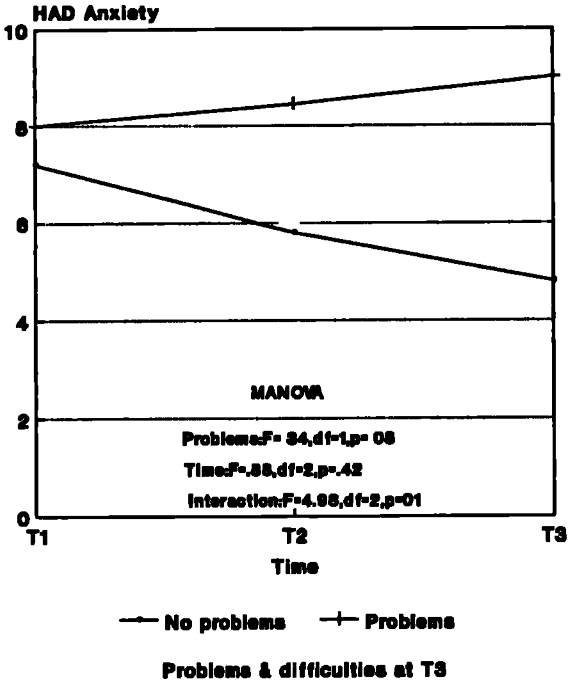
B39.Relationship between representation
& Emotional Wellbeing-
limitation & Happiness(T1)



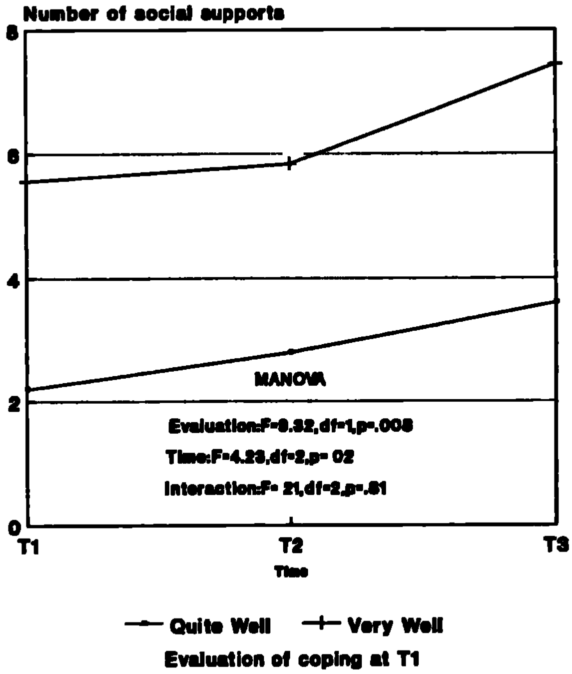
B40 Relationship between representation
& Emotional Wellbeing-
limitation & Happiness(T2)



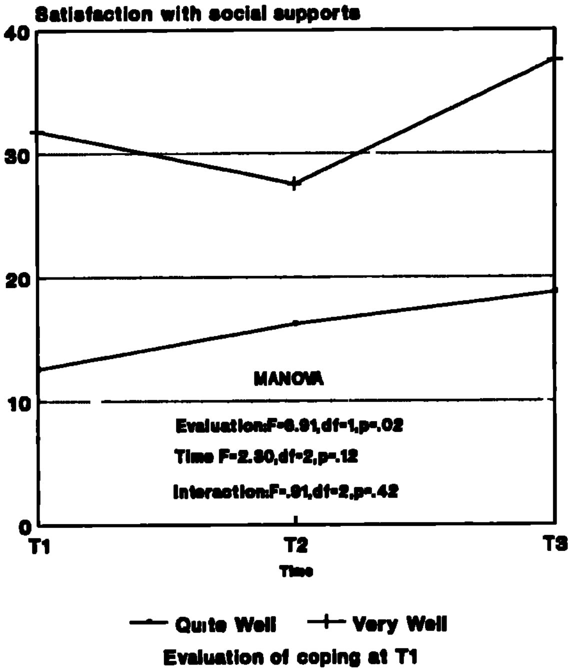
**B41.Interaction between representation, Emotional Wellbeing and time Problems & difficulties & HAD Anxiety**



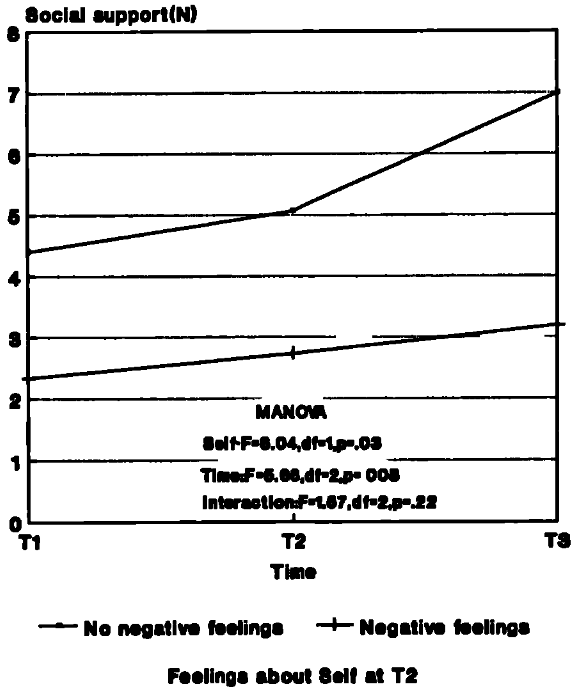
**B42 Relationship between coping & evaluation Social Support(N) & evaluation(T1)**



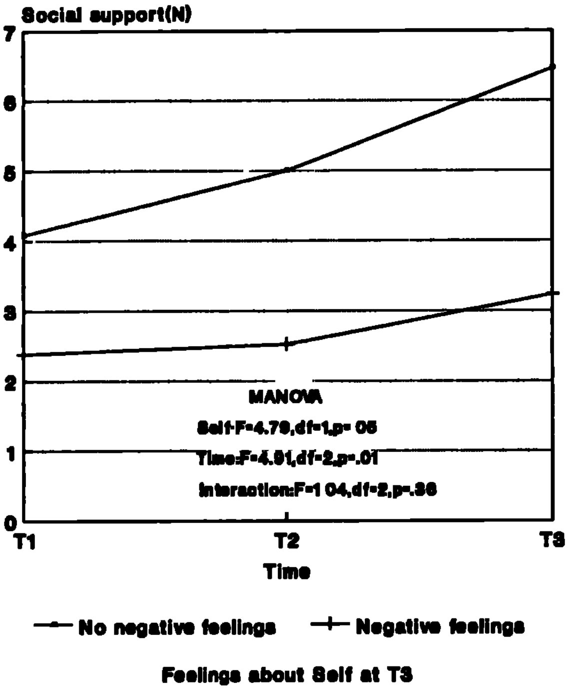
**B43.Relationship between coping and evaluation(T1)**
**Social Support(S) & evaluation(T1)**



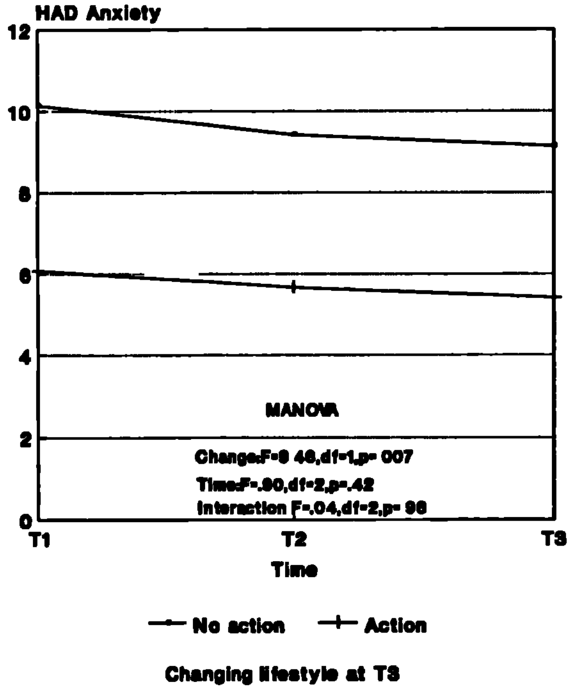
**B44 Relationship between coping and Impact on Self**
**Social Support(N) & self(T2)**



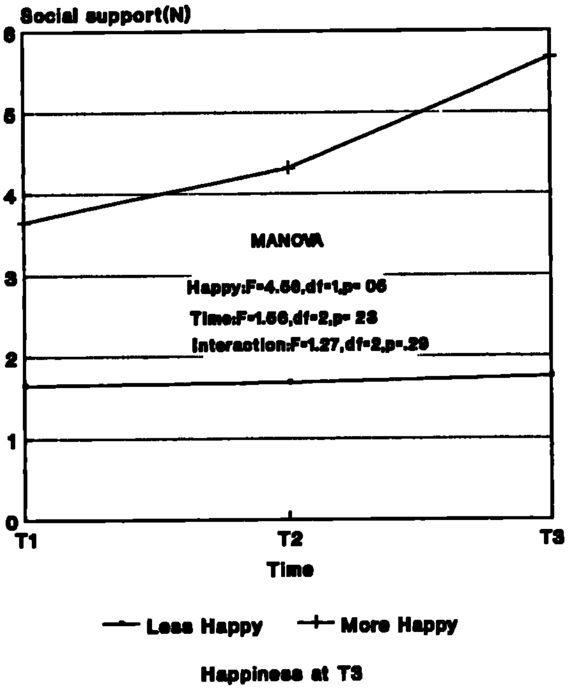
B45 Relationship between coping and
Impact on Self
Social Support(N) & self(T3)



B46 Relationship between coping and
Emotional Wellbeing:
changing lifestyle(T3) & HAD Anxiety



