THE ILLNESS REPRESENTATIONS OF MULTIPLE SCLEROSIS AND THEIR RELATIONS TO OUTCOME

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Acknowledgements

Abstract

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Illness representations were assessed in 103 adults with multiple sclerosis (MS) using the widely accepted generic five-component structure of identity, time-line, consequences, cause and cure/controllability. A cross-sectional, correlational design was employed to examine the relationships between the different components of illness representations and the length of time that people had been diagnosed with MS, which demonstrated that no significant associations existed. The inter-relationships among the five components, as well as, the associations between the different components of illness representations and outcome (i.e. illness intrusiveness, physical functioning, depression, anxiety and self-esteem) were also explored. The consequences component showed the most inter-relationships, being positively related to the identity and time-line components and negatively related with the cure/controllability dimension. The identity and consequences were significantly related with each of the areas of outcome, indicating that a strong illness identity and a belief in more serious consequences were associated with greater impairment in each outcome area. A series of stepwise multiple regression analyses were used to determine whether the illness representation components predicted outcome. Overall, illness representations were important predictors of outcome, where the consequences component was the most important predictor of each outcome area. The perception that MS had serious consequences for the lives of individuals with MS therefore associated with higher levels of illness intrusiveness, greater impairment of physical functioning, higher levels of depression and anxiety, and lower self-esteem. These findings provide evidence to suggest that healthcare professionals who have contact with people with MS should have an awareness of the importance of illness representations and their relations to outcome for this illness population. This would therefore allow individuals with beliefs that may result in psychological, social and physical difficulties to be identified.

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1. Introduction

The way in which people think about and make sense of the illnesses they experience has become an increasingly popular area for psychological study over the last two decades. These beliefs or cognitive models are commonly referred to as illness representations and are considered to play a fundamental role in determining an individual's response to an illness. Illness representations may therefore influence the type of coping styles that an individual adopts, their adherence to medical treatment, their uptake and use of services and their interactions with healthcare professionals (Hampson, Glasgow & Toobert, 1990). More recently, research concerning illness representations has considered the ways in which these beliefs determine outcomes, such as, disability, emotional well-being and social functioning. However, despite the interest in lay peoples' perceptions of illness, few studies have investigated multiple sclerosis (MS) within this context. Hence, very little is known about the illness representations held by individuals with MS and how these beliefs may direct their responses to this condition.

The purpose of the following review is to provide an outline of the nature of illness representations and their importance in relation to chronic illnesses, including MS. Firstly, a description of MS and the potential psychosocial effects of this illness will be outlined. This will be followed by an explanation of the self-regulation model (Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984) as this has provided the general framework for much of the research concerning lay peoples' beliefs about their illnesses. The current literature concerning illness representations will then be discussed with a particular emphasis on their structure, development and whether or not they may change over time. In addition, the inter-relationships

between the different components considered to make up individuals' perceptions of illness, as well as, the relationships between illness representations and outcome will be considered.

1.1 Description of multiple sclerosis and its psychosocial effects

MS is a chronic progressive degenerative disease which destroys the covering, or myelin, of the nerve fibres in the central nervous system, resulting in the delayed or blocked transmission of nervous impulses (Marsh, Ellison & Strite, 1983; Devins & Seland, 1987). It is the most common of the neurological diseases among the young adult population, affecting approximately 85,000 people within the UK (The Multiple Sclerosis Society, 1997). Onset is most typically between the ages of 20 and 40 years, where females are more commonly afflicted than males by a ratio of 3:2 (Dupont, 1997).

MS is characterised by a wide range of seemingly unrelated neurological signs and symptoms, which to the individual can be extremely confusing. These include, fatigue, weakness, visual impairments, loss of sensation, difficulties with co-ordination, bladder disturbances, spasticity, sexual dysfunction, tingling or numbness of limbs and cognitive changes (Dupont, 1997). The combination of these symptoms can vary greatly from person to person, and even in the same person at different times. The course of MS is also extremely variable and unpredictable, with the majority of people experiencing the relapse-remitting type of MS, which includes episodes of symptom exacerbations (relapses) and remissions. Some individuals, however, experience the chronic-progressive type, where there is a gradual worsening of symptoms and a slow and steady decline in function from the

onset of the illness. Nevertheless, despite the general pattern of their MS, individuals ultimately experience increasing deterioration and disability over time. Although MS in itself does not usually cause death, life expectancy may be reduced by the occurrence of secondary infections, usually of the respiratory and urinary systems (Devins & Seland, 1987).

Another important feature of MS is that it is typically extremely difficult for physicians to diagnose. As yet there is no definitive diagnostic test for MS and therefore individuals often undergo many medical investigations and tests for other serious diseases before a diagnosis of MS can be determined. Consequently, it is not uncommon for people to experience symptoms for many years before being diagnosed with this illness. The diagnosis of MS is further complicated by the multitude of different symptoms (many of which cannot be directly observed), the transient nature of early symptoms and its variable course (Devins & Seland, 1987). There is still much debate about the aetiology of MS with various explanations proposed, including a genetic susceptibility to MS and a virus or bacterial infection (The Multiple Sclerosis Society, 1997). In addition, there is currently no known cure and although individuals often receive treatments to help manage some of their symptoms, limited symptomatic relief is generally achieved.

Due to the many important features of MS, that is, a diversity of neurological symptoms, the variable and unpredictable course, diagnostic difficulties, unknown aetiology and lack of specific treatments, it has often been suggested that this illness will result in a wide range of emotional, behavioural and social consequences. As a result, individuals with MS are considered extremely likely to encounter a range of

psychosocial challenges and adaptive demands (Devins & Seland, 1987). However, despite the general acceptance that MS has the potential to produce serious difficulties for those who experience it, there is conflicting empirical evidence concerning the exact nature of its psychosocial impact.

The occurrence of depression in people with MS has received a great deal of attention and is frequently described as a common emotional response within this illness population. Reported prevalence figures for clinical depression in those experiencing MS range from 27 to 54 per cent (Dupont, 1997), indicating higher rates than for the general population. In a study by Hickey & Greene (1989), depression scores for people with MS on The Centre for Epidemiological Studies Depression Scale (CES-D) were found to be significantly higher than those previously reported for the general population, although, not as great as an in-patient psychiatric sample. However, contrary to these findings, some studies have failed to find evidence to support an increase in depression (Murray, 1995).

One of the main difficulties with identifying depression within this illness population is that some of the symptoms of MS, for example, concentration and memory difficulties, and fatigue are also characteristic of a depressive illness (Murray, 1995). Hence, suggesting that caution must be taken when interpreting such symptoms to avoid the possibility of misdiagnosis. However, according to Dupont (1997) qualitative differences exist between the symptoms of depression experienced by people with MS and the general population. Depression in MS tends to be characterised by worry, irritability, anger and discouragement, rather than self-criticism, withdrawal and loss of interest. Whilst there is the possibility that some

people with MS may be wrongly diagnosed as experiencing a depressive illness, it has also been proposed that depression among this illness population is actually frequently underdiagnosed and undertreated, and therefore may be more common than the research evidence suggests (White, Catanzaro & Kraft, 1993).

Although much of the research concerning depression in people with MS has focused upon it as an emotional response to the experience of this illness, two alternative explanations have also been proposed by other studies. These are: a) that depression in MS may be a direct result of the underlying neurological disease process itself or b) that it is an important contributing factor to the onset and progression of MS (Devins & Seland, 1997). However, as yet, there is no conclusive evidence to support either of these notions and therefore the causes and role of depression in people with MS remains open to debate.

Anxiety has also been considered a common emotional response to the experience of MS. However, in accordance with the studies concerning depression, there is also conflicting empirical evidence regarding whether there is an increase in anxiety disorders within this illness population (Marsh et al, 1983). The effect of MS on an individual's self concept is a further area where no firm conclusions can be made. Some studies have reported relatively high levels of self-esteem among people with this illness (Barnwell & Kavanagh, 1997; Eklund & MacDonald, 1991). Although, Brooks & Matson (1982) found that when compared to a non-MS sample, individuals with MS demonstrated a significantly reduced self-concept. However, they also proposed that people with this illness tend to gain an improved self-

concept over time, where those who had experienced MS for over 20 years reported the most positive changes in their perceptions of themselves.

In addition to the psychological consequences of MS, its effects on an individual's general lifestyle are also important. Due to the particular nature of this illness, for example, the wide range of symptoms that can be produced and its unpredictable course, MS can be extremely disabling. As a result, it is likely to disrupt or even prevent an individual from participating in activities and interests which they once valued and enjoyed. Such disruptions have been referred to as illness intrusiveness, which is defined as "illness-induced life-style disruptions that interfere with continued involvements in valued activities and interests" (Devins, Edworthy, Leendert, Mandin, Seland & Klein, 1993a, p.401).

Research concerning the illness intrusiveness of several chronic illnesses, namely, end-stage renal disease (ESRD), rheumatoid arthritis (RA) and MS has consistently found evidence to support the two main assumptions of this construct proposed by Devins, Edworthy, Guthrie & Martin (1992). The first assumption states that illness intrusiveness derives from illness-related characteristics, such as anatomical changes (e.g. demyelination of the nerve fibres), functional deficits (e.g. effects on motor function) and physical disabilities (difficulties with balance and co-ordination). Secondly, illness intrusiveness is hypothesised to have an adverse affect on psychosocial well-being and contribute to increased emotional distress, which occurs through two complementary mechanisms. Such that, an individual experiences: a) a decrease in the availability of positive and rewarding experiences due to their reduced participation in activities and interests and b) diminished

feelings of personal control over meaningful facets of their lives. Consequently, illness intrusiveness mediates between the factors associated with an illness and psychosocial well-being and emotional distress (Devins, 1994).

Illness intrusiveness and its related effects have been found to be particularly evident in MS. In a study conducted by Devins, Edworthy, Seland, Klein, Leendert & Mandin (1993b) evidence was provided to suggest that individuals experiencing MS reported more disruptions to their lifestyles as a result of their illness than those with ESRD and RA. The findings also showed that the levels of intrusiveness of MS varied across the thirteen life domains studied, although it was particularly intrusive into three of the domains, that is health, work and active recreation. Devins et al (1993b) proposed that this differential pattern of illness intrusiveness across life domains for people with MS is most likely to be attributable to the distinct signs and symptoms which are characteristic of this illness. It has also been found that higher levels of illness intrusiveness tends to be associated with the chronic-progressive type of MS, rather than the relapse-remitting course, greater severity of MS and greater physical disability (Devins, Seland, Klein, Edworthy, Saary, 1993c). Although illness-related factors have been found to be an important determinant of the level of illness intrusiveness an individual with MS experiences, as yet no studies have considered the role that illness representations may play in this construct. It is therefore not known how individuals' beliefs about their illness may contribute to its intrusiveness.

1.2 The self-regulation model

The self-regulation model (which is also referred to interchangeably as an information-processing model, a parallel-processing model and a common-sense model of illness representations) has been used as the basis for the majority of the research conducted into illness representations. It was developed following the early work of Leventhal and his colleagues which examined the use of fear communications to facilitate change in peoples' attitudes and behaviours for dealing with health threats (Leventhal et al, 1980; Leventhal et al, 1984). The basic premise of this model is that the way in which individuals respond to a particular illness is directed by their perceptions of that illness. Hence, the central feature of the self-regulation model is the concept of illness representations, which are defined as patients' own implicit, common-sense beliefs about their illness (Leventhal et al, 1980).
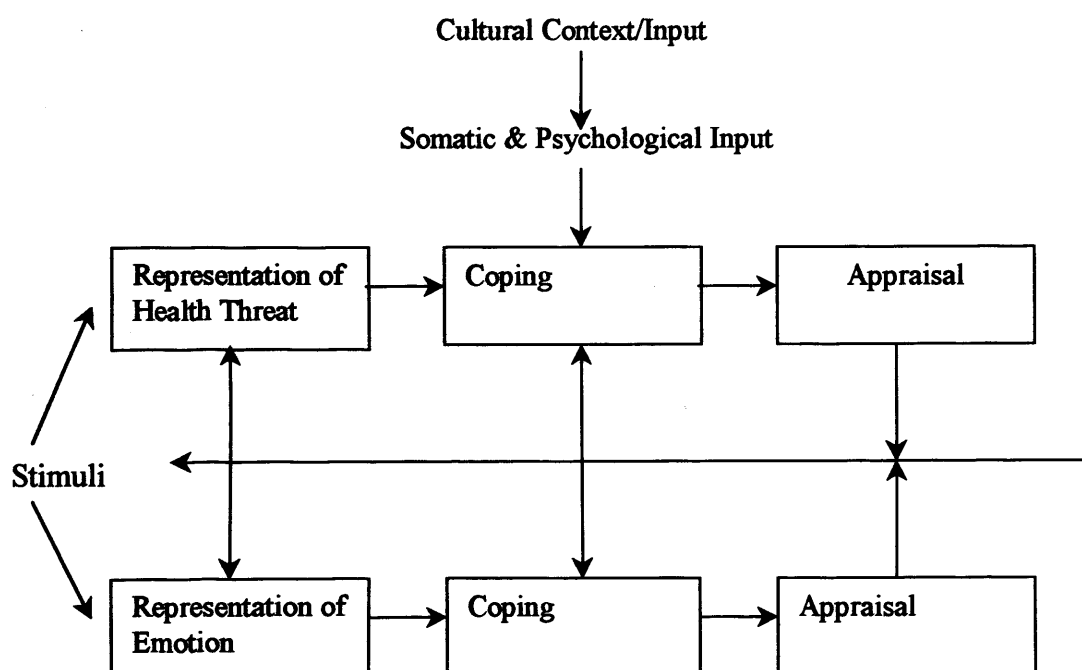
Figure 1. The self-regulation model (From: Diefenbach & Leventhal, 1996, p.21)

There are four basic assumptions underlying the self-regulation model (Figure 1). The first assumption is that individuals are active problem solvers, such that, they actively construct a representation of their illness which serves to guide their illness behaviour. Individuals are therefore not simply passive recipients of medical advice, but continually endeavour to make their own sense of their illness.

The second assumption is that the model consists of two parallel pathways. Hence, once faced with an illness, the individual will not only construct an 'objective' representation of that health threat and a plan for coping with that threat, but also produce an emotional response to the illness and a plan for managing the emotions. These two pathways interact throughout the illness experience which is referred to as 'parallel processing'.

The third assumption of the self-regulation model is that it consists of three processing stages which are recursive: (i) the formation of the illness representation or beliefs about the illness and the accompanying emotions (representation stage); (ii) the development and execution of plans for coping with both the illness and the emotions (coping stage); and (iii) the appraisal of the coping response, which feeds back into the prior stages and hence, can alter the individual's coping response or the representation of the illness (appraisal stage) (Leventhal et al, 1984; Moss-Morris & Petrie, 1994).