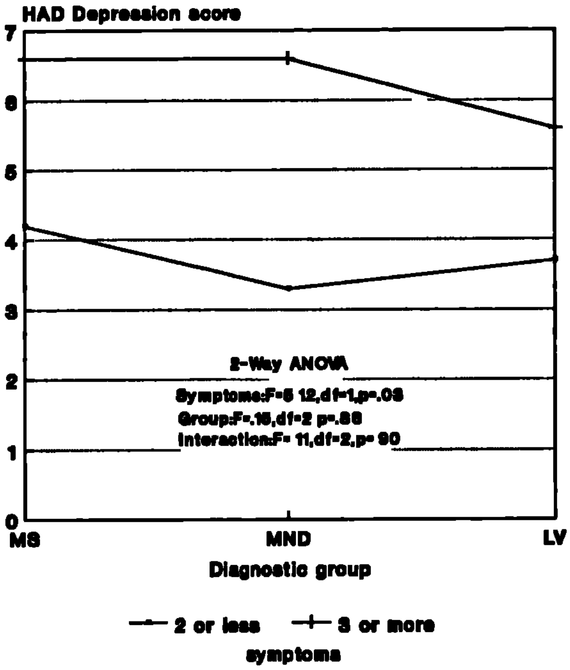
B47.Relationship between Coping and
Emotional Wellbeing:
Social Support(N) & Happiness(T3)



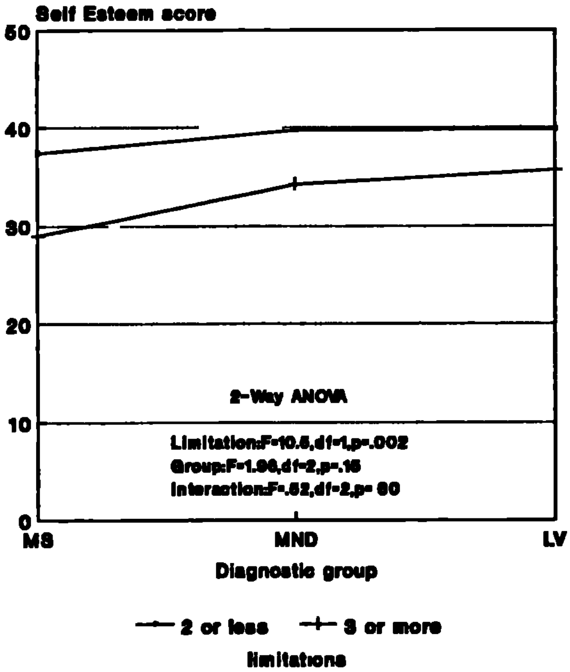
# Appendix C

## Study 2: Figures

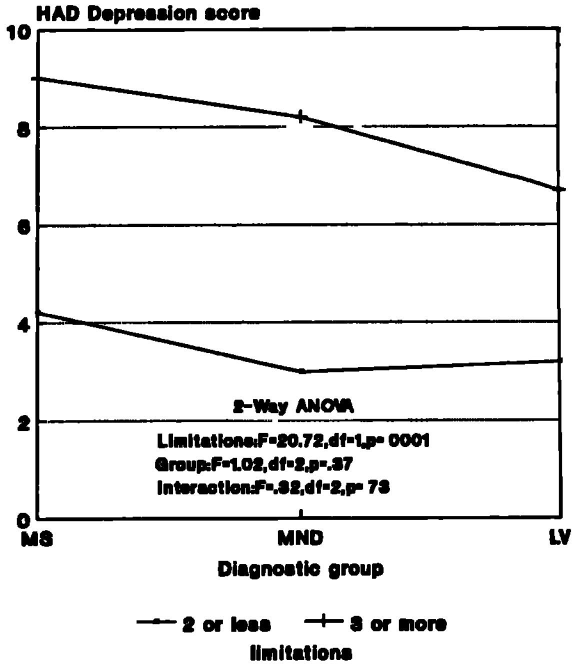
C1 Relationship between representation & outcome. symptoms and depression



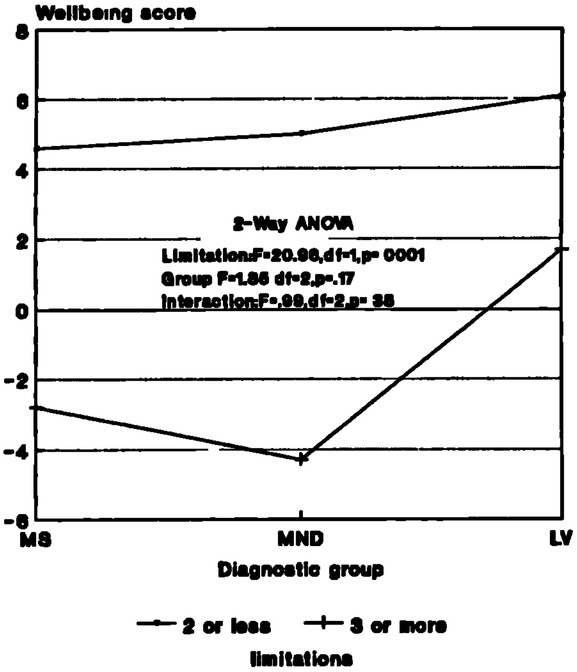
C2 Relationship between representation & outcome limitations and Self Esteem



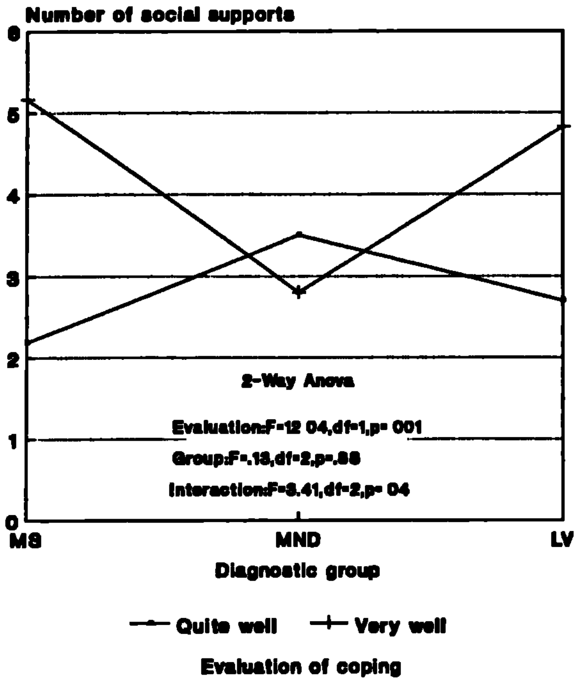
C3 Relationship between representation & outcome- limitations & HAD Depression



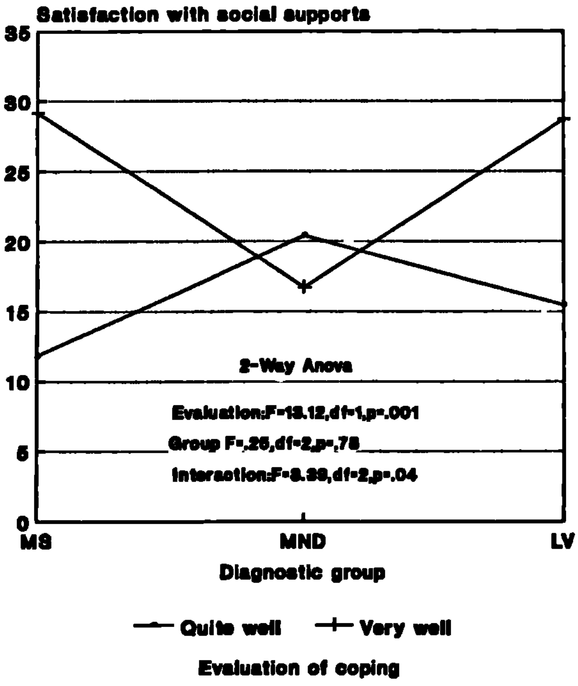
C4 Relationship between representation & outcome limitations & Wellbeing



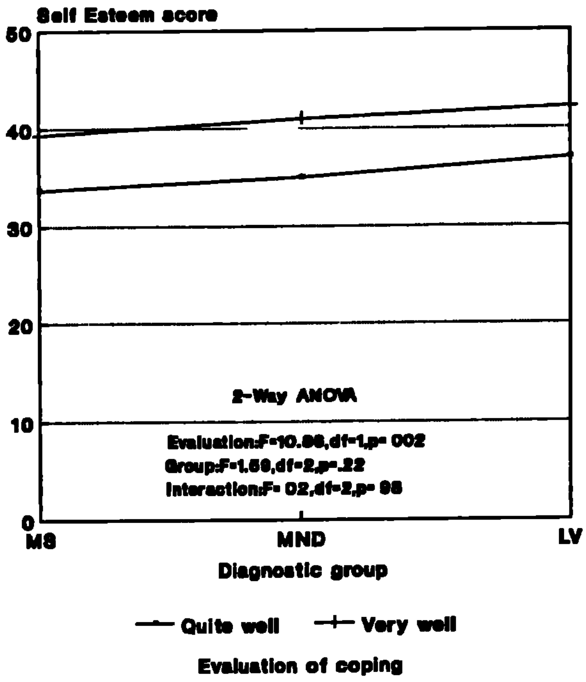
C5 Relationship between coping and evaluation. Social Support(N)



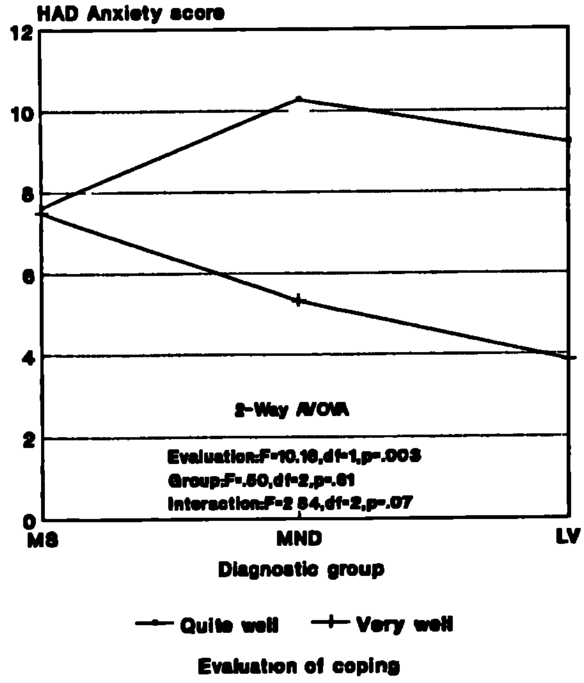
C6 Relationship between coping and evaluation Social Support(S)



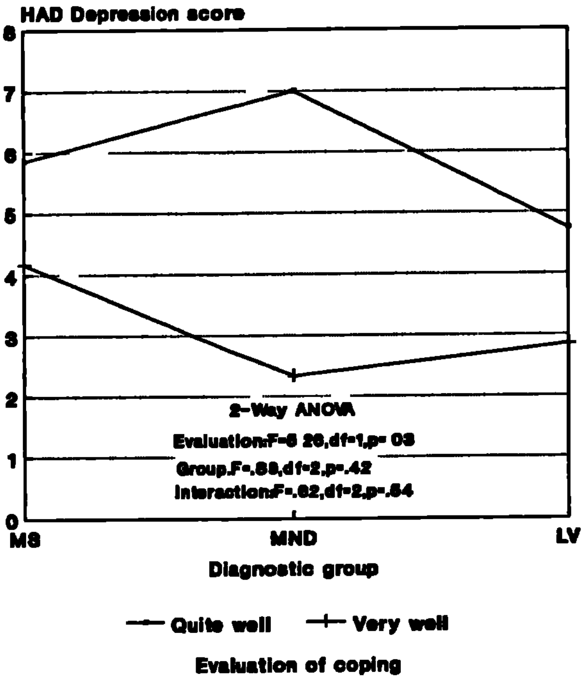
C7. Relationship between evaluation and outcome· Self Esteem



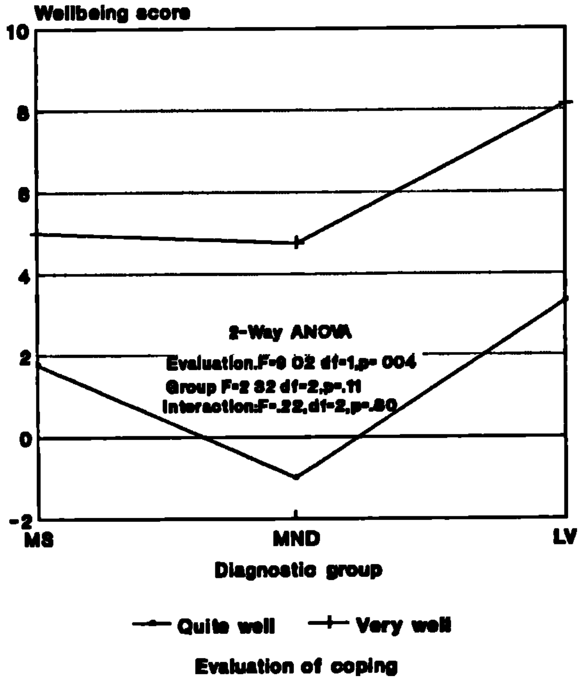
C8 Relationship between evaluation and outcome HAD Anxiety



C9 Relationship between evaluation and outcome HAD Depression



C10 Relationship between evaluation and outcome Wellbeing

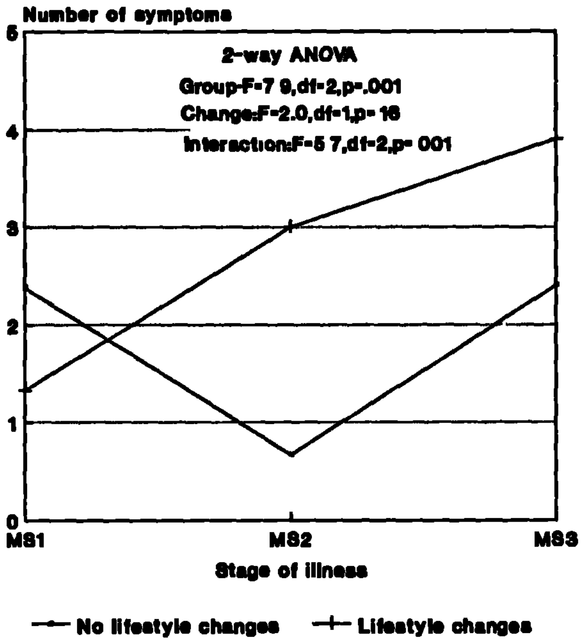


# Appendix D

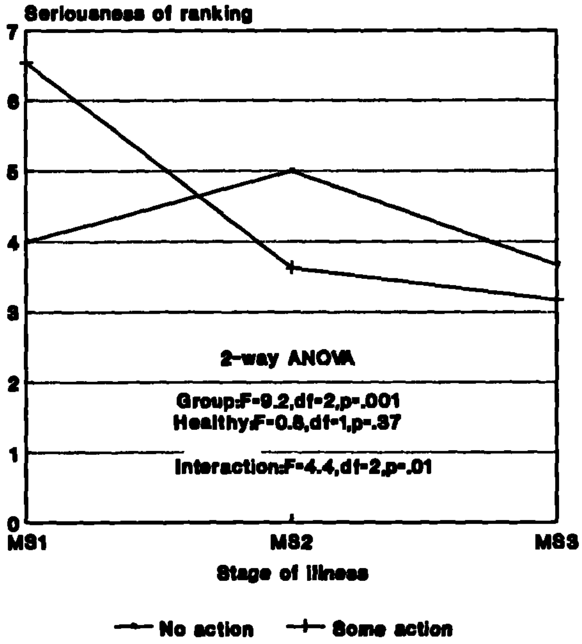
## Study 3: Figures

D 1. Interaction between representation coping & stage of illness

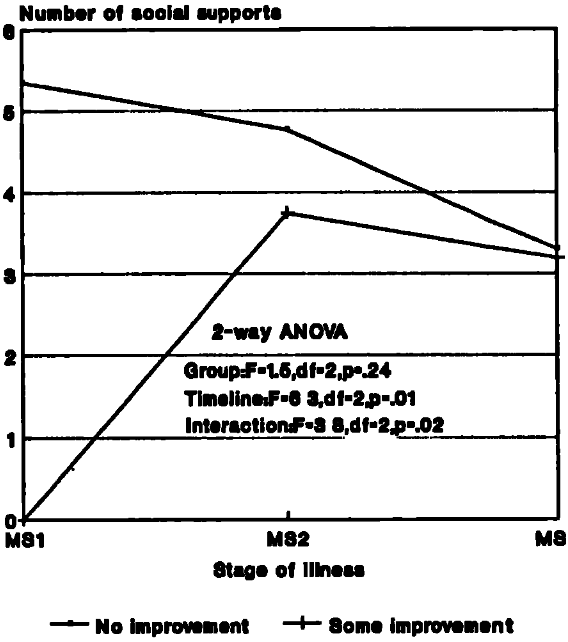
no. of symptoms, change in lifestyle and stage of illness



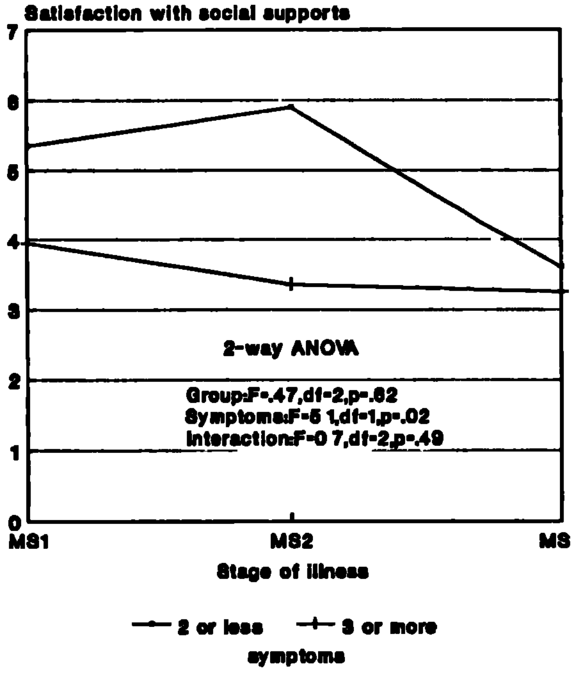
D 2 Interaction between representation coping and stage of illness actions taken to keep healthy & ranked seriousness



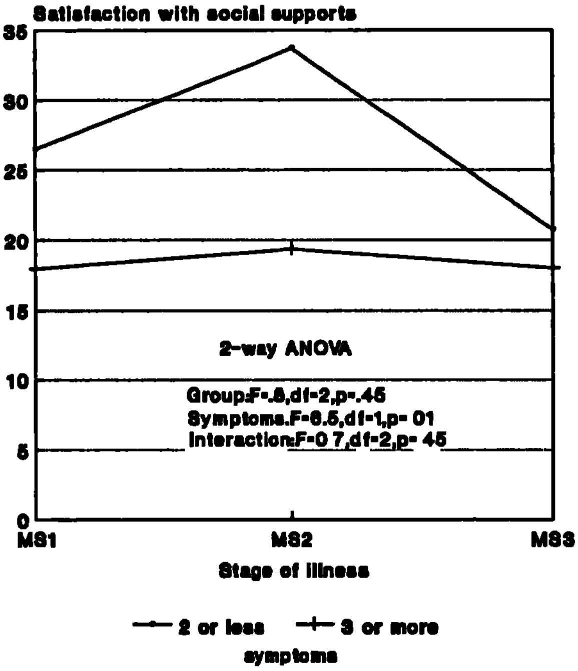
**D 3. Interaction between representation coping and stage of illness timeline & number of social supports**



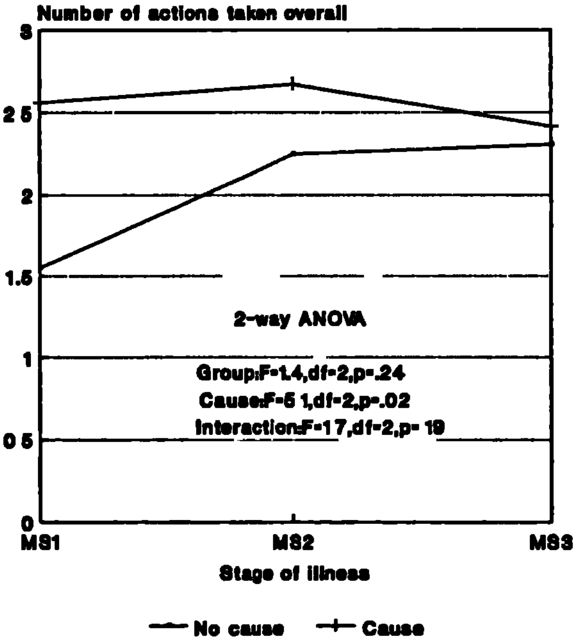
**D 4. Relationship between representation & coping- symptoms & Social Support(N)**