The fourth and final assumption of the model is that it is hierarchically organised, where at each stage (i.e. representation, coping and appraisal) it operates at both concrete and abstract levels. Hence, illness experiences consist of both concrete

features (e.g. chest pain) and abstract features (e.g. the idea that one has had a heart attack). Due to the hierarchical nature of the model, discrepancies can occur between the concrete and abstract levels, where what the individual thinks and feels is inconsistent with what is actually taking place. Leventhal et al (1984) gave the example of chemotherapy treatment for a tumour to illustrate this. Such that, the patient may feel worse following treatment (e.g. nauseous and tired), but have experienced a significant improvement in their condition (e.g. a reduction in the size of the tumour). Discrepancies of this kind can therefore produce intense emotional reactions or difficulties with coping.

The focus for the remainder of this review will be the first stage of the self-regulation model, that is, the representation of illness. To illustrate the importance of individuals' illness perceptions in guiding their response to an illness, some reference will also be made to how these beliefs may influence their coping behaviours. More emphasis, however, is placed on the relationships between illness representations and outcome.

1.3 The structure of illness representations

The term illness representations has been referred to in the literature in a variety ways. Other expressions which have been used include: illness perceptions, cognitive models, common-sense or lay representations, implicit models or beliefs and personal models of illness. However, despite the many different terminologies, each describe the same concept, that is, the models or beliefs that an individual holds of the illnesses they experience.

The main focus for the initial research into illness representations was concerned with the identification of the structure of these representations. Particularly, whether a generic cognitive structure existed which could be applied to different illnesses and different populations. Early work in this area undertaken by Leventhal and his colleagues, which included patients with hypertension and cancer patients undergoing chemotherapy identified that the way in which people think about their illnesses consisted of four basic components (Leventhal et al, 1980; Leventhal et al, 1984; Meyer, Leventhal & Gutmann, 1985). These components were elicited through the use of structured interviews consisting of a series of open-ended questions and were: **identity** (the label attributed to the illness and the symptoms associated with it), **time-line** (the expected course and duration of the illness), **consequences** (the short and long-term effects of the illness, and its physical, social, economic and emotional effects) and **cause** (the factors considered to have led to the development and onset of the illness).

Further evidence for these four components was provided by later studies concerning common, everyday illnesses, such as the flu or a cold (Lau & Hartman, 1983; Lau, Bernard & Hartman, 1989). These studies included the use of interviews where a group of students were asked to identify the last time that they were unwell and to answer a series of open-ended questions about that illness experience. As well as confirming the existence of the four previously identified components of illness representations, an additional dimension was also proposed, that is, cure/controllability. This refers to the beliefs people have about what they themselves or medical staff can do to bring about recovery or to control the course of the illness (Scharloo & Kaptein, 1998).

As the work of Leventhal and his colleagues had primarily included individuals with serious and life-long illnesses from which many would not have recovered, Lau & Hartman (1983) and Lau et al (1989) proposed that they had overlooked the possibility of a cure/controllability component. Consequently, within their studies, Lau and his colleagues explicitly asked their respondents to provide their perceptions of how they had recovered from their illnesses in an attempt to elicit details of this particular factor. However, due to the aims and design of their studies, it is therefore possible that this attribute only became apparent because they specifically set out to investigate it.

A further study that has verified the existence of the five components of illness representations is that of Bishop, Briede, Cavazos, Grotzinger & McMahon (1987) who conducted an experiment with a group of students on disease prototypes. Their participants were presented with sets of physical symptoms which they had to imagine were being experienced by friends. They were then required to add any other details which they felt may be associated with the persons' symptom experience. The general findings of this study showed that approximately 76 per cent of the respondents' responses could be coded into the five illness representation dimensions identified by previous researchers (i.e. identity, time-line, consequences, cause and cure/controllability). Thus, providing further evidence to support this particular structure of lay persons' illness cognitions.

Despite the general agreement that illness representations consist of five factors, some variations to this structure have been suggested. For example, Turk, Rudy & Salovey (1986) reported a factor analytic study of the Implicit Models of Illness

Questionnaire (IMIQ), a 38-item questionnaire they developed which attempted to operationalise the five constructs of illness representations already mentioned. On the basis of their results, Turk et al (1986) proposed a four-factor structure of illness representations, which they labelled seriousness, personal responsibility, controllability and changeability. The IMIQ was further factor analysed in a separate study by Schiaffino & Cea (1995). However, they identified a different four-factor structure of illness cognitions to that of Turk et al (1986) which consisted of curability, personal responsibility, symptom variability and serious consequences.

Although these two alternative structures of illness representations have been reported, it is apparent that the components considered to make up the four-factor structures are in fact, very similar to the original five attributes. Lau et al (1989) reported that the differences between the structure identified by Turk et al (1986) and what other researchers have found may be more apparent than real and can be accounted for by methodological issues. Hence, Turk et al's 'controllability' factor could be termed consequences, the 'personal responsibility' factor incorporates cause and cure and the 'changeability' factor appears to refer to the time-line. In addition, Schiaffino & Cea (1995) acknowledged that the components they proposed also resembled those which made up the original five-factor structure of illness representations.

On the basis of the research evidence, it is therefore apparent that despite the use of various methodologies and illness groups, and the identification of possible alternative structures, there is sufficient support for a generic five-factor structure of

illness cognitions. Hence, it is now widely accepted that illness representations are organised along the five main dimensions of identity, time-line, consequences, cause and cure/controllability. Each of these five components will now be discussed in further detail.

1.3.1 Identity

The identity component consists of both concrete symptoms, for example, nausea or pain and abstract labels, such as multiple sclerosis or cancer. In order for individuals to construct a representation of their illness the integration of these two elements is necessary. This process can be initiated at either level, where an individual may begin this integration with an abstract label, for example, following a routine health check where they had not suspected that anything was wrong or with concrete symptoms which may or may not be familiar to them.

In their study of peoples' compliance with hypertension treatment, Leventhal and his colleagues provided evidence to support this process, where they identified a symmetry of relationship between symptoms and labels. They reported that when symptoms are experienced, an individual will seek a diagnostic label and once presented with a label they will endeavour to find symptoms that are consistent with it. This symmetry was demonstrated for many of the people with hypertension included within their studies, who despite agreeing with the general medical opinion that this illness is asymptomatic, reported using symptoms, such as headaches and dizziness to monitor changes in their blood pressure (Leventhal et al, 1980; Leventhal et al, 1984; Meyer et al, 1985).

Concrete symptoms and abstract labels are thought to be important in guiding peoples' illness behaviour. However, on the basis of the findings reported by Leventhal and his colleagues, it would seem that symptoms, rather than labels are the main determinant of the particular action a person chooses to take in an attempt to manage their illness. Generally, it is recognised that many people with a diagnosis of hypertension do not adequately control their blood pressure and hence, simply knowing they have this illness is not sufficient for directing their behaviour. Also, Leventhal and his colleagues found that this illness group had a tendency to take their medication according to symptoms and not as prescribed by their physician. It would therefore seem that many individuals with hypertension tend to treat symptoms and not abstract disease labels (Leventhal et al, 1984).

The importance of symptoms in the management of illness has also been observed in people with diabetes. Hampson (1998) reports that the majority of individuals with diabetes believe that they can identify the symptoms of abnormal blood glucose levels and it is their experience of these symptoms which guides their self-management behaviour, for example, eating a snack. However, in accordance with hypertension, the use of symptoms to monitor this illness is not always appropriate, particularly, as the relation between symptom experience and actual blood glucose levels is largely inaccurate.

1.3.2 Time-line

Individuals experiencing an illness tend to conceptualise the time-line component (i.e. its expected duration and course) in terms of one of three main models. These are acute, where the illness is symptomatic but curable; chronic, where the illness is

a stable part of the self regardless of its symptomatic nature, and cyclical, where the symptoms of the illness are recurrent (Leventhal et al, 1984; Meyer et al, 1985). These temporal models are considered to evolve over time. Leventhal et al (1984) found for people with hypertension that the longer they had received treatment, then the more likely they were to shift from an acute to a chronic representation of their illness. They also reported that the time-line models had an influence on the length of time individuals remained in treatment. Such that, those who were new to treatment and who viewed their illness as acute were more likely to discontinue treatment within six months than those who held a chronic illness model of hypertension. As noted by Moss-Morris & Petrie (1994), the time-line component is an important factor in an individual's adjustment to a chronic and life-long illness. Due to early experiences, people often assume that illnesses can be cured and hence, difficulties can arise when they are faced with an illness from which they will not recover.

1.3.3 Consequences

The consequences of an illness refer to its perceived severity in terms of the effects that it has on an individual's life (Moss-Morris & Petrie, 1994). These effects can be either short or long-term and include physical, social, economic and emotional consequences. An illness therefore has the potential to interfere with all aspects of an individual's life. Fewer findings are reported concerning the perceived consequences of an illness and their direct effects on coping behaviour. However, some evidence has been provided to suggest that the consequences component is an important feature of peoples' representations of their illness. For example, the perceived consequences of an illness have been found to influence the use of

medical services, quality of life and performance of self-management activities in people with osteoarthritis (Hampson, Glasgow & Zeiss, 1994). In addition, Prohaska, Keller, Leventhal & Leventhal (1987) reported that beliefs about the consequences of an illness tend to influence coping more than the time-line and identity components.

1.3.4 Cause

The beliefs that people have about the possible causes of illness have been classified into three main categories (Moss-Morris & Petrie, 1994). These include internal, external and 'chance' factors. Individuals may therefore believe that the illness they are experiencing is the result of external factors over which they have little control, for example, a germ or pollution of the environment. Conversely, they may hold the belief that they are personally responsible for their illness and consider factors, such as, poor eating habits and their state of mind to be the primary cause. In addition, individuals may perceive 'chance' factors, including genetic or hereditary causes as the most likely explanation.

As noted by Petrie & Weinman (1998), when confronted with an unforeseen negative event, such as the onset of a severe illness, individuals have a natural tendency to find a cause for it. The identification of causal factors is an important process in the construction of an individual's representation of their illness. Whereby, the searching for causes not only assists the individual in making sense of their illness experience, but also provides a framework for guiding their choice of strategies for managing that illness. Consequently, having some idea of the reason

for becoming ill helps make the experience less anxiety provoking and the future more predictable and stable for the individual.

In their study, Meyer et al (1985) found that many of their participants with hypertension held some idea about what had caused their condition. The most frequently stated causes were diet, home or job situation and heredity. Those individuals who were new to treatment or had returned to receiving treatment tended to attribute the cause of their illness to personal factors (i.e. diet and their home or job situation) and were more likely to report not knowing the cause of their raised blood pressure. Those in continuing treatment were more likely to believe that their hypertension was hereditary and least likely to say they did not know what had caused it. It would therefore seem that those individuals who received treatment for long and continuous periods of time were more likely to believe that they had had no influence over what had caused their illness, such that, their genetic make-up was to blame. Whereas, individuals new and returning to treatment tended to feel that life-style factors were responsible for its development. Consequently, beliefs about the cause of an illness would appear to be an important factor influencing an individual's decision whether or not to remain in treatment.

Similar causal factors have been reported by people recovering from myocardial infarction (MI). In a study conducted by Petrie & Weinman (1998) stress was the most commonly reported cause for having an MI. Causal attributions relating to lifestyle factors (e.g. eating fatty foods, being overweight, high cholesterol levels and lack of exercise) and heredity were also considered important. These lifestyle causal factors were found to influence future changes in health behaviour. Holding

the beliefs that the MI was caused by a faulty lifestyle was related to improvements in diet and increased participation in exercise. Whereas, individuals who attributed the cause to stress or believed it was hereditary were less likely to make changes to their lifestyle. The belief that the MI was the result of internal factors (e.g. eating a poor diet and taking little exercise) was therefore more important in producing change than believing that external factors (i.e. stress and hereditary) were to blame. Hence, a feeling of greater control over the cause of MI was an important factor in determining whether or not individuals actively attempted to manage their illness.

1.3.5 Cure/Controllability

The cure/controllability component includes peoples' perceptions of the possibility of recovery, as well as, the control that they themselves and providers of medical care have over the course and progression of their illness. For common and acute illnesses it is usually only a matter of time before recovery takes place and hence, beliefs concerning a cure are appropriate. However, for illnesses of a chronic nature, for example, multiple sclerosis there are no known cures and therefore the emphasis is on the management or control of the illness.

The controllability component of illness representations has been studied in relation to the concepts of health locus of control and self-efficacy. Health locus of control refers to beliefs about whether or not an illness is considered to be under an individual's personal control and is commonly classified into internal and external locus of control. Self-efficacy is concerned with the beliefs that an individual has about their ability to perform a specific treatment regime or self-management task (Hampson, 1998). Both concepts have been found to be important factors for

guiding the action that individuals take to cope with their illness, where people with a strong sense of control over their illness tend to engage in more self-management behaviours. (Moss-Morris & Petrie, 1994). Evidence to support this has been provided by studies of people with diabetes, where it has been found that individuals who had stronger perceived control over their illness and greater self-efficacy were more likely to engage in appropriate illness behaviours (e.g. eating an appropriate diet and taking exercise) and demonstrate better glycaemic control (Kavanagh, Gooley & Wilson, 1993; Bradley, Gamsu, Moses, Knight, Boulton, Drury & Ward, 1987).

1.4 The development of illness representations

According to Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille (1998) illness representations do not develop in a social vacuum. Cultural, institutional, social and personal factors are considered to influence this process and hence, it is inter-personal, as well as intra-personal. On the basis of this, Leventhal et al (1984) have identified three main sources of information which are used by the individual to construct a representation of the illness they are experiencing.

The first source is concerned with the general illness information that is available and accepted within an individual's culture. Such cultural influences can include, the way in which healthcare services are organised, specific cultural beliefs and the language used to describe particular illnesses. In western societies, for example, the healthcare system is designed according to an acute model of disease, where the experience of bodily symptoms automatically creates an expectation of diagnosis,

treatment and cure. Also, the language used to describe an illness may suggest specific meanings for that illness. For example, the diagnostic label, hypertension is typically viewed by lay people as the result of stress, which is likely to reflect confusion about the meaning of this word, namely, that hyper-activity and tension are the main symptoms and causes (Leventhal et al, 1998).

The second source of information is social communication or the information obtained from direct contact with others. The content of an individual's illness representations may therefore be influenced by information gained through the media, from the sharing of information with people within the individual's social network (e.g. family members and friends) and from contact with healthcare providers (Leventhal et al, 1980).

The final source of information that is considered to influence the content of illness representations is the individual's personal experiences with illness. Both past and present illness experiences are important. The role of past encounters with illnesses in the development of illness perceptions has been studied by Lau et al (1983). They proposed that people develop 'common illness schemata' as a result of repeated experiences with minor, everyday illnesses, and it is with these that individuals attempt to fit a current illness. However, inconsistencies may arise and as a result, the individual may realise that they are likely to have a new and more serious illness for which a different schema needs to be developed. This explanation is similar to that of Bishop et al (1987) who referred to the use of illness prototypes or templates against which people match symptom experiences. Such that, the closer the symptoms an individual is experiencing correspond with the symptoms making up

the person's prototype for a particular disease, the more likely they are to interpret the symptoms as indicating that disease. Hence, it is apparent that individuals' past experience of illness can guide their illness representations for future illnesses through the use of illness schemata or prototypes.

1.5 Changes in illness representations over time

The self-regulation model proposes that the content of an individual's illness representations has the potential to change over time and hence, can be considered 'dynamic'. As noted by Leventhal, Diefenbach & Leventhal (1992), illness episodes constantly change and therefore concomitant changes in illness representations occur in response to variations in symptom experience, the acquisition of new information, or as a result of negative coping appraisals. The notion that the way in which an individual perceives their illness can change over time is particularly relevant to the experience of chronic illness. Such that, as recovery from these illnesses is often unlikely, illness representations will typically change with disease progression. For example, following diagnosis, individuals with mild symptoms or symptoms that respond to medication may consider their chronic illness to be acute. It is only when the symptoms reappear or are so severe that they no longer respond to medication that the individual might begin to realise that their illness is in fact, chronic in nature (Schiaffino, Shawaryn & Blum, 1998). Consequently, illnesses that are unstable and unpredictable in their symptoms and course are especially likely to result in repeated modifications to an individual's perception of their illness (Weinman, Petrie, Moss-Morris & Horne, 1996).

Although there is a general acceptance that illness representations can change and develop over time, there is little empirical evidence available to illustrate the way in which this process takes place (Petrie & Weinman, 1998). The dearth of research in this area is most likely to be due to the inherent difficulties with examining illness representations from the time of onset of an illness. For many illnesses, it is not possible to identify a definitive onset and therefore a measure of an individual's perception of their illness at the time it is first experienced can not be established. Consequently, difficulties arise when attempting to make meaningful and accurate inferences about how an individual's illness representations change over the course of their illness.

A study conducted by Petrie & Weinman (1998) has been one attempt to investigate the way in which illness perceptions change over time. They used a sample of people who had experienced a myocardial infarction (MI), which is a particularly useful illness to use for this type of investigation as it has a definitive onset and hence, illness representations can be evaluated from the outset. A repeated design was employed for this study, where individuals' perceptions of their MI were assessed on four occasions, shortly after the onset of MI and then at three, six, and twelve month intervals. The illness representation components were compared over the four time periods which provided evidence to suggest that two dimensions remained stable and two changed over time. Although the perceived consequences and identity of MI showed some variation over the 12 months from onset, the changes were small suggesting that these components showed stability. However, the participants' perceptions of the time-line showed a highly significant increase over the 12 month period, whereas, their perceptions of the cure/controllability of

their MI showed a significant decrease over this time. The increased perception of the time-line would therefore appear to correspond with Leventhal et al's (1984) finding that over time people tend to change from an acute to a chronic view of their illness. This change in time-line model is also consistent with the participants' reduced belief in the possibility of cure or control of their MI.

Although few studies have examined changes in illness representations over time in detail, some have reported brief findings in this area. For example, Buick (1998) found that peoples' perceptions of the importance of chance and genetic factors in the cause of their breast cancer strengthen during and following treatment, whereas, internal and self-blame causal attributes tended to stay stable over time. This therefore suggests that some changes occurred in the individuals' beliefs about the possible cause of their illness. A study of people with chronic fatigue syndrome (CFS), however, failed to find any evidence to support the notion that illness representations can change over time (Moss-Morris & Petrie, 1996; cited in Moss-Morris, 1998). Over a six month period, it was found that four of the five components of illness representations remained remarkably stable for people with this illness.

On the basis of the research described, it is therefore apparent that there is conflicting evidence concerning how illness representations change over time. These studies have also failed to include all of the five components of illness representations in their analysis and hence, findings are only reported for selected dimensions. For example, Petrie & Weinman (1998) and Moss-Morris & Petrie, 1996 (cited in Moss-Morris, 1998) did not report on whether or not individuals'

perceptions of the cause of their illnesses changed over time, whereas, Buick (1998) only provided findings for this one particular component. The methodology of these studies can also be criticised, such that, they all involved the repeated use of the same questionnaire at the different time frames. Consequently, this may have resulted in the respondents attempting to provide consistent responses for each administration of the questionnaire, which would have therefore masked any real variations in illness representations (Petrie & Weinman, 1998). There is therefore a need for more prospective or repeated design studies to further investigate the important area of how individuals' perceptions of the illnesses they experience change over time.

1.6 Illness representations and multiple sclerosis

Although there is now an extensive literature concerning the illness representations of a wide range of illnesses including hypertension, diabetes, cancer, rheumatic disease and chronic fatigue syndrome, there has been limited focus on the study of MS within this context. Studies conducted by Schiaffino & Cea (1995) and Schiaffino et al (1998) are the only two examples currently available that have explored the illness perceptions of people experiencing MS. However, as these studies used the Implicit Models of Illness Questionnaire - IMIQ (Turk et al, 1986), the findings were interpreted on the basis of an alternative four-factor structure of illness representations. As a result, the beliefs that people with MS hold of their illness have not been considered in detail using the original and most widely accepted five component structure.

Due to the particular nature of MS it may be difficult to generalise the findings from previous studies concerning illness representations to this illness. There are certain characteristics of MS, for example, difficulties with diagnosis and no treatment that differentiates it from other illnesses, such as hypertension and diabetes. However, MS does share some important features with other chronic illnesses, such as, the rheumatic diseases and therefore it is possible that similarities in illness representations between these illnesses may be apparent.

There are a number of features of MS which are likely to influence the content of the illness representations held by people with this illness. The diagnosis of MS is typically difficult for the medical profession to establish and hence, individuals often experience symptoms for many years before being diagnosed. Consequently, there is a great deal of uncertainty and potential for emotional distress during this time. MS is a chronic and progressive illness with extreme variability in its long-term course, which for the majority of individuals is characterised by repeated episodes of relapses and remissions. This unpredictability in symptom experience has the potential to create feelings of loss of control and reduced self-efficacy for the individual. The cause of MS is also unknown and hence, individuals may experience confusion about what factors led to the development of their illness. In addition, no cure is currently available for MS and therefore, individuals are faced with living with this illness for the rest of their lives, which may result in adjustment difficulties. Furthermore, MS frequently results in a wide range of consequences for the person's life affecting for example, relationships, leisure activities and work.

As there is limited empirical evidence available concerning the illness representations of people with MS, it is difficult to make accurate inferences about the content of these beliefs for this illness population. It is also not clear whether people with MS develop common illness perceptions or whether such beliefs vary greatly within this illness group. Pimm and Weinman (1998) propose that for people with rheumatic disease, similar difficulties and challenges will be experienced and hence, some common illness representations may be developed. Evidence to support this notion has been reported in studies conducted by Hampson and her colleagues. In their study of people experiencing osteoarthritis (OA) it was found that the majority perceived their illness to be chronic and incurable, where 93 per cent expected their OA to be permanent and 79 per cent believed that a cure was unlikely (Hampson et al, 1994). In addition, some evidence has been provided to suggest that people with diabetes may also hold certain shared beliefs, where in a separate study it was found that 89 per cent believed that their illness was chronic in nature (Hampson et al, 1990).

Although there is currently no research available regarding the existence of common illness representations for people with MS, some indication of the general content of the illness perceptions held by people with this illness has been provided by Schiaffino & Cea (1995). They reported mean scores for the five components of illness representations for their sample of people with MS on the basis of their responses on the IMIQ. These scores suggested that MS was viewed as having few symptoms, to be reasonably chronic in nature, to have no specific cause, that a cure was unlikely and to have several serious consequences for the individuals' lives. Some similar findings have been reported for people with rheumatoid arthritis (RA)

using The Illness Perception Questionnaire - IPQ (Weinman et al, 1996). It was found that those with RA also demonstrated a chronic time-line model of their illness and the perception that it had a number of serious consequences. However, they considered their RA to have more symptoms and held the belief that it was more controllable and that a cure was more likely than those individuals with MS.

The results reported by Schiaffino & Cea (1995) must however, be treated with caution, particularly, as the internal consistency for some of the illness representation scales was low. Also, the use of mean scores may render the findings less meaningful due to potential distortions by extreme values. It is also important to note that the score for the identity component may not accurately reflect the individuals' symptom experience as this scale consisted of a series of general symptoms, some of which are not typically associated with MS.

1.7 Relationships between the components of illness representations

Defining the relationships between the different components of illness representations has been an important topic for investigation. However, difficulties arise when comparing the findings of the studies within this area, as although they have been guided by the five component structure of illness representations, they have tended to use a range of different structures for the basis of their data analysis. Different constructs have therefore been used, each conceptualising the identity, time-line, consequences, cause and cure/controllability dimensions in a variety of ways.

Schiaffino et al (1998) used a four-factor structure comprising of curability (which included the cause, cure and time-line components), personal responsibility (cause, consequences and identity), symptom variability (time-line) and serious consequences (consequences and the notion of illness label) to assess the illness perceptions of 66 people with MS and 63 people with rheumatoid arthritis (RA). Within this study, evidence was found to suggest that for both the MS and RA samples, the belief that their illness was curable was strongly related to the belief that they were in some way responsible for the onset of their illness. For the RA sample only, symptom variability was associated with the belief that the illness had serious consequences for the individuals' lives. In a study of people with OA, the same relationship between variability in symptoms and perceived consequences was found, such that, those who reported more symptoms viewed their OA as more serious (Hampson et al, 1994). However, for this study, a different structure of illness representations was employed which consisted of six constructs: symptoms (reflecting the identity component), seriousness (course and consequences), cause (particularly whether participants felt personally responsible for developing OA), control (cure/controllability), helpfulness of treatment and feelings about treatment.

Further relationships between the different components of illness representations have been reported by Heijmans (1998) in an investigation of chronic fatigue syndrome (CFS). Within this study, illness perceptions were assessed using interviews consisting of 45 structured questions which measured each of the five original dimensions (identity, 20 items; time-line, 3 items; consequences, 5 items; cause, 15 items and cure/controllability, 2 items). The results provided conclusive evidence to suggest that important inter-relationships exist between the dimensions,

where a number of strongly significant correlations were found. A particularly important finding was the strong relationship between the identity and time-line components, where the experience of a greater number of symptoms was associated with a more chronic view of CFS. Heijmans (1998) proposed that this suggests that individuals with CFS interpret the experience of severe or frequent symptoms as an indication of an increase in the severity of their illness. The experience of more symptoms was also related to the perception that CFS was less controllable and had more serious consequences for the individuals' lives. Similarly, a chronic view of CFS was associated with the belief of reduced control and more serious consequences. In addition, those who perceived their CFS to be caused by psychological or environmental factors experienced increased control over their illness compared to those who believed in a biological cause, which itself correlated with the belief that CFS had serious consequences. Similar findings have also been reported by other studies. For example, Moss-Morris et al (1996) who also investigated CFS and Weinman et al (1996) for people who had experienced a myocardial infarction (MI).

From the findings of her study, Heijmans (1998) concluded that due to the definitive inter-correlations among the dimensions of illness representations, such perceptions should be conceptualised as groups of beliefs or schemata instead of single cognitions. Hence, the overall sense that an individual makes of their illness is based on the interplay between the five components of illness representations (Buick, 1998).

The view that illness representations comprise of groups of beliefs has also been noted by other researchers. On the basis of this assumption, Buick (1998) and Moss-Morris (1998) in studies of breast cancer and CFS respectively, explored the relationships between the components of illness representations in an alternative way. In their separate studies, they analysed the data obtained using the Illness Perception Questionnaire - IPQ (Weinman et al, 1996) by the means of cluster analysis to investigate how the varying ratings on the individual subscales clustered together to form illness belief clusters.

In the study of people with breast cancer, Buick (1998) identified two clusters which differentiated those undergoing radiation and chemotherapy treatments. Radiation patients demonstrated more negative illness beliefs than those receiving chemotherapy, which were characterised by the experience of a greater number of symptoms, a more chronic view of their illness, more consequences for their lives, greater internal/self-blame and a reduced belief in the possibility of a cure or control. Moss-Morris' (1998) study resulted in the identification of three distinct clusters which were labelled low identity, high identity and extreme negative. Generally, each of the three clusters represented negative illness beliefs, where the low and high identity clusters differed only by the latter having a higher illness identity score. The extreme negative cluster represented the most negative illness beliefs, comprising of the highest mean scores on the identity, time-line and consequences subscales and the lowest score on internal cure/controllability. Further analysis showed that people with CFS tended to hold beliefs about their illness which were characteristic of the high identity cluster, whereas, those with CFS who also had a diagnosis of depression fell in the extreme negative cluster.

It is therefore apparent that there are important relationships between the different dimensions of illness perceptions. Several studies (Schiaffino et al, 1998; Hampson et al, 1994; Heijmans, 1998) which used different illness populations were consistent in finding evidence to suggest that the experience of many symptoms was associated with the perception that an illness had more serious consequences for an individual's life. In addition, it has been proposed that illness representations do not comprise of individual beliefs, but that it is more appropriate to conceptualise peoples' perceptions of their illness as schemata containing clusters or groups of beliefs. This was demonstrated by Buick (1998) and Moss-Morris (1998) who identified clusters of illness beliefs for people experiencing breast cancer and CFS.

1.8 Illness representations and outcome

According to the self-regulation theory, illness representations are directly related to coping and via coping, to outcome, such as, disability, mood and work status. Hence, within this model, coping is considered to mediate between illness representations and outcome (Weinman et al, 1996; Heijmans, 1998). More recently, research has sought to investigate this assumption further, where there has been a particular emphasis on identifying the role that illness representations play in governing outcome. There are therefore a growing number of studies which have explored the direct associations between illness representations and different areas of outcome, including the extent to which individuals' perceptions of their illness have predictive value in determining outcome.

One such study conducted within this area was that by Moss-Morris, Petrie & Weinman (1996) which included a sample of people with CFS. Within this study,

outcome was conceptualised as three factors, psychological adjustment, subjective well-being and illness-related dysfunction (e.g. the effects of an illness on work and social interactions). The findings of this research provided evidence to suggest that there were meaningful associations between illness representations and coping. For example, individuals who held the belief that their illness would last a long time (i.e. expressed a chronic time-line view of their illness) had a tendency to engage in more negative coping responses, such as, reducing activities and behavioural disengagement. Hence, Moss-Morris et al (1996) proposed that individuals' perceptions of their CFS impact on the coping strategies which they adopt or alternatively, that their coping responses influence the way in which they view their illness.

Perhaps the most important and interesting finding of this study was that although both coping strategies and illness representations were significantly related to each of the outcome variables, it was the illness representation components that accounted for the greatest amount of variance in outcome. The beliefs that individuals' hold of their CFS were therefore found to be a stronger predictor of their levels of adjustment, well-being and dysfunction than the coping strategies they adopted.