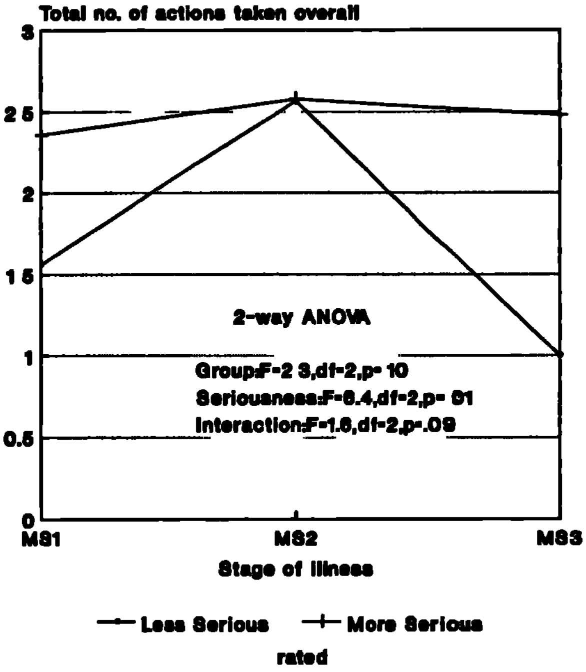
D 5. Relationship between representation & coping symptoms & Social Support(S)



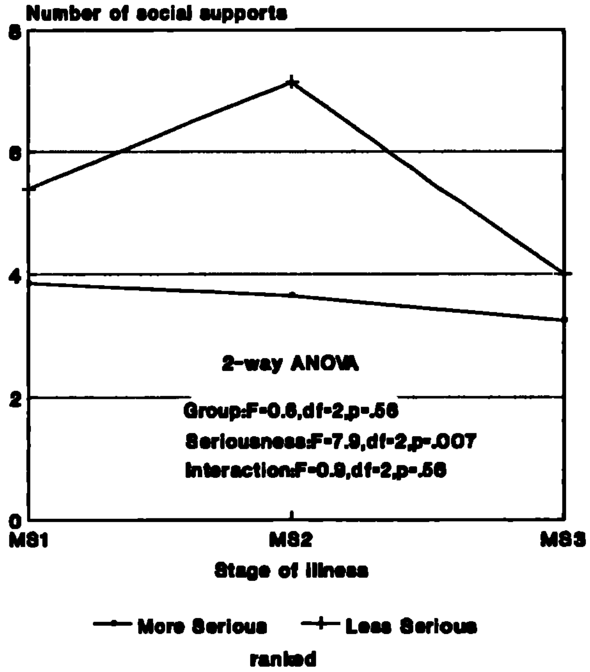
D 6. Relationship between representation & coping. cause & total actions taken



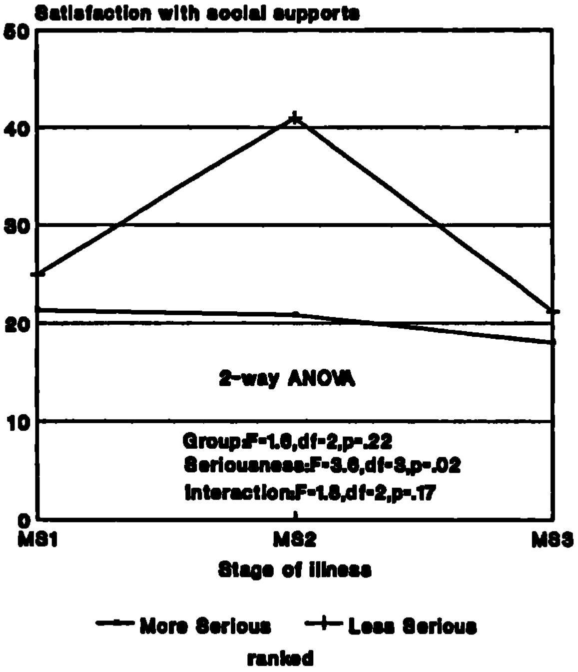
D 7 Relationship between representation & coping rated seriousness & total no. of types of actions taken overall



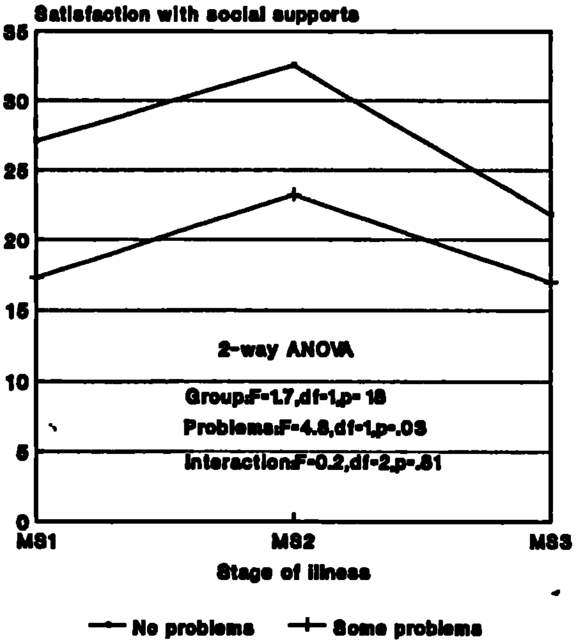
D 8 Relationship between representation & coping: ranked seriousness & Social Support (N)



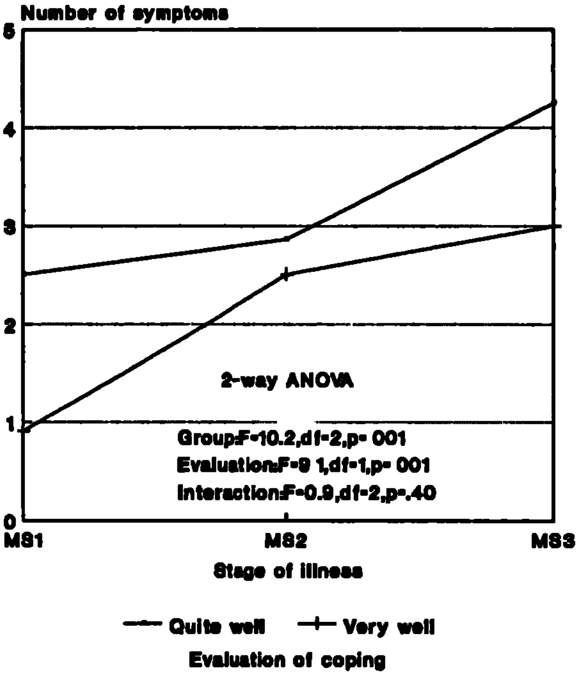
D 9. Relationship between representation & coping: ranked seriousness & Social Support (S)



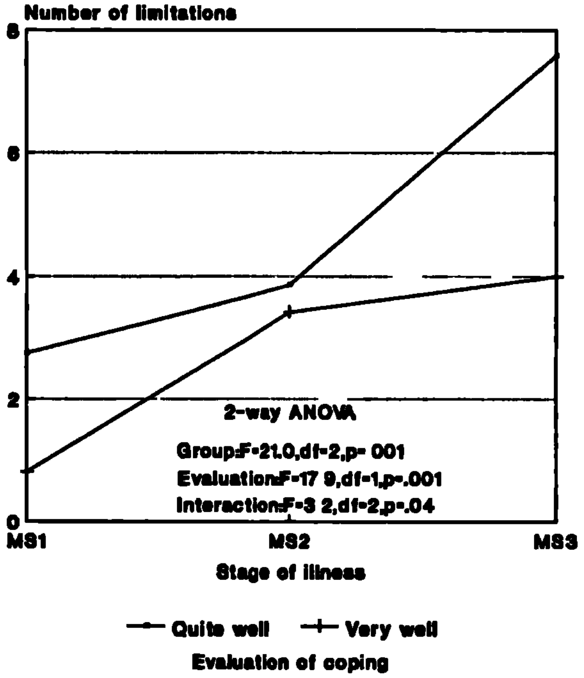
D 10.Relationship between representation & coping: problems & difficulties and Support (S)



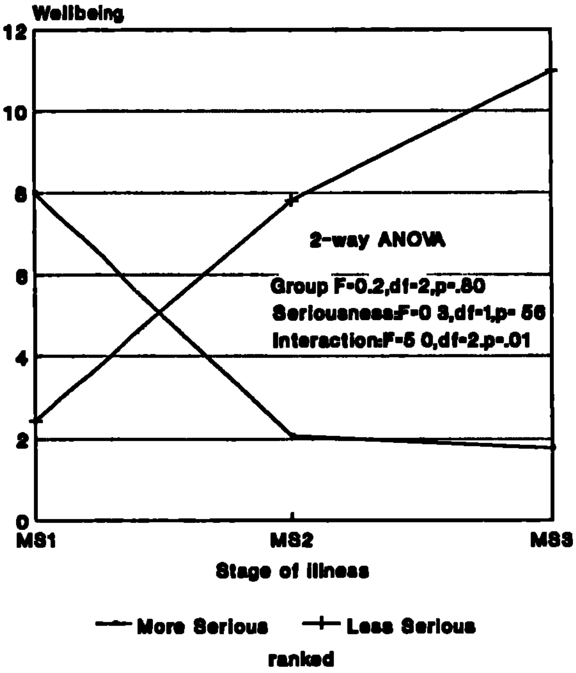
D11. Relationship between representation & evaluation- symptoms