Of the five components of illness representations, illness identity was found to be the most significant predictor of overall outcome, such that, a strong illness identity was associated with lower levels of adjustment and well-being and an increase in dysfunction. With the exception of the time-line dimension, the remaining components were also found to be important in relation to outcome, but to a lesser

extent than identity. For example, the belief that CFS was the result of emotional causes was a negative predictor of adjustment, but a positive predictor of well-being. In addition, individuals who considered their CFS to have more serious consequences for their lives experienced more dysfunction, whereas, internal control was a positive predictor of adjustment.

Similar findings to those of Moss-Morris et al (1996) have been reported by other studies (Earll, Johnston & Mitchell, 1993; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman & Rooijmans, 1998). In a further investigation of CFS carried out by Heijmans (1998), simple correlations showed that there were some significant relationships between the different components of illness representations and coping behaviour. However, these components were more strongly associated with outcome (i.e. physical and social functioning, psychological adjustment and subjective well-being) than with coping. The results therefore indicated that a strong illness identity, a chronic time-line view of CFS and the belief in more serious consequences were correlated with greater impairment in all areas of outcome. Also, the belief that psychological factors were responsible for the onset of CFS was associated with poorer adjustment in the form of increased mental health difficulties, whereas, the perception of control over the illness was positively related to well-being. The findings of this study also demonstrated that there were generally weak relationships between coping behaviour and outcome, where only cognitive-avoidant and problem-focused coping styles correlated significantly with different aspects of outcome.

In accordance with the findings of Moss-Morris et al's (1996) study, regression analysis showed that illness representations were the strongest predictor of outcome, where coping strategies contributed minimally to the explained variance in physical and social functioning, adjustment and well-being. Two dimensions were found to be particularly important for predicting overall outcome. Such that, illness identity was a significant negative predictor of physical functioning, adjustment and well-being which is consistent with the findings reported by Moss-Morris et al (1996). The consequences component, however, was a significant predictor of more areas of outcome than for this previous study, where the belief in more serious consequences predicted impairment in physical and social functioning, and well-being. Finally, Heijmans (1998) also reported that the different components of illness representations were limited in their ability to predict coping, where they only added significantly to the explanation of variance for social support seeking and cognitive-avoidant coping.

On the basis of the research findings discussed, it is therefore apparent that the assumption of the self-regulation theory that coping is a mediating factor between illness representations and outcome has not been supported. Overall, the different dimensions of illness perceptions were found to be better predictors of outcome than coping strategies and hence, it can be concluded that individuals' beliefs about their illness have direct effects on outcome that are not medicated by coping. In particular, the identity component, that is, the individual's perception of the symptoms associated with their illness was the most important predictor, which tended to be more significantly related to all areas of outcome.

It is, however, important to note that due to the cross-sectional design of these studies and the correlational nature of the data, inferences can not be made regarding the causal relationships between illness representations, coping and outcome. Consequently, it is possible that such relationships could be reciprocal, where an individual's beliefs about their illness may determine their coping responses and outcome factors, such as, disability and emotional distress, as well as, the converse. The use of prospective and longitudinal studies would therefore clarify the nature of these associations, particularly, as the self-regulation theory postulates that the three stages (i.e. representation, coping and appraisal) are recursive.

As the investigation of the associations between illness representations, coping and outcome over time is a relatively new focus for research, there are currently few studies available that have attempted to explore this area. However, one example of a prospective study which has sought to investigate these relationships is that of Orbell, Johnston, Rowley, Espley & Davey (1998). They used a sample of 107 people with osteoarthritis (OA) who were undergoing joint replacement surgery to explore the extent to which peoples' perceptions of their condition had predictive value in determining change in functional activity and depressed mood. Data was collected at three points in time, that is, prior to surgery and at three and nine month follow-ups, where illness representations were measured at the pre-operative stage only, and functional activity and mood were assessed both pre and post-operatively.

Although it was found that none of the illness representation dimensions were predictive of functional activity at the three month time point, two components, that

is, causal beliefs and control were significant predictors at nine months. Individuals' who attributed their illness to the process of ageing were less active over the period following discharge, whereas, those who believed that they had control over their symptoms gained more function. It was also found that the addition of illness representations into a regression analysis increased the amount of explained variance in functional activity at nine months, which was over and above that accounted for by three month functional activity. Hence, Orbell et al (1998) proposed that this could indicate that illness perceptions explained the change in functional activity over the six month period, consequently, suggesting that the beliefs individuals hold of their illness may play a causal role in determining outcome.

In addition, the findings of this study showed that even though levels of depression remained relatively stable over the course of the study, several illness representation components were predictive of lowered mood. At the three month follow-up, individuals were more depressed if they considered their illness to have greater consequences for their lives. Interestingly, those who perceived greater control over their OA also experienced higher levels of depression at this point in time. Orbell et al (1998) proposed that this may have been due to individuals experiencing an unexpected loss of control over their illness following surgery where repeated attempts to regain control were unsuccessful hence, leaving them vulnerable to depression. At the nine month time point, only the belief that osteoarthritis was caused by wear and tear was predictive of depressed mood. The results of this study therefore provided evidence to suggest that generally illness perceptions were important for predicting outcomes for people with OA following surgery.

In a similar study, Schiaffino et al (1998) also explored the relationships between illness representations and outcome over time. Using people with MS and RA, outcome data (i.e. levels of depressed mood and disability) was collected at two time points that were four months apart. For both samples it was found that at the initial stage, illness representations were unrelated to levels of depressed mood. However, at the four month time point, the illness representation components were associated with a change in depression differently for the two samples. For MS, only symptom variability was associated with increased levels of depression, whereas, for those with RA, the perception that they were personally responsible for the onset of their illness and beliefs in its curability were related to an increase in depression over time. In addition, some relationships between illness representations and disability were apparent at the initial stage, but not at the four month time point. For the MS sample, individuals who perceived their illness to have many serious consequences experienced higher levels of disability, whereas, those who believed in the curability of MS were less disabled. Perhaps an unexpected finding was that for the RA sample, symptom variability was associated with lower levels of disability at this same time, which is contrary to the findings of other researchers (Moss-Morris et al, 1996; Heijmans, 1998).

As there is currently limited empirical evidence regarding the relationships between illness representations, coping and outcome over time it is difficult to come to any firm conclusions within this area. It is also important to note that the studies by Orbell et al (1998) and Schiaffino (1998) only investigated the relationship between illness representations and changes in outcome, and therefore no insight has been provided into the possible role of coping strategies in predicting long term

outcomes. Consequently, the nature of the causal relationships between illness representations, coping and outcome are still largely unknown, although, the studies described are an important step towards understanding these issues. Further prospective and longitudinal studies within this area are therefore necessary to explore this area in more detail.

1.9 Summary

Illness representations, that is, the beliefs that people hold of the illnesses they experience are considered to consist of five distinct components: identity, time-line, consequences, cause and cure/controllability. According to the self-regulation model, such beliefs are an important factor in determining an individual's response to an illness, in particular, their coping efforts. Evidence has also been provided to suggest that illness representations direct other illness behaviours, such as, adherence to treatment and use of services. In addition, recent research within this area has started to show that these beliefs have a direct affect on outcome variables, including levels of disability and emotional well-being. Although all of the five illness representation dimensions have been found to predict outcome, illness identity appears to be the most significant predictor. These important findings therefore challenge the assumption that coping is a mediating factor between illness representations and outcome. As a result, modifications may need to be made to Leventhal et al's model of self-regulation to include the outcome factor.

1.10 Description of study and research questions

The main aim of the present study was to investigate the illness representations of people with MS according to the generic five-factor structure. Relationships were

explored between a) illness perceptions and the length of time people had been diagnosed with MS, b) the different components of illness representations themselves and c) illness representations and outcome, which included illness intrusiveness, physical functioning, depression, anxiety and self-esteem. In addition, the way in which illness representations predicted outcome was examined. The following research questions were formulated for this purpose:

Research question 1

What are the illness representations of people with MS?

Research question 2

Are the different components of illness representations for MS related to the length of time that people have been diagnosed with this illness?

Research question 3

In what ways are the different illness representation components inter-related for people with MS?

Research question 4

Are the illness representations held by people with MS related to outcome, that is, illness intrusiveness, physical functioning, depression, anxiety and self-esteem?

Research question 5

Which of the illness representation components are the best predictors of outcome for people with MS?

2. Method

2.1 Design

The present study adopted a cross-sectional, correlational design to explore the relationships between illness representations and length of diagnosis of MS, the inter-relationships between the different components of illness representations, and the associations between illness representations and outcome. The study also sought to determine which of the illness representation components were the most important predictors of outcome.

The study was conducted as a postal survey which was considered the most appropriate means of data collection for several key reasons. Firstly, a large sample was needed in order for the intended data analysis to be completed. The use of a postal survey therefore allowed as many people as possible to be contacted in an attempt to maximise the sample size. Secondly, as many past research studies had used interviews to investigate illness representations it was decided to utilise an alternative means of assessment and therefore a self-completion instrument was used. Compared to interviews, this was a much briefer measure of illness representations which therefore allowed a wider range of other factors to be investigated. If interviews had been conducted, a substantial amount of time would have been spent on obtaining information on individual's illness representations hence, resulting in either very lengthy interviews or the exclusion of the other areas that were explored in this study. Finally, as the questionnaire used within the study consisted of a series of self-completion measures it was not considered necessary to conduct interviews for them to be administered.

2.2 Participants

The participants in the study were 103 adults who had a formal diagnosis of Multiple Sclerosis (MS). The majority of the sample (N = 99) were drawn from records of past referrals of people with MS to the Health Psychology Department at Gloucestershire Royal Hospital. Participants were selected on the basis of full details of their home address and registered GP being available. Any individual that was known to have a severe cognitive impairment was excluded from the study. The remaining four participants were recruited through local branches of the MS Society.

The hospital from which the participants were accessed provide a service where individuals are routinely referred by two consultant neurologists to the Health Psychology Department following a formal diagnosis of MS. Typically, individuals are initially offered one to two sessions with a psychologist to discuss the impact of their diagnosis and receive factual information about MS. If further input is not required at this point in time, individuals are placed on open contact where they can request additional psychological input at any point in the future.

Sufficient details were available from the psychology records for a total of 204 individuals, of which 170 were subsequently invited to take part in the study. The remaining individuals were not contacted, as following communication with their General Practitioners (GP) they were found to be unsuitable for inclusion. Of the sample that were invited to participate in the study, 114 responded, where 108 agreed to take part and who were sent a questionnaire. Ninety-nine questionnaires

were returned which represented a response rate of 92 per cent of those who agreed to participate and 58 per cent of the potential sample.

The overall sample for this study included 79 females and 24 males with MS. Ages ranged from 21 to 73 years with a mean age of 45.29 years (SD = 9.96). The majority of the sample were married (75%). Forty-five per cent were in employment either full or part-time, or self-employed, 18 per cent unemployed or on sick leave due to their MS, 18 per cent retired, 16 per cent housewives, 3 per cent unemployed and 1 per cent students. The self-reported mean length of diagnosis of MS was 5.66 years (SD = 6.12, range 0-39 years) and the self-reported mean length of time since first symptoms were experienced was 11.29 years (SD = 9.72; range 0-49 years). No information was available regarding the type of MS that each participant experienced (e.g. relapse-remitting or chronic progressive). Of the sample, ninety-six individuals had received some type of input following their referral to a psychologist, whether in the form of individual psychological input, attendance at a group for people newly diagnosed with MS or both.

2.2.1 Representiveness of the sample drawn from psychology referrals

In an attempt to determine whether the final sample of participants with a past psychology referral was representative of the overall sample that was contacted, a comparison was made between those who were invited to take part in the study and those who returned their questionnaires. It was only possible to consider gender and length of diagnosis in this comparison as limited information was available for those who did not respond to the initial correspondence.

Of the potential sample of 170 individuals, 74 per cent were female and 26 per cent were male. Of those who returned their questionnaires this proportion was similar, with 77 per cent being females and 23 per cent males. There was also similarity in the mean length of diagnosis for the potential sample and for those who returned their questionnaires, which were 5.52 years (SD = 5.16) (based on 166 participants for whom this information was available) and 5.12 years (SD = 4.96) respectively. The final sample can therefore be considered representative of the initial sample that was contacted to take part in the study on these two factors.

As the overall sample for this study comprised 79 females and 24 males it does not reflect the national proportion of females and males diagnosed with MS. It is estimated that the ratio of females to males for this chronic illness is 3:2 (Dupont, 1997). For the current sample, this ratio is more in the region of three females to one male. Consequently, it includes fewer males than would be expected, which may reflect a regional variation in the number of males and females diagnosed with MS or the nature of the referral patterns to psychology in the service from which the sample was taken.

2.3 Procedure

Prior to contacting the participants with a previous psychology referral for their consent to be included in the study, details of the proposed research were sent to their GP who were asked to contact the researcher if they had any concerns about their patients being approached (see Appendix A for GP letter). It was explained that if they did not respond within two weeks of receiving the correspondence it would be assumed that they were willing for their patients to be contacted.

After this time period had elapsed an initial letter of invitation to participate in the study (Appendix B), along with an information sheet detailing the nature of the research (Appendix C) and consent form (Appendix D) were sent to all of the individuals identified. They were instructed to return the consent form to the researcher in the stamped addressed envelope that was provided indicating whether or not they would like to be included in the study. Those individuals who agreed to take part were subsequently sent a questionnaire with a stamped addressed envelope for its return and a letter of thanks for their participation. Participants were given a period of approximately two weeks to complete and return the questionnaire. Due to the acceptable response rate, no reminders were sent to those who either did not respond to the initial invitation or did not return their questionnaires. The above procedures were not necessary for the participants recruited through the MS Society as they met the researcher at a local MS Society meeting and provided verbal consent to participate in the study.

Due to the physical effects of MS, it was acknowledged that it would be likely that some participants would experience difficulty with filling in the questionnaire. It was therefore explained in the information sheet that anyone who was unable to complete the questionnaire by themselves could ask someone they knew to help them or alternatively, they could contact the researcher who would visit them at home and complete the questionnaire with them. Of the sample with a past psychology referral, 13 had help from someone they knew and 4 were visited by the researcher.

2.4 Measures

The questionnaire completed by the participants consisted of five individual instruments which included measures of illness representations and the different aspects of outcome, that is, illness intrusiveness, physical functioning, depression, anxiety and self-esteem. These measures were not referred to by their original name in the questionnaire, but titles were given to make them more meaningful to the participants. In addition, a section titled 'about you and your MS' (Appendix E) was included covering general demographic information, which also required the participants to state the year that they were diagnosed with MS and the year that they first experienced their symptoms. This was considered necessary as due to the nature of this illness a considerable period of time can often elapse between its onset and a definitive diagnosis being given.