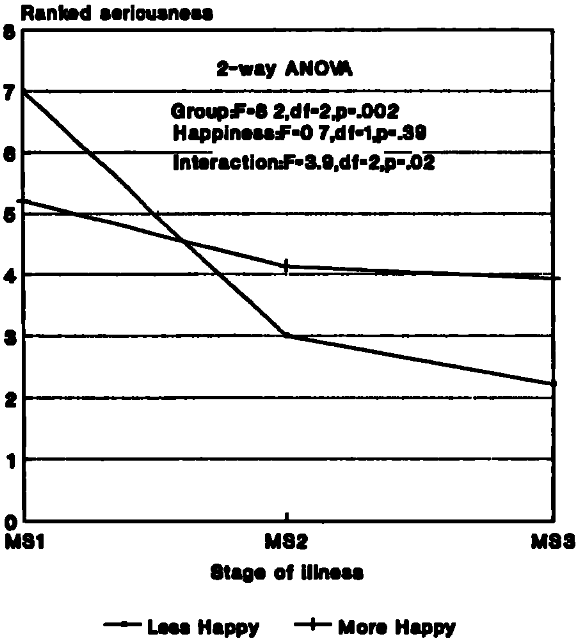
D 12. Interaction between representation evaluation & stage of illness. limitations



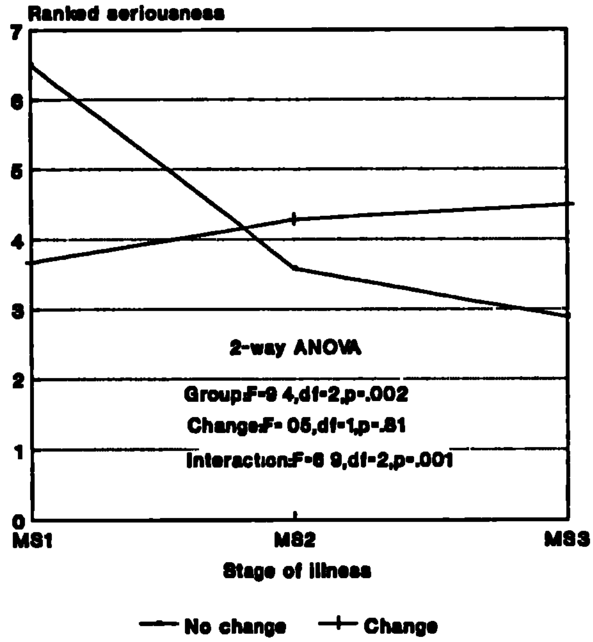
D 13 Interaction between representation emotional wellbeing & stage of illness: ranked seriousness & Wellbeing



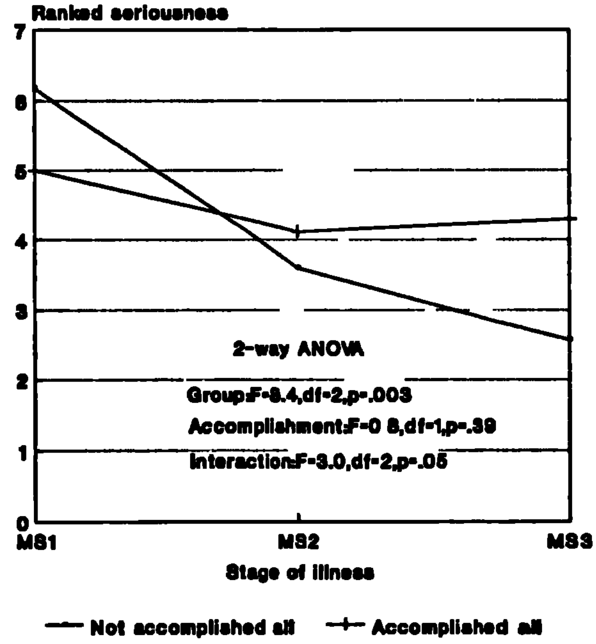
D 14. Interaction between representation emotional wellbeing & stage of illness. ranked seriousness & Happiness



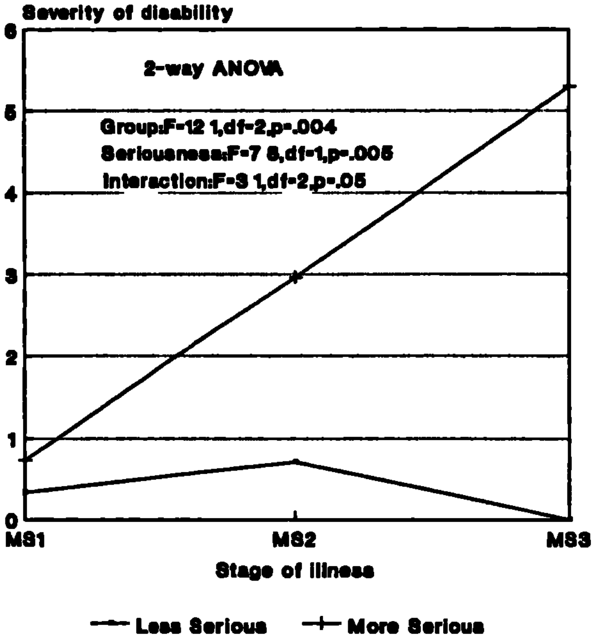
D15. Interaction between representation, emotional wellbeing & stage of illness: ranked seriousness & desire to change



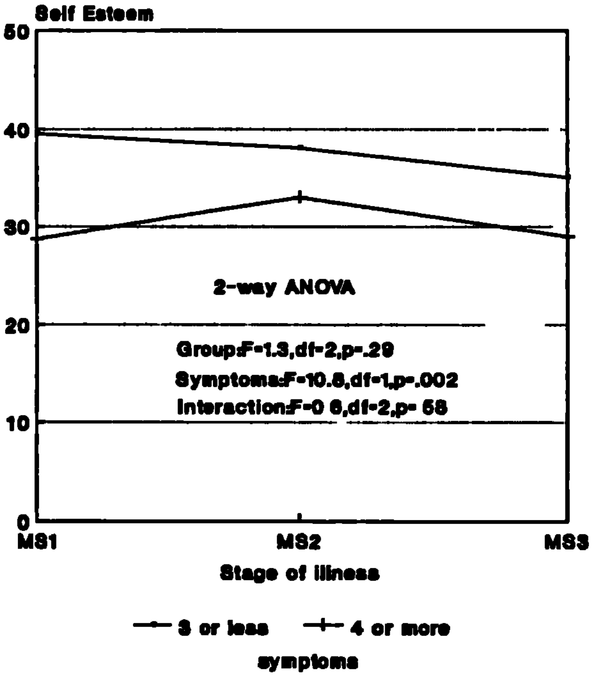
D 16 Interaction between representation emotional wellbeing & stage of illness· ranked seriousness & accomplishment



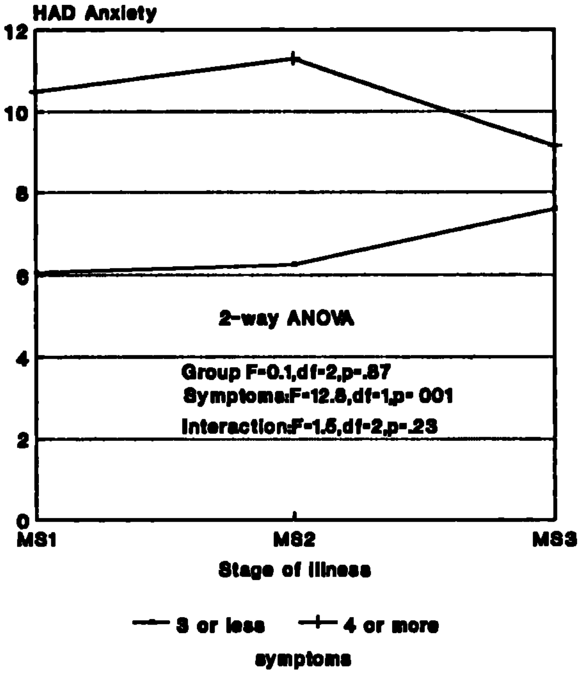
D 17 Interaction between representation
disability & stage of illness
rated seriousness



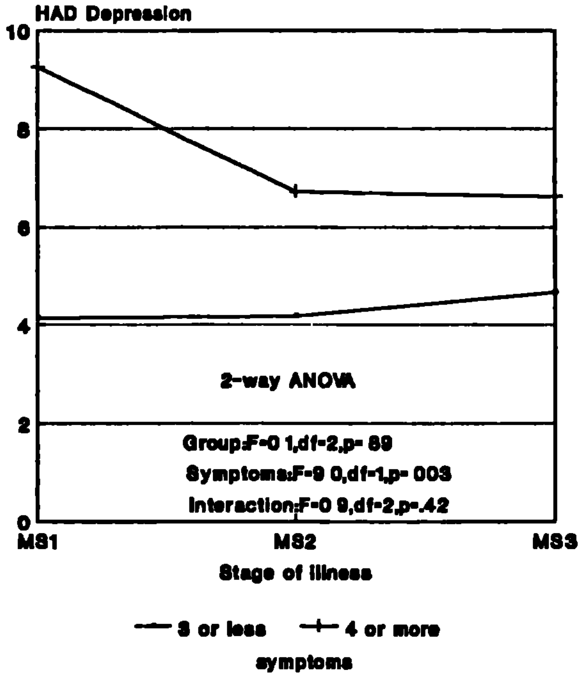
D 18. Relationship between representati
& impact on self. symptoms & Self Esteem



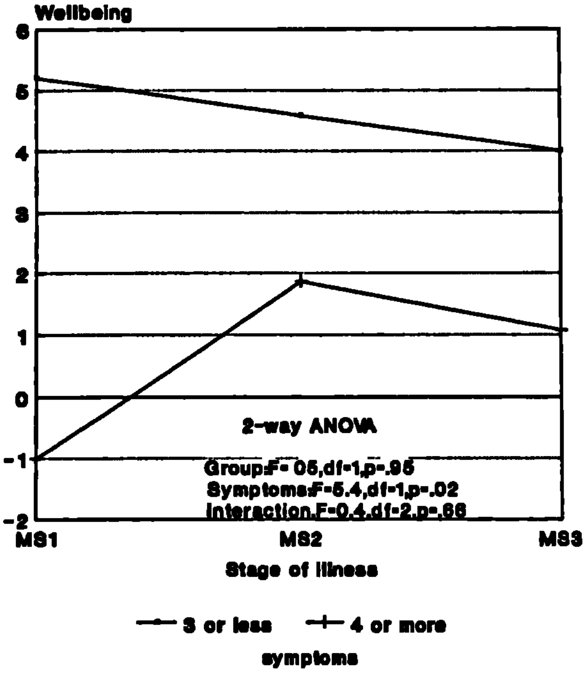
D 19.Relationship between representation
& emotional wellbeing symptoms &
HAD Anxiety



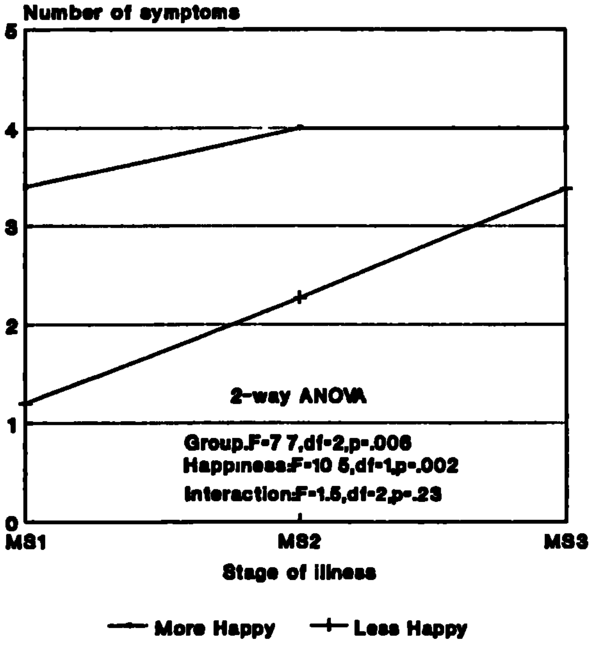
D 20 Relationship between representation
& emotional wellbeing- symptoms &
HAD Depression

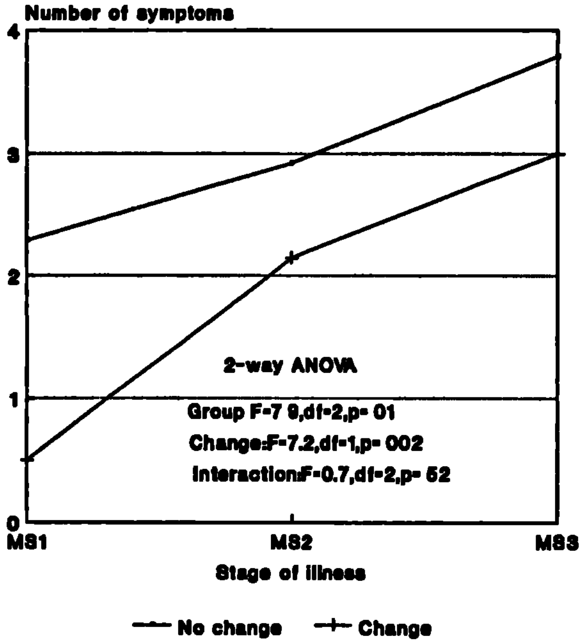


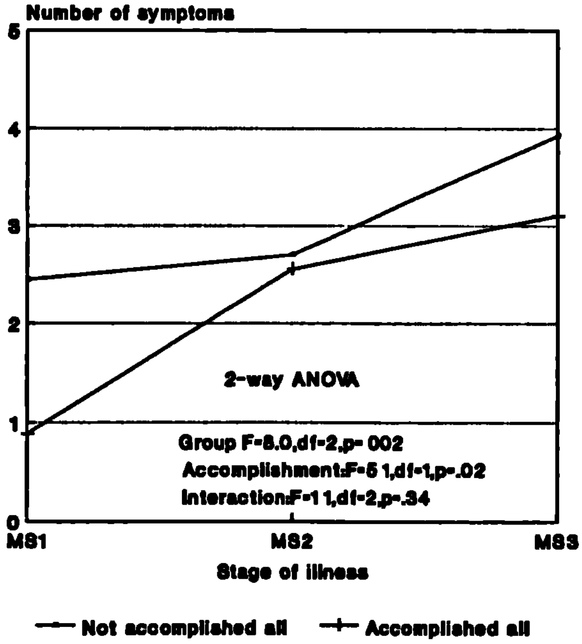
D 21. Relationship between representatio & emotional wellbeing symptoms & Wellbeing



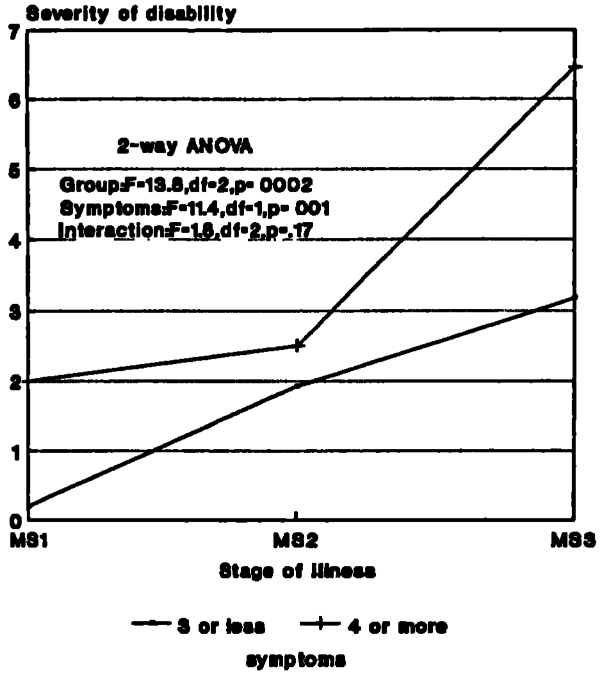
D 22. Relationship between representation & emotional wellbeing symptoms & Happiness



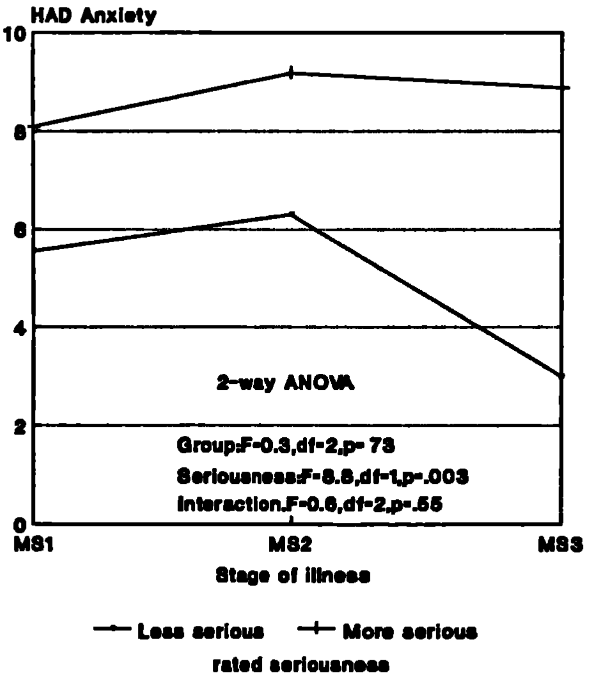

D 23.Relationship between representation & emotional wellbeing. symptoms & desire to change


D 24.Relationship between representation & emotional wellbeing. symptoms & accomplishment

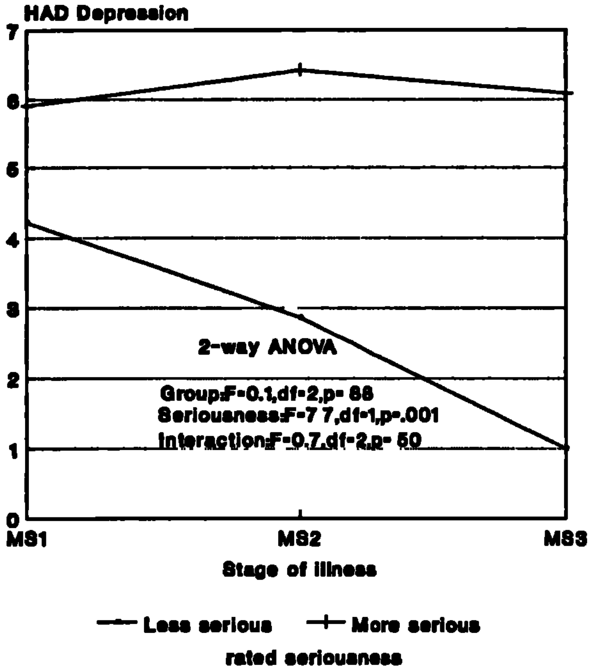
D 25 Relationship between representation & emotional wellbeing symptoms & severity of disability



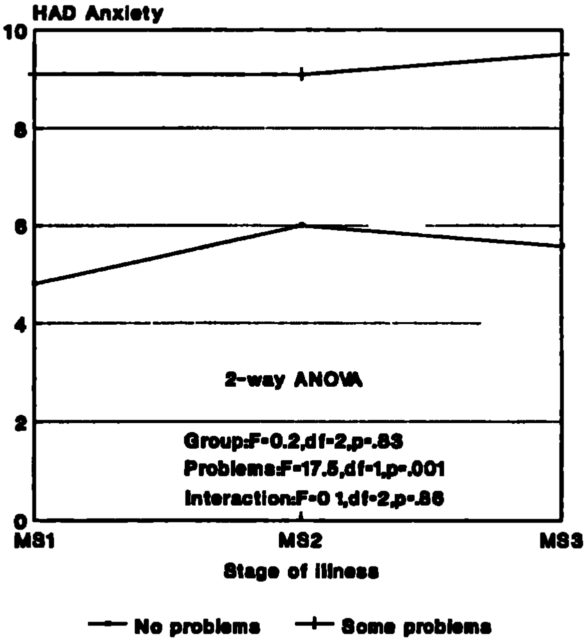
D 26 Relationship between representation & emotional wellbeing rated seriousness & HAD Anxiety