The instruments which made up the questionnaire are as follows:

2.4.1 Measure of illness representations

The Illness Perception Questionnaire – IPQ (Weinman, Petrie, Moss-Morris & Horne, 1996).

The Illness Perception Questionnaire was titled 'your views about your MS' and was used as a measure of the participants' illness representations (Appendix F). This questionnaire is based upon Leventhal et al's (1980) cognitive model of illness representations and consists of five scales, each assessing one of the five components of illness perceptions. The IPQ was specifically designed for use with individuals experiencing a chronic illness and was developed using seven illness populations. These were: individuals with diabetes, rheumatoid arthritis, renal

failure, asthma, chronic fatigue syndrome, chronic pain and those having experienced a myocardial infarction.

The IPQ was considered the preferred measure of illness representations as it is relatively brief and easy to complete and hence, suitable for postal surveys. It is also theoretically derived and although there is not extensive data available on its psychometric properties, that which does exists has demonstrated that it is a reasonably reliable and valid measure. Weinman et al (1996) have reported high levels of internal consistency and test-retest reliability for the IPQ, as well as, good discriminant validity since within their study the IPQ differentiated patients with chronic pain, rheumatoid arthritis, chronic fatigue syndrome and diabetes. Other questionnaires for assessing illness representations have been developed. However, they have not tended to be based on theory and have only been evaluated on one patient group (Weinman et al, 1996). One such measure is the Implicit Model of Illness Questionnaire (IMIQ) developed by Turk et al (1986). This questionnaire was not considered appropriate for use in this study as there are conflicting views concerning whether or not it is consistent with the self-regulation model.

The first section of the IPQ is concerned with illness identity and consists of 12 symptoms. Individuals rate each symptom according to the frequency that they are experienced as part of their illness on a four-point scale ranging from 'all the time' to 'never'. The identity scale is scored by summing the number of items rated at 'occasionally' or greater and hence, the total score can range from 0 to 12. A simple measure is therefore provided of the number of symptoms considered by the individual to be associated with their illness.

For the present study, Weinman et al's (1996) original list of symptoms was modified to include the typical symptoms of MS. Only four of their original symptoms were used, these being pain, fatigue, sleep difficulties and loss of strength, with eight new symptoms being added (urinary frequency and/or urgency, numbness and/or tingling, heavy feeling in arms and legs, visual problems, difficulties with balance and/or co-ordination, loss of fine movement in hands, soreness in muscles, and muscle cramps and/or spasms). Weinman et al (1996) endorse tailoring the identity scale to specific illnesses, where symptoms from the core list can be replaced or added to. For example, in a study conducted by Moss-Morris et al (1996) concerning the illness representations of individuals with chronic fatigue syndrome, the original symptom list was extended to a 25-item identity scale. The internal consistency of the revised MS identity scale was assessed using Cronbach's alpha which yielded a coefficient of .87 demonstrating a high level of internal consistency.

The second part of the questionnaire consists of a total of 26 items which cover the four other IPQ dimensions: 'cause' (10 item scale; items 1-10), time-line (three items; items 11-13), consequences (seven items; items 14-20) and cure/controllability (six items; items 21-26). Individuals are required to rate their level of agreement with each item on a five-point scale ranging from 'strongly agree' = 5 to 'strongly disagree' = 1. For the data collection stage of the present study the scores for this scale were reversed (i.e. strongly agree = 1 and strongly disagree = 5) to maintain consistency with the direction of scoring for the other measures included in the questionnaire. However, for data analysis, the original

scoring system was used and therefore the direction of total scores for each of the IPQ scales were in accordance with those of Weinman et al's (1996).

Total scores for the time-line, consequences and cure/controllability scales are obtained by summing the scale items and dividing the sum by the number of items, resulting in a range from 1 to 5. In order to do this it is necessary to reverse the scoring for items 11, 16, 17, 23 and 25. Higher scores for the time-line, consequences and cure/controllability scales suggest that individuals believe that their illness will last for a long time, has a profound impact on their lives and that they have greater control over their illness or that there is a likely cure.

The internal reliability of these three scales for the present study was calculated using Cronbach's alpha, which showed high levels of internal consistency for the time-line and consequences scale and a lower value for the cure/controllability scale. The alpha coefficients are presented in Table 1 along with those reported by Weinman et al (1996) and Moss-Morris et al (1996) for comparison.

Table 1. Internal consistency scores (Cronbach's alpha) for IPQ scales: Present study, Weinman et al and Moss-Morris studies

Scale	Present study α	Weinman et al α	Moss-Morris et al α
Time-line	.83	.73	.58
Consequences	.79	.82	.63
Cure/Controllability	.59	.73	.69

For the cause scale of the IPQ, an overall total score is not calculated as each item represents a specific causal belief and hence, a single score would be meaningless. However, Weinman et al (1996) suggest that items can be combined for specific research purposes. In order to utilise the IPQ cause data obtained in the present study, a principle components factor analysis using the varimax rotation method was performed on the cause scale to determine which items went together to form individual factors. On the basis of this analysis (see Appendix G for summary of factor analysis), the cause scale was divided into physical (items 1, 2 and 3) psychological (items 6, 7, 8 and 10) and fate (items 4, 5 and 9) causal factors. Total scores for these factors were calculated by summing the items and dividing the sum by the number of items, where again scores range from 1 to 5.

2.4.2 Measures of outcome

Illness Intrusiveness Ratings Scale – IIRS (Devins, Binik, Hutchinson, Hollomby, Barre & Guttmann, 1983)

The Illness Intrusiveness Ratings Scale was used to measure the participants' perception of the extent to which their illness 'interfered' with their lifestyle, activities and interests and was titled 'how your Multiple Sclerosis affects your life' (Appendix H). This measure requires individuals to rate levels of illness-related intrusiveness into 13 life domains on a seven-point scale, ranging from 'very little' = 1 to 'very much' = 7. These domains have been found to be central to quality of life (Flanagan, 1982) and include: health, diet, work, active recreation, passive recreation, financial situation, relationship with spouse/partner, sex life, family relations, other social relations, self-expression/self-improvement, religious expression, and community and civic involvement. Where a life domain is regarded

as not applicable, respondents are instructed to rate that item as 1 to indicate that their illness does not interfere very much with that particular domain, for example item 7, 'relationship with partner/spouse', where they are not in a relationship.

Scores for the Illness Intrusiveness Ratings Scale are obtained by summing across the 13 individual life domains, where total scores can range from 13 to 91. The higher the score, the more the illness is perceived to interfere with the individual's life. Although there is no normative data for the IIRS, mean scores have been provided for different illness populations. Devins et al (1993b) have reported a mean score of 42.60 (SD = 14.56) for people with MS, where for end-stage renal disease, Devins (1994) reports that mean scores range from 27.70 to 36.40 depending on the type of treatment received. In addition to the calculation of an overall illness intrusiveness score, comparisons can also be made between ratings on individual life domains or between subsets of domains. In a study of illness intrusiveness and quality of life in end-stage renal disease, Devins, Mandin, Hons, Burgess, Klassen, Taub, Schorr, Letourneau & Buckle (1990) generated five subscales which included: physical wellbeing and diet; work and finances; marital, sexual and family relations; recreation (active and passive) and (nonfamily) social relations; and other aspects of life (including self-expression and self-improvement). For the present study, only the overall illness intrusiveness score was calculated.

The Illness Intrusiveness Ratings Scale was originally developed using a sample of individuals with end-stage renal disease, but has since also been used with other illness groups, for example, MS, rheumatoid arthritis, sleep disorders, and head and neck cancer. The scale is generally characterised by excellent psychometric

properties with high levels of internal consistency, coefficient alpha ranging from .80 to .95. Test-retest reliability has also been high ranging from r = .79 to .85 (Devins 1994). For the present study, a coefficient alpha of .83 was obtained which indicated that the IIRS had a high level of internal consistency for the current sample.

Activities of Daily Living Scale - ADL Scale (Wright, Stein & Walls, 1998)

Participants' level of physical functioning and how this was affected by their MS was measured using a scale of activities of daily living. This was titled ' the impact of your Multiple Sclerosis on your ability to complete daily activities' (Appendix I). Assessment of independence in such activities is now commonly used as a measurement of disability and many ADL scales are available (Barer & Nouri, 1989).

The ADL Scale used for the present study was devised initially for use with individuals experiencing end-stage renal disease. It includes a combination of items from two separate ADL scales which were developed by Nouri & Lincoln (1987) and Julius, Hawthorne, Carpentier-Alting, Kneisley, Wolfe & Port (1989). The decision to use this particular scale was primarily based on the need to find a measure of ADL that was suitable for use in a postal survey, that is, one that was sufficiently brief and able to be completed by the respondents themselves. Other such measures were considered including the Barthel Index (Mahoney & Barthel, 1965), Functional Limitations Profile (Patrick & Peach, 1989), the Short Form 36 Health Survey Questionnaire (SF36) (Ware, Kosinski & Keller, 1994) and a shortened version of this measure, the SF12 (Ware, Kosinski & Keller, 1996), the

expanded disability status scale (EDSS) (Kurtzke, 1983) and the Office of Population Census and Surveys' (OPCS) disability scale (Martin, Meltzer & Elliot, 1988). However, all of these measures were deemed inappropriate for a postal survey, as they were either not suitable for self-completion or too extensive.

The present ADL Scale consists of 23 items which are divided into five categories: mobility, in the kitchen, domestic tasks, self-care and leisure activities. Individuals are asked to rate whether they do each activity on a four-point scale: 'Not at all' = 0, 'With help' = 1, 'Alone with difficulty' = 2 and 'Alone easily' = 3. Scores for the ADL Scale are calculated by summing individual item ratings, where total scores can range from 0 (complete dependence in daily living) to 69 (complete independence). Thus, the higher the score, the greater the level of physical functioning.

Due to the nature of MS, particularly for those with the relapse-remitting type, it was recognised that respondents' symptoms may fluctuate and hence, their ability to complete daily activities could vary. The instructions for the ADL Scale were therefore extended to take account of this, where respondents were asked to base their answers on their ability on an 'average day'.

Although the psychometric properties of the ADL Scale have not been rigorously tested, a factor analysis of the scale conducted by Wright et al (1998) suggests that it is a one-factor scale. They also found the scale to have good internal consistency (Cronbach's alpha = .94). For the present study, the internal consistency was further tested which yielded an extremely high coefficient alpha of .97.

Hospital Anxiety and Depression Scale – HADS (Zigmond & Snaith, 1983)

Levels of depression and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS) which was titled 'about how you feel' (Appendix J). This measure was developed specifically for use with individuals attending medical out-patients as a screening instrument for anxiety and depression. The HADS has therefore been constructed largely excluding the physiological symptoms characteristic of these emotional problems, many of which can be experienced as part of a physical illness. Consequently, scores of anxiety and depression on the HADS are not considered to be influenced by physiological symptomology. This scale can also be used to provide an indication of the severity of anxiety and depression being experienced.

The HADS consists of 14 items divided evenly into two subscales, anxiety and depression. Each item is scored from 0 to 3 and therefore total scores for both the anxiety and depression subscales range from 0 to 21. The higher the score, the greater the level of anxiety and depression. Zigmond & Snaith (1983) suggest that for each scale, possible clinical disorder is indicated by a score ranging from 8 to 10 and probable clinical disorder by scores from 11 to 21. Furthermore, as an indication of the severity of anxiety and depression, Johnston, Wright & Weinman (1995) recommend the following classifications and score ranges: normal (0-7), mild (8-10), moderate (11-14) and severe (15-21).

Previous studies using the HADS have reported mean scores for the anxiety and depression subscales. For a sample of people with cancer, mean scores were 5.44 (SD = 4.07; range = 0-19) and 3.02 (SD = 2.98; range = 0-15) for anxiety and

depression respectively (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). A study conducted by Earll et al (1993) on motor neurone disease (MND) found higher levels of anxiety and depression with mean scores of 7.28 (SD = 7.28) and 7.38 (SD = 3.29) respectively.

On the basis of data from medical out-patients and people with cancer, the HADS has been shown to have good psychometric properties. In Moorey et al's (1991) study of cancer patients, the internal consistency for the two scales using Cronbach's alpha was 0.93 for anxiety and 0.90 for depression. In the same study, a factor analysis of the HADS items confirmed the construct validity of the scale as a measure of two factors. Within the present study, the internal consistency of the HADS was further analysed where Cronbach's alpha yielded coefficients of .86 and .84 for anxiety and depression respectively.

Rosenberg Self-Esteem Scale – RSE Scale (Rosenberg, 1965)

The impact of the experience of MS on the self was measured using the RSE Scale, which is a 10-item measure of the concept of self-esteem and was titled 'your feelings about yourself' (Appendix K). Although it was originally developed using adolescents, it is now commonly used with the adult population and is the most widely used measure of self-esteem in health psychology (Johnston et al, 1995). For each RSE Scale item, individuals are required to rate their level of agreement on a four-point scale, ranging from 'Strongly Agree' = 1 to 'Strongly Disagree' = 4. The scale has been developed so that half of the items are statements of positive self-esteem (1, 3, 4, 7, 10) and half are negative (2, 5, 6, 8, 9).

The RSE Scale is scored by summing the individual ratings for each item to obtain a total score ranging from 10 to 40. In order to do this, it is necessary to reverse the scoring for the negatively worded items. Consequently, low scores indicate high self-esteem. Johnston et al (1995) report that scores for the RSE Scale for the adult population are negatively skewed, that is, tending to show low self-esteem. They report mean RSE Scale scores for a sample of 2,294 adults aged between 18 and 65 years as 35.01 (SD = 4.78) for men and 34.52 (SD = 4.91) for women. Although the RSE Scale is widely used there is little data on its psychometric properties. In a study conducted by Fleming & Courtney, 1984 (cited in Blascovich & Tomaka, 1991), a coefficient alpha of .88 and a test-retest correlation of .82 were reported. In the present study, the internal consistency using Cronbach's alpha was .92, indicating that the RSE Scale had a high level of internal consistency for the current sample.

A summary of the measures incorporated within the questionnaire which have been described is provided in Table 2.

Table 2 Summary of measures used in questionnaire

Construct measured	Measure used	Title used for questionnaire
Illness Representations	Illness Perception Questionnaire (IPQ)	Your views about your MS
Outcome		
Illness Intrusiveness	Illness Intrusiveness Ratings Scale (IIRS)	How your MS affects your life
Physical Functioning	Activities of Daily Living Scale	The impact of your MS on your ability to complete daily activities
Depression	Hospital Anxiety and Depression Scale (HADS)	About how you feel
Anxiety	Hospital Anxiety and Depression Scale (HADS)	About how you feel
Self-Esteem	Rosenberg Self-Esteem Scale (RSE)	Your feelings about yourself

2.5 Pilot Study

A small pilot study was completed prior to the commencement of the main research project to check the feasibility of the questionnaire to be used. Four people with MS completed the questionnaire and provided verbal feedback. Only one alteration was made to the questionnaire following the pilot study. For the ADL Scale, the additional instruction of 'if your symptoms vary, then choose the response that best reflects your ability on an average day' was included. Generally, the respondents considered the questionnaire as acceptable, both in terms of the type of measures and questions that were used and the length of time it took to complete. The data from this pilot study was not included in any of the data analyses conducted for the main study.