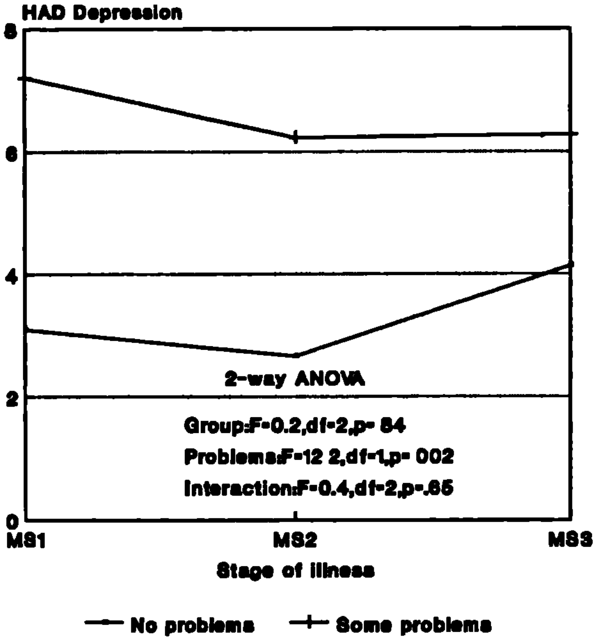
D 27.Relationship between representation & emotional wellbeing rated seriousness & HAD Depression



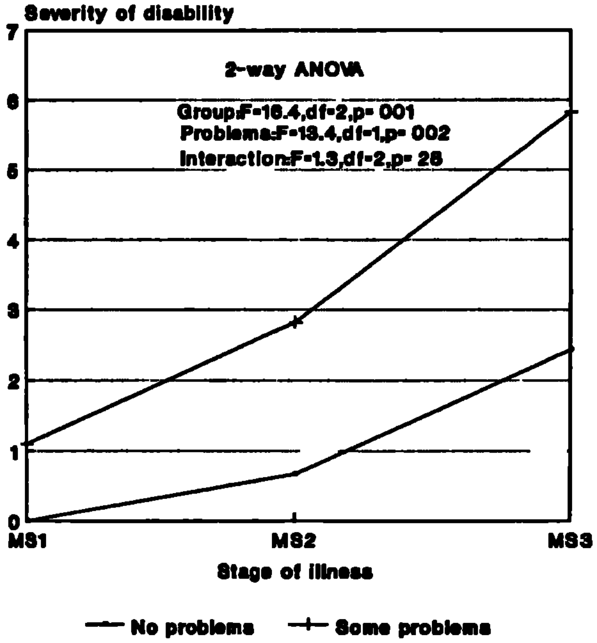
D 28.Relationship between representation & emotional wellbeing problems & difficulties & HAD Anxiety



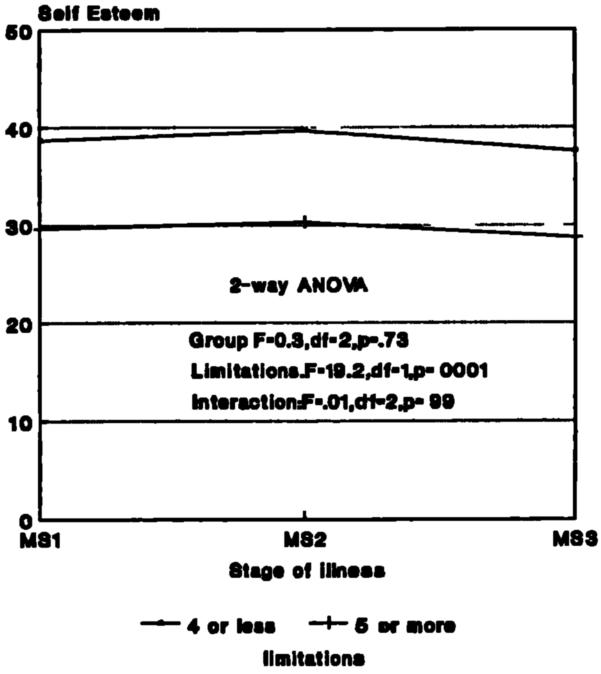
D 29 Relationship between representation & emotional wellbeing- problems & difficulties & HAD Depression



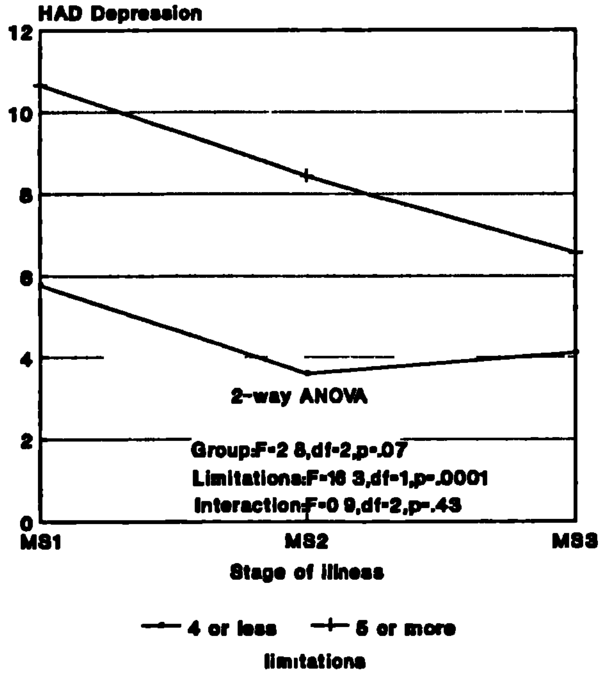
D 30 Relationship between representation & disability problems & difficulties



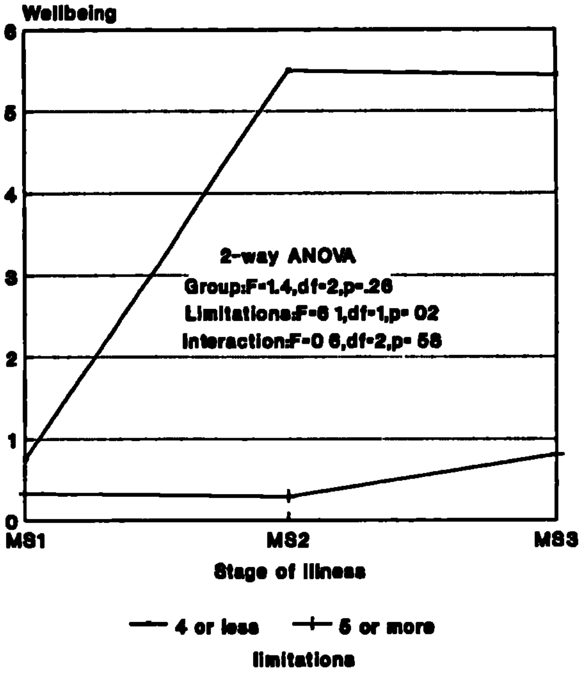
D 31 Relationship between representation & impact on self limitations & Self Esteem



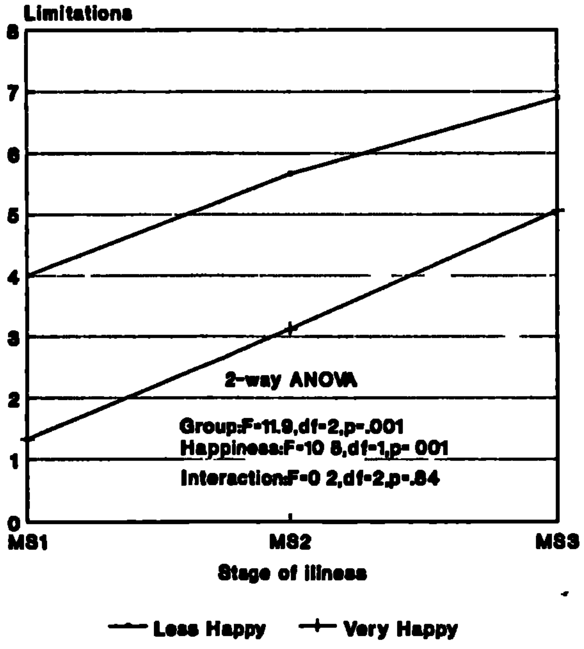
D 32.Relationship between representation & emotional wellbeing- limitations & HAD Depression



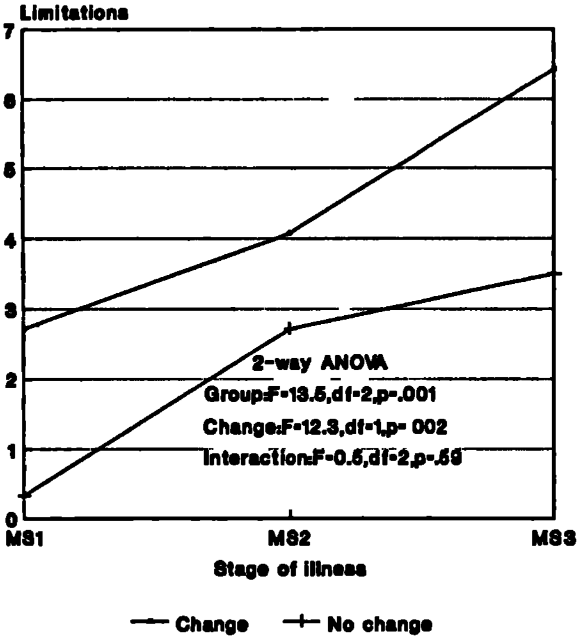
D 33.Relationship between representation & emotional wellbeing limitations & Wellbeing



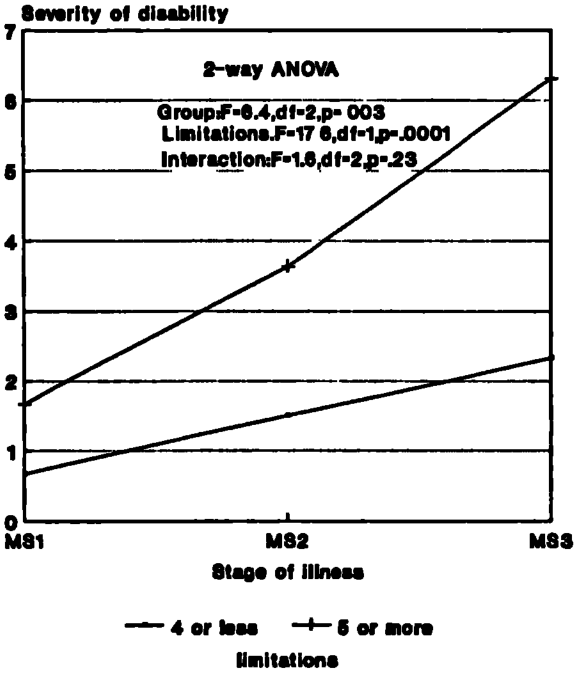
D 34 Relationship between representation & emotional wellbeing limitations & Happiness