2.6 Ethical Approval

Ethical approval was sought from the West Gloucestershire Local Regional Ethics Committee as they covered the geographical area from which the respondents were drawn. Final approval to proceed with the study was provided by this committee in October 1998 (see Appendix L for ethical approval letter).

3. Results

3.1 Selection of statistical procedures

Parametric statistics were used to analyse the data of this study. However, before this decision was reached careful consideration was given to the nature of the data in relation to the conditions generally recommended for the use of these tests. These conditions are: (1) the level of measurement must be at least interval, (2) the sample data are drawn from a population that is normally distributed and (3) the variances of both variables are not significantly different, that is, there is homogeneity of variance (Coolican, 1995).

Despite these seemingly definitive criteria there is still much debate concerning whether it is necessary to completely fulfil these three conditions for the use of parametric tests. There are therefore some arguments to support the need to be more flexible, where it is suggested that such tests can be performed on data that does not fit the assumptions exactly. Within psychology, the variables investigated tend to be ordinal in nature, although as noted by Bryman & Cramer (1997) it is common practice for parametric tests to be applied to them. This decision is often deemed acceptable as it is argued that statistical tests are simply applied to numbers themselves, since what they represent in terms of the nature of the underlying metric is of little importance in the actual statistical procedure. In addition, psychological research often includes multiple-item measures, which some argue may be considered interval variables as they include a wide range of categories (Bryman & Cramer, 1997). On the basis of these arguments, the data obtained from the measures within the study were regarded as acceptable for the use of parametric tests.

Consideration was also given to the distribution of the scores for each measure or subscale, which were explored using stem and leaf displays and box plots. This preliminary analysis showed a number of skewed distributions both in the positive and negative directions. Bryman & Cramer (1997) propose that when data reflects marked discrepancies from a normal distribution, caution must be taken when applying parametric tests. Hence, in accordance with their recommendations, comparisons were made of the results obtained from both parametric and non-parametric tests in order to ascertain whether the use of parametric methods was appropriate. To explore this further, parametric statistics were also performed on the data once it had been transformed using logarithmic and square root transformations for positive and negative skews respectively. Comparisons were then made between the results of the parametric tests on the original and transformed data.

Generally, it was found that there were no striking differences between the results for parametric and non-parametric tests or between the results obtained using parametric statistics on the data prior to and after transformations. On the basis of these findings, and the preference to use the more powerful parametric methods, it was decided to use the results from the parametric analyses that were run on the data in its original form. This conclusion was supported by the well attested fact that deviations from normal assumptions have little effect when the number of observations is relatively large (Cohen, 1965).

3.2 Description of statistical analysis

Pearson's Product Moment Correlation Coefficient (Pearson's r) was used to investigate the relationships between the variables within this study. This statistical

test is a measure of linear correlation and provides an indication of the strength and direction of the relationship between a pair of variables. In order to explore how the illness representation components predicted each of the outcome measures, stepwise multiple regression was used. This particular type of analysis allows the overall and relative importance of a series of independent variables to the dependent variable to be determined. In stepwise multiple regression, the independent variables or predictors are entered into the equation one at a time depending on the contribution of each variable to the explained variance. The variable with the highest correlation with the dependent variable is entered first, followed by the other variables according to how much extra they add to the explained variance. Variables may also be excluded from the equation if they fail to meet the necessary statistical criteria for inclusion.

Due to the large number of relationships examined, which consequently increased the likelihood of finding statistically significant results, the Bonferroni test was performed for each group of correlations in order to avoid Type 1 errors, that is, accepting that relationships exist between variables when there are actually no such relationships. This test adjusts the standard level of significance of $p < 0.05$ to take account of the number of correlations being made. This is achieved by dividing 0.05 by the total number of correlations hence, resulting in a stricter level of statistical significance. In addition, as the study did not have directional hypotheses, two-tailed significance levels were used. All of the analyses performed within this study were carried out using the Statistical Package for the Social Sciences (SPSS) for Windows, Version 8.

3.3 Missing data

As there was minimal missing data and the study sample was fairly large, it was not considered necessary to use mean scores in order to calculate totals for measures or subscales of a measure that had missing values. Missing values were therefore treated as such, where for each participant a total score was not calculated for any measure or subscale which had uncompleted items. For both the Pearson's r and multiple regression analyses, pairwise deletion was used where participants were excluded from an analysis only for variables where a total score was actually missing. As a result, each analysis was performed on varying numbers of participants.

3.4 Exploration of gender and age differences

As the sample consisted of substantially more females than males, it was considered necessary to investigate whether there were any gender differences for the scores on each of the measures/subscales. An unrelated t-test was used for this purpose. The results of this analysis demonstrated that no significant differences existed between the mean scores for males and females on each of the individual measures/subscales (see Appendix M for the means and standard deviations for males and females for each measure/subscale).

Possible age differences were also explored for all of the obtained data. Following the categorisation of participants into six age-groups (i.e. 21-30, 31-40, 41-50, 51-60, 61-70 and 71-80), a one-way analysis of variance was performed. The results of this analysis demonstrated that there were no significant differences between the six age-groups for each of the measures/subscales. (see Appendix N for means and

standard deviations for the different age-groups for each measure/subscale). On the
basis of no significant gender and age differences being found, the analyses used to
address the research questions were consequently performed on the sample as a
whole.

The results of the parametric tests will now be presented in relation to the study's
research questions.

3.5 Research findings

3.5.1 Research question 1. What are the illness representations of people with MS?

Mean scores for each of the IPQ components are presented in Table 3. For the cause
dimension, mean scores were calculated for the three causal factor categories:
physical, psychological and fate.

Table 3. Mean scores and standard deviations (SD) for each of the IPQ components

Component	Mean	SD
Identity (N = 94)	10.24	2.31
Time-line (N = 100)	4.22	0.79
Consequences (N = 100)	3.55	0.77
Physical cause (N = 100)	2.31	0.80
Psychological cause (N = 101)	2.36	0.81
Fate (N = 98)	2.22	0.62
Cure/Controllability (N = 98)	2.79	0.62

The identity score shows that the participants had a strong illness identity since they reported experiencing many of the symptoms from the 12-item symptom list as part of their MS. A large proportion of the sample (68.9%) reported experiencing 10 symptoms or more. The IPQ identity scale was further analysed to determine the percentage of participants that reported experiencing each symptom as part of their MS (Figure 2). As can be seen from Figure 2, all of the individual symptoms were experienced by a substantial proportion of the sample. The most commonly reported symptom was fatigue which was experienced by 97.1% of participants, where the least reported symptom was soreness in muscles which was experienced by 66%.
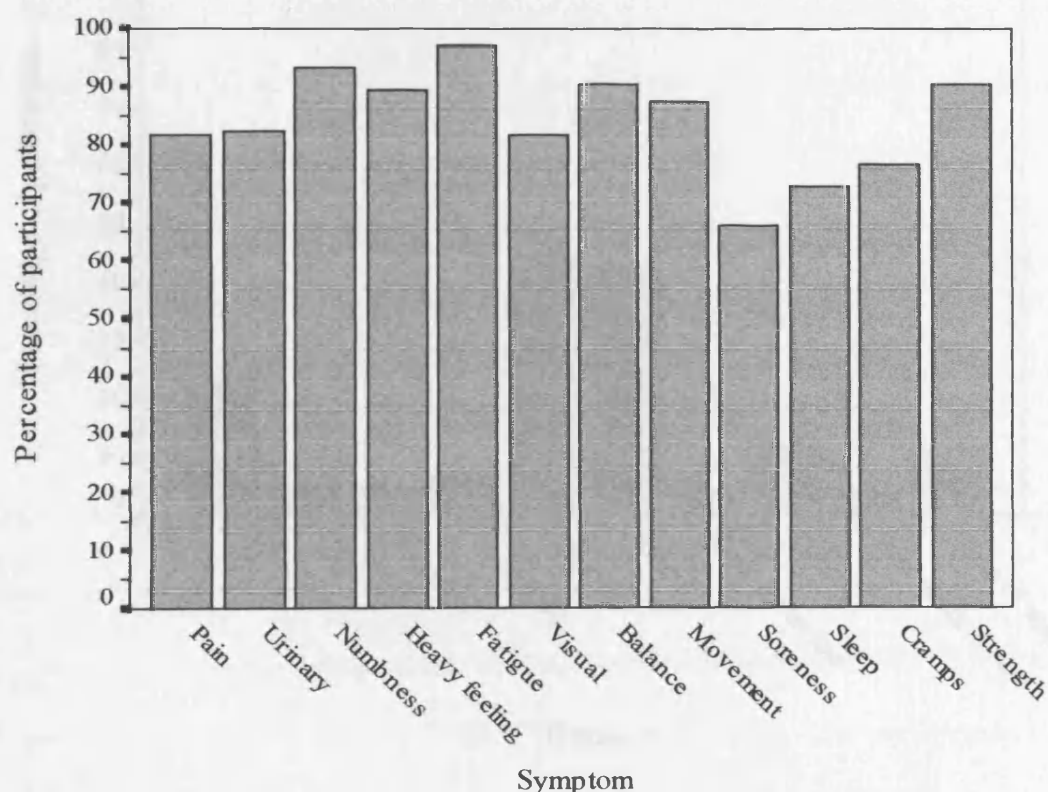
Figure 2. Symptoms experienced as part of MS

The mean scores for the time-line, consequences and cure/controllability components show that the participants held a chronic view of their MS, considered it to have serious consequences for their lives, and held the belief that they had limited control over their MS and that a cure was unlikely. The mean scores for the three groups of causal factors, that is, physical, psychological and fate indicate that overall the participants did not believe these factors to be important in the development of their MS. Figure 3 illustrates the percentage of participants that reported each of the IPQ causes as contributing to the onset of their MS.
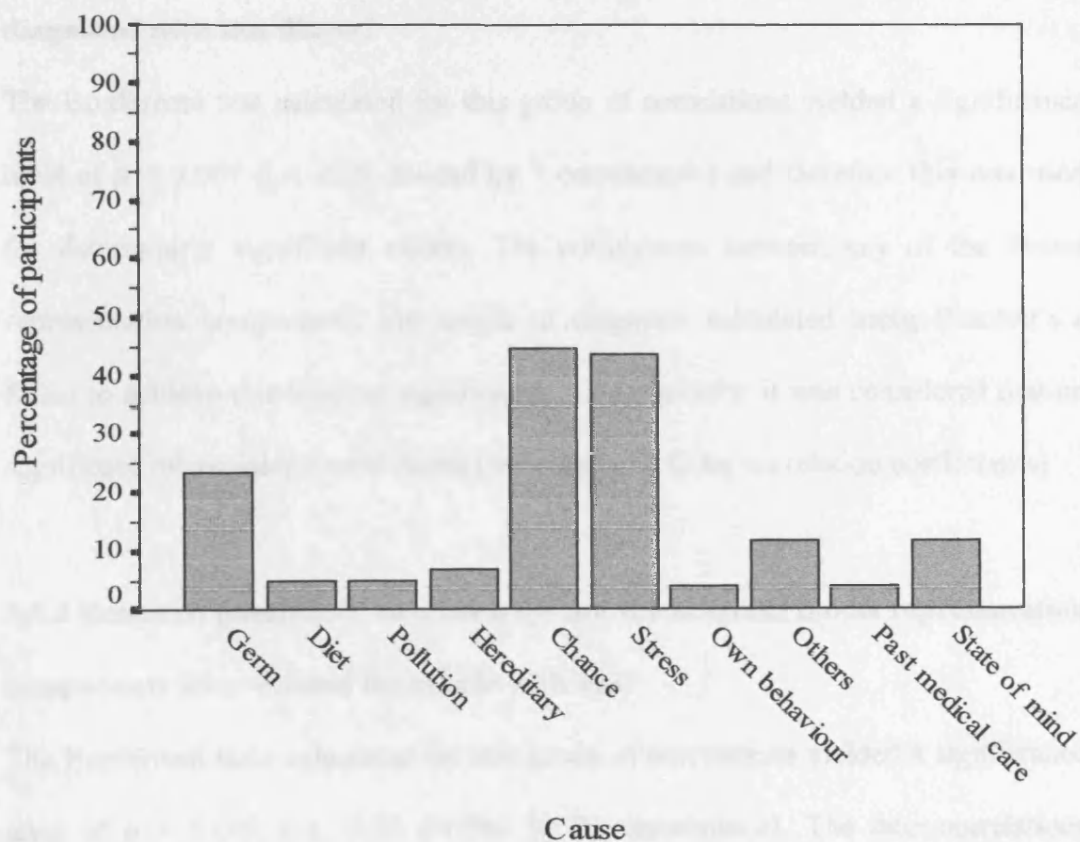
Figure 3. Beliefs about the causes of MS

Although the majority of the individual causes were reported by a small proportion of the sample, chance and stress were considered the most important. These were reported by 44.7% and 43.7% of the participants respectively. The causes considered least likely to have led to the onset of their illness were diet, pollution of the environment (both reported by 4.9% of the sample), the participants' own behaviour and past poor medical care (both reported by 3.9% of the sample).

3.5.2 Research question 2. Are the different components of illness representations for MS related to the length of time that people have been diagnosed with this illness?

The Bonferroni test calculated for this group of correlations yielded a significance level of $p < 0.007$ (i.e. 0.05 divided by 7 correlations) and therefore this was used for determining significant results. The correlations between any of the illness representation components and length of diagnosis calculated using Pearson's r failed to achieve this level of significance. Consequently, it was considered that no significant relationships were found (see Appendix O for correlation coefficients).

3.5.3 Research question 3. In what ways are the different illness representation components inter-related for people with MS?