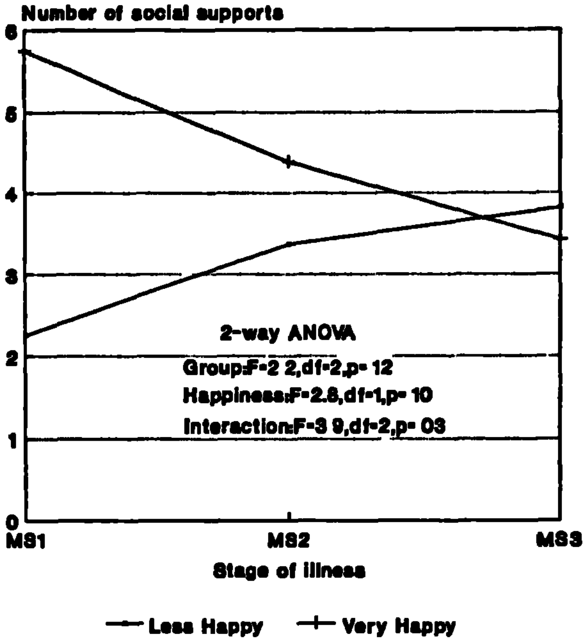
D 35 Relationship between representation & emotional wellbeing: limitations & desire to change



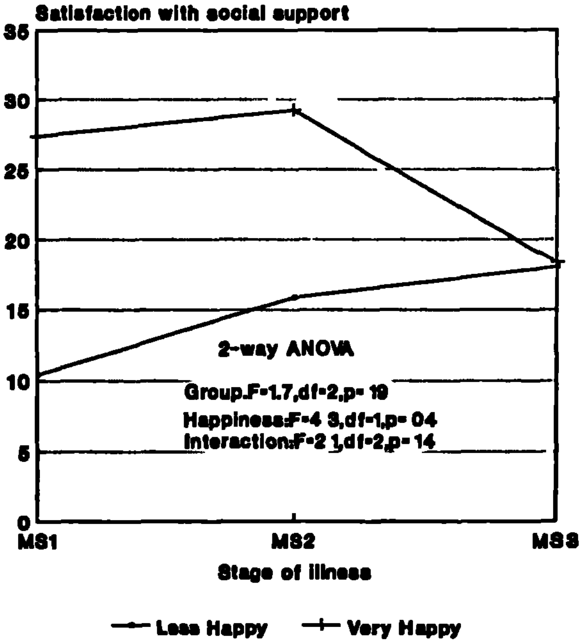
D 36 Relationship between representation & disability : limitations



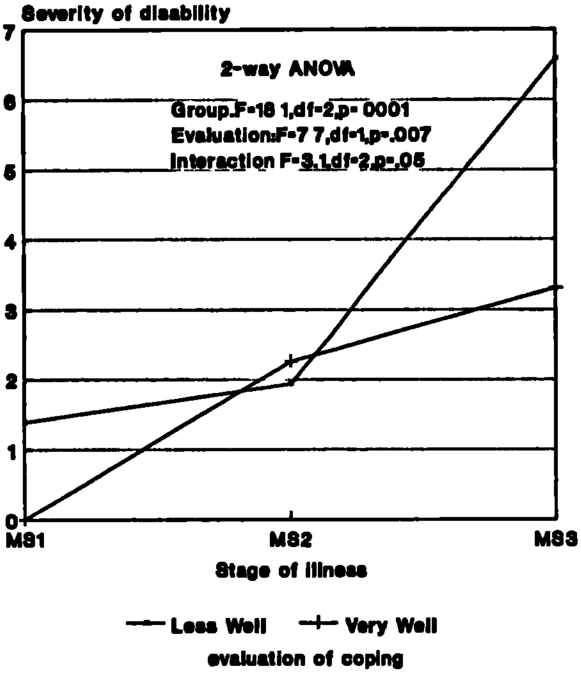
**D 37.Interaction between coping, emotional wellbeing & stage of illness Social Support (N) & Happiness**



**D 38.Relationship between coping & emotional wellbeing Social Support(S) & Happiness**



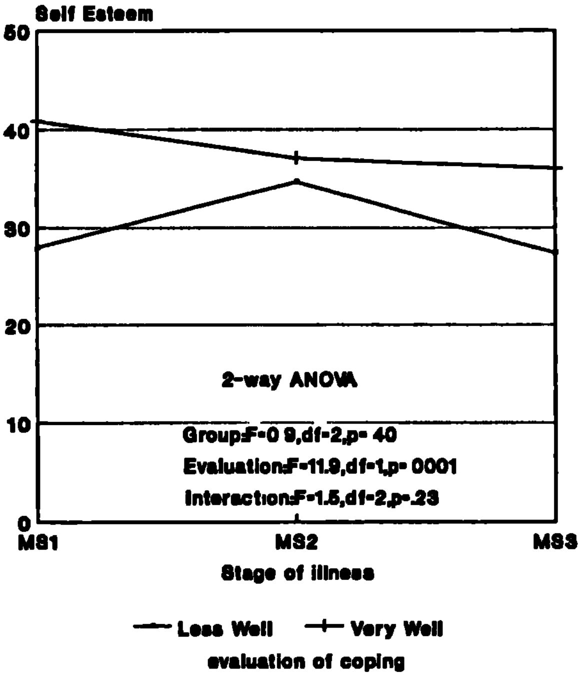
D 39 Interaction between evaluation, disability & stage of illness



2-way ANOVA

Group:F=18 1,df=2,p= 0001
Evaluation:F=7 7,df=1,p=.007
Interaction F=3.1,df=2,p=.05

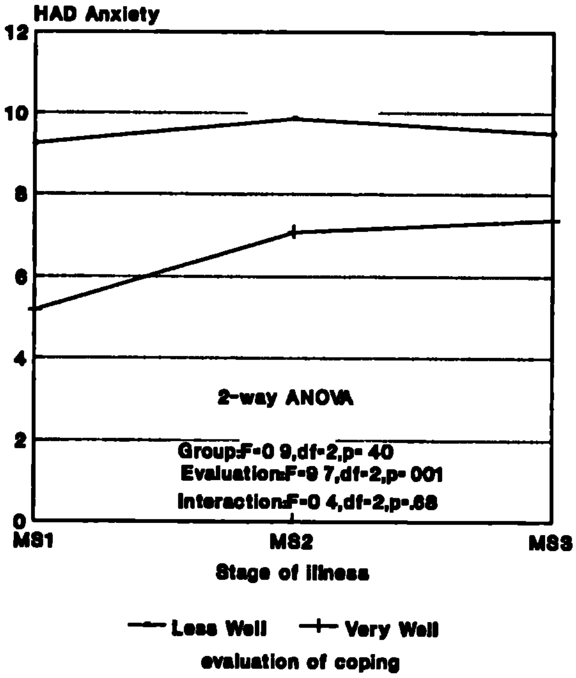
D 40 Relationship between evaluation & impact on self Self Esteem



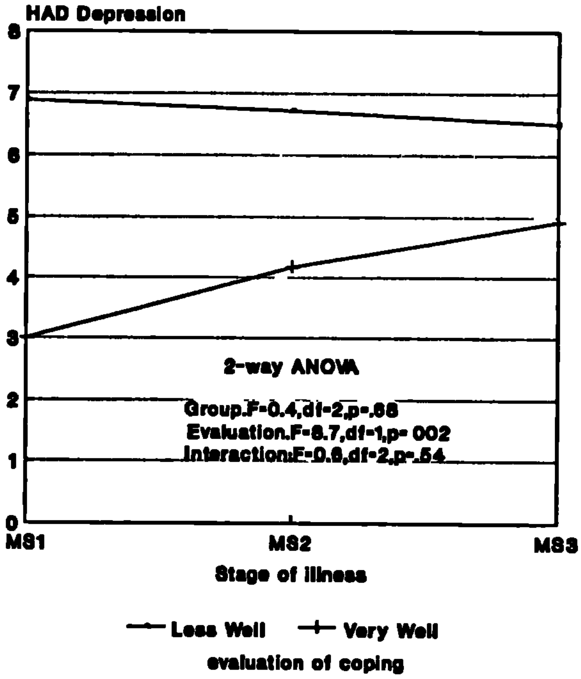
2-way ANOVA

Group:F=0 9,df=2,p= 40
Evaluation:F=11.9,df=1,p= 0001
Interaction:F=1.5,df=2,p=.23

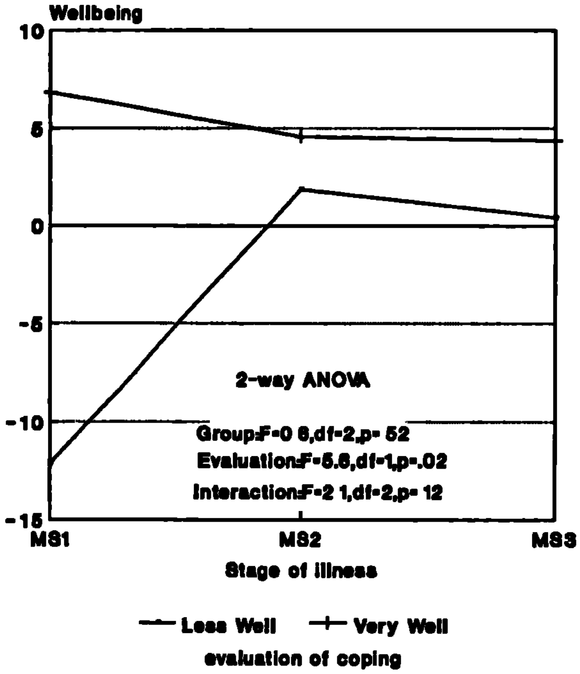
D 41.Relationship between evaluation & emotional wellbeing- HAD Anxiety



D 42 Relationship between evaluation & emotional wellbeing HAD Depression



D 43 Relationship between evaluation & emotional wellbeing- Wellbeing



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