The Bonferroni tests calculated for this group of correlations yielded a significance level of $p < 0.002$ (i.e. 0.05 divided by 21 correlations). The inter-correlations among the illness representation components calculated using Pearson's r are shown in Table 4. As can be seen some statistically significant relationships were obtained which according to the guidelines proposed by Cohen & Holliday, 1982 (cited in Bryman & Cramer, 1997) can be considered as ranging from low to modest (low =

Table 4. Inter-correlations among the different components of illness representations

	Identity	Time-line	Consequences	Physical cause	Psychological cause	Fate
Identity						
Time-line	.19 $p = 0.065$ N = 92					
Consequences	.43** $p < 0.001$ N = 93	.46** $p < 0.001$ N = 99				
Physical cause	.15 $p = 0.158$ N = 91	-.04 $p = 0.735$ N = 97	.18 $p = 0.078$ N = 97			
Psychological cause	.03 $p = 0.812$ N = 92	-.11 $p = 0.289$ N = 99	-.05 $p = 0.613$ N = 99	.28 $p = 0.005$ N = 99		
Fate	.20 $p = 0.059$ N = 89	.02 $p = 0.860$ N = 96	.07 $p = 0.496$ N = 96	.14 $p = 0.172$ N = 97	.32* $p = 0.001$ N = 98	
Cure/Controllability	-.15 $p = 0.151$ N = 91	-.46** $p < 0.001$ N = 96	-.54** $p < 0.001$ N = 97	.05 $p = 0.629$ N = 95	-.02 $p = 0.841$ N = 97	-.12 $p = 0.239$ N = 94

Bonferroni adjustment for multiple correlations indicated a significance level of $p < 0.002$

* $p < 0.002$; ** $p < 0.001$

0.20 to 0.39; modest = 0.40 to 0.69). Respondents who reported experiencing a greater number of symptoms as part of their MS considered their illness to have more consequences for their lives. Similarly, a more chronic time-line model of MS was positively related to the consequences component, although it was inversely related to the cure/controllability dimension. Hence, those who perceived their illness to be more chronic in nature experienced more serious consequences, lower control over their illness and were less likely to believe that there was a cure. There was also a negative relationship between the consequences and cure/controllability components. In addition, the perception that psychological factors contributed to the cause of MS was associated with the belief in fate as a causal factor. There was also a near significant relationship between the psychological and physical causal factors, although, the correlation coefficient for this association was just below that required for statistical significance ($r = .28; p = 0.005$).

3.5.4 Research question 4. Are the illness representations held by people with MS related to outcome, that is, illness intrusiveness, physical functioning, depression, anxiety and self-esteem?

Mean scores were calculated for each of the outcome variables which are presented in Table 5. The illness intrusiveness score shows that the participants viewed their MS to be moderately intrusive into their lives. This was similar to the mean score of 42.60 reported by Devins et al (1993b) for MS, but greater than that found by Devins (1994) for end-stage renal disease (ESRD) (mean scores = 27.70 to 36.40 depending on the type of treatment received). A mean score of 50.48 on the ADL scale indicates that the sample's physical functioning was reasonably high. Overall, participants showed low levels of depression and anxiety, although 15.5% and

26.2% scored 11 and over on the HADS for depression and anxiety respectively, indicating probable clinical disorder. Self-esteem was also relatively high among the sample with a mean score well below those of 35.01 for males and 34.52 for females provided by Johnston et al (1995).

Table 5. Mean scores and standard deviations (SD) for each of outcome variables

Outcome variable	Mean	SD	Range
Illness Intrusiveness (N = 98)	43.06	17.34	14-91
Physical Functioning (N = 94)	50.48	18.78	0-69
Depression (N = 103)	6.27	4.19	0-18
Anxiety (N = 101)	8.56	4.68	1-21
Self-Esteem (N = 100)	23.21	6.14	11-38

The Bonferroni test calculated for the correlations between illness representations and outcome yielded a significance level of $p < 0.01$, which was the result of dividing 0.05 by 5 correlations, (i.e. the number of correlations made for each of the individual illness representation components with each of the outcome variables). Table 6 shows the correlations between the different illness representation components and outcome variables that were obtained using Pearson's r.

All components except the fate causal factor correlated significantly in some way with outcome. Although, this factor demonstrated one relationship (i.e. with self-esteem) that had a correlation coefficient which was very near the level of statistical significant ($r = .25; p = 0.013$).

Table 6. Correlations between the illness representation components and outcome

	Identity	Time-line	Consequences	Physical cause	Psychological cause	Fate	Cure/ Controllability
Illness Intrusiveness	.46** $p < 0.001$ N = 89	.19 $p = 0.071$ N = 95	.77** $p < 0.001$ N = 95	.27* $p = 0.008$ N = 95	.13 $p = 0.199$ N = 96	.13 $p = 0.198$ N = 94	-.49** $p < 0.001$ N = 93
Physical Functioning	-.31* $p = 0.004$ N = 87	-.29* $p = 0.006$ N = 91	-.67** $p < 0.001$ N = 91	-.04 $p = 0.696$ N = 91	-.001 $p = 0.990$ N = 92	-.11 $p = 0.305$ N = 89	.56** $p < 0.001$ N = 89
Depression	.41** $p < 0.001$ N = 94	.14 $p = 0.154$ N = 100	.48** $p < 0.001$ N = 100	.07 $p = 0.504$ N = 100	.20 $p = 0.045$ N = 101	.06 $p = 0.568$ N = 98	-.46** $p < 0.001$ N = 98
Anxiety	.36** $p < 0.001$ N = 92	.19 $p = 0.068$ N = 98	.45** $p < 0.001$ N = 98	.05 $p = 0.651$ N = 98	.19 $p = 0.057$ N = 99	.11 $p = 0.303$ N = 96	-.20 $p = 0.055$ N = 96
Self-Esteem	.27* $p = 0.008$ N = 92	.11 $p = 0.304$ N = 97	.53** $p < 0.001$ N = 97	.21 $p = 0.042$ N = 97	.26* $p = 0.009$ N = 98	.25 $p = 0.013$ N = 95	-.40** $p < 0.001$ N = 96

Bonferroni adjustment for multiple correlations indicated a significance level of $p < 0.01$

* $p < 0.01$;   ** $p < 0.001$

The identity and consequences components were found to have the most associations, where a strong illness identity and the belief that MS had serious consequences was related to greater difficulties in all areas of outcome, that is, higher levels of illness intrusiveness, greater impairment of physical functioning, higher levels of depression and anxiety, and lowered self-esteem. The cure/controllability dimension also showed many significant associations, indicating that participants who perceived themselves to have more control over their MS experienced lower illness intrusiveness, less impairment in physical functioning, lower levels of depression (but not anxiety) and higher self-esteem. A belief in a chronic time-line model of MS was only significantly related to increased impairment in physical functioning. Finally, a belief that physical factors contributed to the onset of MS was associated with higher levels of illness intrusiveness, while believing in a psychological cause was related to lower self-esteem.

3.5.5 Research question 5. Which of the illness representation components are the best predictors of outcome for people with MS?

To examine the role of the illness representation components in predicting outcome, a series of stepwise multiple regression analyses were performed. Prior to carrying out these analyses the relationships between the illness representation dimensions were checked for multicollinearity. Multicollinearity refers to a situation where two variables are highly correlated and therefore the regression coefficients may be unstable, that is, they are likely to vary greatly from sample to sample. As none of the correlations produced by Pearson's r for the previous analysis of the inter-relationships between the components of illness representations were 0.80 or above,

it was considered that multicollinearity was not an issue of concern (Bryman & Cramer, 1997).

When computing the multiple regressions a residuals analysis was also performed. A residual is the difference between the actual and predicted values of the dependent variable and therefore provides an indication of the accuracy of the predictions. Such an analysis allows outliers to be detected which are cases that show a large discrepancy between the actual and predicted values. Of the five outcome variables only depression showed an outlier and therefore that case was excluded from this multiple regression analysis.

A summary of the multiple regression analyses for each of the outcome variables, that is, illness intrusiveness, physical functioning, depression, anxiety and self-esteem is presented in Table 7.

For each of the outcome variables, a different combination of illness representation components were important for explaining their variance. Only the consequences component was entered into the multiple regression equations for all of the outcome measures. The physical and fate causal factors failed to reach the criteria for inclusion into the regression procedure for all of the five measures of outcome indicating that they did not contribute to the explained variance in outcome.

Table 7. Summary of multiple regression analyses for the prediction of each outcome variable by the illness representation components

Component	Illness Intrusiveness		Physical Functioning		Depression		Anxiety		Self-Esteem	
	β	p	β	p	β	p	β	p	β	p
Identity	.16	0.018*			.26	0.006**				
Time-line	-.25	0.001**			-.25	0.011*				
Consequences	.73	< 0.001***	-.52	< 0.001***	.29	0.011*	.46	< 0.001***	.54	< 0.001***
Physical cause										
Psychological cause	.14	0.030*					.22	0.024*	.29	0.001**
Fate										
Cure/Controllability	-.18	0.017*	.29	0.002**	-.43	< 0.001***				
	Adj. R^2 = .68 $F = 38.15$ $p < 0.001$***		Adj. R^2 = .50 $F = 43.23$ $p < 0.001$***		Adj. R^2 = .41 $F = 30.78$ $p < 0.001$***		Adj. R^2 = .23 $F = 13.91$ $p < 0.001$***		Adj. R^2 = .34 $F = 24.10$ $p < 0.001$***	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Illness intrusiveness demonstrated the highest adjusted multiple coefficient of determination (Adj. R^2 = .68) indicating that 68% of its variance was accounted for by the identity, time-line, consequences, psychological causal factor and cure/controllability components. For physical functioning only two components, consequences and cure/controllability accounted for 50% of the explained variance (Adj. R^2 = .50). The depression outcome variable had 41% of its variance (Adj. R^2 = .41) explained by the identity, time-line, consequences and cure/controllability dimensions, where for anxiety and self-esteem, consequences and psychological cause accounted for 23% (Adj. R^2 = .23) and 34% (Adj. R^2 = .34) of the variances respectively. The F ratios and associated significance levels show that the multiple correlation (R) (which is the square root of the multiple coefficient of determination (R^2) and expresses the correlation between each individual outcome variable and all of the illness representation components) demonstrated extremely high levels of statistical significance. Hence, indicating that collectively the illness representation components correlated well with each of the outcome variables.

On the basis of the standardised regression coefficients (β), consequences was the most important predictor of four of the five outcome variables, that is, illness intrusiveness, physical functioning, anxiety and self-esteem. This component also predicted depression, although to a lesser extent. The remaining dimensions show fewer predictive relationships with outcome, where cure/controllability was a positive predictor of physical functioning and a negative predictor of illness intrusiveness and depression. The time-line component also negatively predicted illness intrusiveness and depression. Illness identity was a further predictor of these two areas of outcome, although the relationships were in the positive direction.

Finally, the psychological causal factor was a positive predictor of illness intrusiveness, anxiety and self-esteem.

4. Discussion

The present study investigated the illness representations of people experiencing MS using the widely accepted five component structure (i.e. identity, time-line, consequences, cause and cure/controllability) which has consistently been identified in past research (Leventhal et al, 1980; Leventhal et al, 1984; Leventhal & Gutmann, 1985; Lau & Hartman, 1983; Lau et al, 1989). Several important areas were explored which included: 1) the nature of the illness representations held by people with MS, 2) the relationship between illness representations and the length of time individuals had been diagnosed with this illness, 3) the inter-relationships between the different components of illness representations, 4) the associations between illness representations and outcome and 5) the extent to which illness representations explained the variance in outcome.

The results of this study will firstly be discussed in relation to the research questions, where relevant theoretical and research implications will also be considered. This will be followed by a discussion of the clinical implications of the findings and an evaluation of the methodological aspects of the study. Finally, some recommendations for future research based on the current findings are proposed.

4.1 Research question 1. What are the illness representations of people with MS?

The findings concerning the content of illness representations suggest that the participants' beliefs about the identity, time-line, cause and cure components were consistent with the general medical nature of MS. Hence, on the whole there was no indication that individuals had developed beliefs about their illness that may be

considered inappropriate. Participants demonstrated a strong illness identity which suggests that a wide range of symptoms were considered to be associated with their experience of MS, where approximately two thirds of the participants reported ten symptoms or more. Although all of the twelve symptoms included in The Illness Perception Questionnaire (IPQ) were reported by a high proportion of the participants, fatigue was marginally the most commonly experienced symptom. This can be particularly debilitating for individuals who, as a result, are often unable to maintain the levels of activity that they enjoyed prior to the onset of their illness.

It was also found that participants held a chronic time-line model of their MS and believed that a cure was unlikely indicating that they expected to experience their illness indefinitely. As described by Leventhal et al (1984) and Meyer et al (1985) there would seem to be an acceptance that MS was a constant part of the individual regardless of whether they were experiencing an exacerbation or remission of their symptoms. However, it can not be assumed that this belief indicates that individuals will be prepared for relapses. Particularly, if long periods of few or mild symptoms are experienced which may lead the individual to believe that their MS is not a serious condition and that their symptoms would be unlikely to get worse. Hence, if an exacerbation was to occur in the future, it would be unexpected and the individual may experience psychological difficulties as a result.

The widely held belief that there were no specific causes for their MS also reflects the current medical understanding of this illness. Although several possible causes of MS have been proposed within the medical literature, for example, a genetic susceptibility and viral or bacterial infections, to date there is no definitive evidence

to support these explanations. Consequently, there is much debate about the aetiology of MS.

The findings regarding the causal component of illness representations shows that the participants in this study did not consider any of the three groups of causal factors (i.e. physical, psychological and fate) to be responsible to any great degree for the development of their illness. However, chance and stress were considered the most likely of the individual causes which were both reported by approximately half of the sample. This suggests that although the onset of MS was believed to some extent to be coincidental, there was also a partial belief in a possible specific precipitating factor. The belief in stress as a causal explanation for MS corresponds with the findings of Petrie & Weinman (1998), who reported that for people who had experienced a myocardial infarction, stress was the most likely reason identified for its onset. Individuals with hypertension have also been considered to typically view their illness as the result of stress (Leventhal et al, 1998). This apparent tendency of different illness populations to commonly attribute the cause of their illness to stress may be explained by this term having a wide range of meanings and hence, could be used as an explanation for a diversity of factors. The identification of chance and stress as possible causes also indicates that participants held the perception that external rather than internal factors were the most probable explanation for their MS, over which they had had little control.

Perceptions concerning the consequences and control components showed that the participants held the belief that their MS had serious consequences and that they had limited control over their illness. MS was therefore considered to have a significant

impact on and be disruptive to many areas of an individual's life with the potential to affect, for example, their economic and financial situation, the way in which they viewed themselves, and the way in which others perceived them. The belief in limited control over MS would seem to be consistent with the unpredictability of this illness, particularly for those experiencing the relapse-remitting type. Individuals with this type of MS are often unable to predict when they will experience exacerbations and remissions of their symptoms, which is likely to produce feelings of lack of control and low self-efficacy. These feelings may also be experienced by individuals with the chronic-progressive type of MS, as it is also characterised by great uncertainty concerning how it will progress and the nature of the difficulties that could be experienced as a result of deterioration.

A comparison of the mean scores on the different components of illness representations obtained for this study with those reported by Schiaffino & Cea (1995) in a previous investigation of MS showed some slight differences. The participants in the present study considered a larger number of symptoms to be associated with their MS and demonstrated a more chronic time-line model, the perception of more serious consequences, a belief of more control over their MS and were more likely to believe in a possible cure. There was, however, similarity in the scores for the cause component, such that, it was considered that no particular group of causal factors were responsible for the development of MS. As these studies used different measures of illness representations, some caution must be taken when considering these comparisons. Schiaffino & Cea used The Implicit Models of Illness Questionnaire (IMIQ) which consists of a larger number of items than the IPQ, although there are some items which are similar. The variation in

scores for the components may therefore reflect differences between the questionnaires rather than any real differences in the illness representations held by the two samples. Compared to the findings of Weinman et al's (1996) study which included a sample of people with rheumatoid arthritis (RA), the current study found that for MS there was a stronger illness identity, the belief in a more chronic time-line model, perceived lower control over this illness and the belief that a cure was more unlikely. Although, for both RA and MS there was similarity in the perception that these illnesses had serious consequences for the individuals' lives.

As previously discussed, the nature of the illness representations identified within the present study suggest that the participants held accurate and realistic beliefs about their MS. There are several possible sources of information which may have assisted the development of these illness perceptions, including cultural and institutional factors, social communication and personal experiences of illnesses (Leventhal et al, 1998). Social communication is likely to have been the most important of these sources, where information may have been received from medical and other healthcare professionals, other people with MS and organisations, particularly, The MS Society.

A large proportion of the participants had received psychological input whether on a one-to-one or group basis, or both which would typically have involved providing the individual with information about the nature of MS and its potential effects. It is also likely that the participants received some factual information from the consultant neurologist when given the formal diagnosis of their illness. Depending on the amount of contact with healthcare services, information may also have been

gained from other professionals, such as, physiotherapists and occupational therapists. Friends or acquaintances with MS are another possible source of information where a sharing of experiences would be expected. In addition, The MS Society provide a range of materials, including information booklets, as well as, running local support groups for people with MS and their families, which is a further means through which the participants may have received relevant information about their illness.

4.2 Research question 2. Are the different components of illness representations for MS related to the length of time that people have been diagnosed with this illness?

In order to determine whether the content of illness representations develop or change with the length of time individuals have been diagnosed with MS, the associations between the different illness representation components and length of diagnosis were explored. No significant relationships were found for this analysis indicating that there were no clear patterns between the beliefs held by the participants and length of diagnosis. Consequently, no assumptions can be made concerning the illness perceptions of people with MS on the basis of how long they have been diagnosed with this illness.

An important feature of the self-regulation model is that the content of an individual's illness representations may change over time. Leventhal et al (1992) consider this assumption to be particularly important in the experience of chronic illnesses, for which a cure is often unlikely. Consequently, as such illnesses progress, individuals will need to make adaptations to their perceptions of their

illness. This process will be particularly necessary for individuals with illnesses that are characterised by an unpredictable symptom experience and course (Weinman et al, 1996). Previous research has suggested that over time, peoples' time-line models of their illness typically change from an acute to a chronic representation (Leventhal et al, 1984; Petrie & Weinman, 1998). Causal beliefs in breast cancer have also been found to change (Buick, 1998). Although for those experiencing chronic fatigue syndrome, the content of illness representations has demonstrated stability over time (Moss-Morris and Petrie, 1996, cited in Moss-Morris, 1998).

Given the nature of MS, it would be expected that the illness representations of those who experience it would be likely to change, not only over time, but with each exacerbation, after which the individual is often left with some residual symptoms and difficulties. It is therefore possible that the length of time people have been diagnosed with MS may reflect the nature of such changes. However, the results from the present study do not provide any evidence to suggest that the illness representations of people with MS change with the length of time they have been diagnosed. Hence, no support has been found for the findings of past research concerning how illness perceptions change over time.

A possible explanation for this finding is that the participants had developed representations about their illness very early on following their diagnosis which they had not needed to make significant modifications to. The content of these representations may have been influenced by the routine contact with a psychologist, which usually takes place within one month of diagnosis. Also, individuals may have gathered relevant information to help them make sense of

their illness, either prior to their MS being confirmed (particularly, if they had suspected that their symptoms were due to MS) or fairly soon after diagnosis. This would appear to correspond with the findings of the present study which suggest that the participants held beliefs about their illness that were appropriate and consistent with the medical nature of MS. Such beliefs would therefore not have needed to be adapted.

However, it is possible that at some point in time the participants' perceptions of the time-line, cause and cure components would have changed to reflect the nature of MS. Such that, when symptoms were initially experienced, individuals may have held an acute time-line model where their expectation was to be treated and cured. The shift to a chronic view of their illness was therefore likely to have taken place when it was either suspected that the individual had MS or around the time of diagnosis. This would correspond with that proposed by Petrie & Weinman (1998), who considered that the diagnosis of an illness has a direct effect on an individual's illness representations.

The findings for the present study regarding the identity, consequences and controllability of MS suggests that overall changes in the participants' perceptions of the number of symptoms experienced, the seriousness of the effects of MS on their lives and their level of control over their illness did not change according to the length of time they had been diagnosed. Consequently, it would seem that overall, adaptations to these representations had not been necessary.

4.3 Research question 3. In what ways are the different illness representation components inter-related for people with MS?

The findings concerning the inter-relationships among the different illness representation components demonstrated some important associations. The consequences component showed the largest number of statistically significant relationships which was positively related to the identity and time-line dimensions, although negatively related to the cure/controllability component. It is therefore apparent that the participants' strong belief that their MS had serious consequences for their lives was related to their perceptions of experiencing a greater number of symptoms as part of their illness, a chronic time-line model, low levels of control over their MS and an unlikely cure.

These associations suggest that the experience of many symptoms has important consequences for an individual's life, which is likely to be the result of the nature of the wide range of symptoms that are typically characteristic of MS. These symptoms themselves can be extremely debilitating, although, the unpredictability of future symptom exacerbations is also likely to contribute to beliefs about the severity of the consequences experienced. A possible explanation for the relationship between the participants' belief that MS is a chronic illness and that it has serious personal consequences is that they may have resigned themselves to having to live with MS for the rest of their lives. Consequently, they may have made unnecessary adjustments to their lifestyles on the basis that they are experiencing a chronic illness and in accordance with what they consider to be appropriate for a person with MS. The association between the consequences and cure/controllability components indicates that an individual is likely to feel that they

have limited control over their MS if it is considered to have serious consequences. They may therefore perceive themselves as unable to influence the way in which their illness affects their lives resulting in low self-efficacy and again, a possible resignation to the illness. The experience of many consequences was also associated with the participants' belief that a cure for their MS was unlikely.

A further finding of the present study was the relationship between the time-line and cure/controllability components, which demonstrated that those participants who viewed their MS to be chronic in nature were less likely to believe that their illness was potentially controllable or curable. It is possible that the awareness that their illness would be a part of them for the rest of their lives may also have led to lowered feelings of self-efficacy, which in part, is likely to be the result of the variable and unpredictable symptom experience and course of MS. Also, it would seem that the length of time an individual considers that they will experience an illness will determine the strength of their belief in a possible cure. Such that, individuals are less likely to believe in a cure for MS when they expect to experience their illness for a long period of time.

The final significant relationship found among the illness representation components was a positive association between the psychological and fate causal factors. This suggests that participants who held a stronger belief in a psychological explanation for MS were more likely to consider that fate was also important. This would appear to reflect the previous finding of the present study were chance (i.e. fate causal factor) and stress (i.e. psychological causal factor) were found to be the two most commonly reported causal attributions. A relationship was also

demonstrated between the psychological and physical causal factors, indicating that those who were more likely to attribute their MS to psychological factors were also more likely to believe in a physical cause. However, this association was just below the necessary level for statistical significance and therefore should be considered a less accurate result.

The inter-relationships between the different components of illness representations found in the present study provide some support for the findings of previous research which have included a range of illness populations, including MS, rheumatoid arthritis (RA), osteoarthritis (OA), chronic fatigue syndrome (CFS) and myocardial infarction (MI). The relationship between the identity and consequences components have been reported elsewhere (Schiaffino et al, 1998; Hampson et al, 1994; Heijmans, 1998; Moss-Morris et al, 1996; Weinman et al, 1996), as well as, the associations between the time-line dimension and the consequences and cure/controllability components (Heijmans, 1998; Moss-Morris et al, 1996; Weinman et al, 1996). Some important research findings from previous studies that have not been supported are the relationships between the identity and time-line components reported by Heijmans (1998) and Moss-Morris et al (1996) for CFS, and Weinman et al (1996) for MI. The negative relationship found between the identity and cure/controllability dimensions by Heijmans (1998) has also not been confirmed. A finding demonstrated by the present study which has not been reported previously was the inverse relationship between the consequences and cure/controllability components suggesting that this association may be most relevant to MS. In addition, the clear inter-relationships identified between some of the different illness representation components show some support for the view that

illness representations should be considered as groups of beliefs rather than individual cognitions (Heijmans, 1998; Buick, 1998; Moss-Morris, 1998).

4.4 Research question 4. Are the illness representations held by people with MS related to outcome, that is illness intrusiveness, physical functioning, depression, anxiety and self-esteem?

The mean scores calculated for each of the outcome variables provided an indication of the general extent of the psychosocial effects for people experiencing MS. The level of illness intrusiveness found for the participants of the present study indicated that MS was considered to be moderately intrusive into their lives, hence, suggesting that this illness interfered to some extent with the activities and interests which they valued and enjoyed. Compared to the findings reported by Devins et al (1993b) for an MS sample, the level of illness intrusiveness demonstrated was similar, although, it was somewhat higher than the levels reported by Devins (1994) for end-stage renal disease (ESRD). This therefore suggests that MS tends to be viewed as more intrusive than ESRD which also corresponds with the findings of Devins et al (1993b).

A possible explanation for the amount of intrusiveness experienced by those with MS is that it is in part due to the distinct and wide range of symptoms that are characteristic of this illness. The nature of the difficulties that result from these symptoms are also likely to contribute to the effects that MS has on the activities that an individual participates in. Depending on the severity of these symptoms and the associated consequences, even very simple activities can be affected. For example, visual problems, which are commonly experienced by people with MS,

are likely to interfere with a variety of activities, such as reading, writing letters and watching television. It has also been proposed by Devins et al (1993b) that the higher levels of intrusiveness reported by people with MS may be due to an over-generalisation of the effects of this illness. Such that, the consequences of MS may lead individuals to over-generalise its disruptiveness and hence, cease to participate in activities which may not otherwise be affected.

Overall, the participants demonstrated high levels of physical functioning which suggests that they had minimal physical disabilities as a result of their MS. This provides a contrast with the finding concerning the intrusiveness of MS where an assumption of the concept of illness intrusiveness is that it arises from illness-related factors, including anatomical changes, functional deficits and physical disabilities (Devins et al, 1992). On the basis of the level of illness intrusiveness found, it would therefore have been expected that the participants would have demonstrated lower physical functioning.

The findings from the present study suggest that the depression and anxiety scores for the majority of participants were below that which was indicative of a clinical disorder. Compared to previous research which has used the Hospital Anxiety and Depression Scale (HADS) for people experiencing chronic illnesses, the mean scores found in the current study were above those reported by Moorey et al (1991) for people with cancer, although similar to those reported by Earll et al (1993) for motor neurone disease (MND). It was also demonstrated that the mean anxiety score was higher than that for depression which is in accordance with the findings of Moorey et al (1991). On the basis of these results, it can therefore be suggested

that compared to individuals with cancer, those with MS are likely to experience higher levels of depression and anxiety. Although, when compared to people with MND, the levels are very similar.

Despite the overall low levels of depression and anxiety, it was found that approximately 15 and 26 per cent of the participants could be considered as experiencing probable depressive and anxiety disorders respectively. The rate of depression found for the participants was markedly below the prevalence rates that have been previously reported for individuals experiencing MS which are considered to range from 27 to 54 per cent (Dupont, 1997). When compared to the prevalence of depression within the general population, the rate demonstrated by the current findings was similar, where it has been reported that between 9 and 20 per cent of adults experience significant depressive symptomatology at any given time (Fennel, 1996; Boyd & Weissman, 1981, cited in Gotlib & Hammen, 1996). It would therefore seem that depression among people with MS is an important consideration, although the findings do not suggest that it is more common than for the general population. Consequently, support has not been found for White et al's (1993) view that depression among this illness population is more prevalent than what the research evidence indicates due to it being underdiagnosed.

The rate of probable anxiety disorder found in the present study can be considered as fairly high, which may be the result of the great uncertainty that people with MS experience. Individuals are therefore likely to feel concerned and distressed by the unpredictability of how their MS will progress, the possibility of exacerbations

which is confounded by being unable to predict when they will occur and how severe and disabling they will be, and concerns for the future.

Overall, the level of self-esteem found indicated that the participants had a strong sense of self-worth which was substantially above that reported for the general population. This is an interesting finding as it is often assumed that experiencing a chronic illness, such as MS will have important implications for how an individual views themselves. Support has therefore not been found for the findings reported by Brooks & Matson (1982) who consider that people with MS experience a lowered self-concept, particularly, in the earlier years following diagnosis which gradually improves over time. As this study does not provide an indication of whether the participants' self-esteem decreased as a result of receiving a diagnosis of MS, it is impossible to draw any conclusions about a change in their perceived self-worth over time. However, as the majority of participants had been diagnosed for ten years and under, the level of self-esteem found may suggest that important improvements in the perceptions that people with MS have of themselves occurred earlier than proposed by Brooks & Matson (1982).

The findings concerning the relationships between the different illness representation components and each of the outcome variables demonstrated many statistically significant associations. This provides evidence to suggest that the participants' beliefs about their MS played a direct and important role in governing outcome. Two of the components were significantly related to all areas of outcome, where a stronger illness identity and beliefs in more serious consequences were associated with higher levels of illness intrusiveness, greater impairment in physical

functioning, higher levels of depression and anxiety, and lowered self-esteem. This therefore suggests that for those individuals who perceive that they experience many symptoms as part of their MS and consider their illness to have many consequences for their lives will be more likely to encounter a range of psychosocial difficulties, including physical disabilities and emotional distress. This finding is consistent with that reported by Heijmans (1998) in her study of people with CFS. Although, a direct comparison is complicated by the use of some different conceptualisations of outcome for this study, which consisted of physical and social functioning, psychological adjustment and subjective well-being. Compared to the other components of illness representations, the consequences dimension displayed the strongest relationships with the outcome variables indicating that these beliefs were of particular importance.

Cure/controllability was the only other dimension which showed many associations with outcome, where it only failed to demonstrate a significant relationship with anxiety. The findings indicate that the participants who perceived themselves to have lower control over their MS and who had a weaker belief in a cure were more likely to experience increased illness intrusiveness, greater impairment in physical functioning, higher levels of depression and reduced self-esteem. The previous study conducted by Heijmans (1998), however, found the cure/controllability dimensions to be related to only one area of outcome, that is, subjective well-being. Consequently, for the present study this dimension can be considered to have wider implications for the outcomes of people with MS.

The remaining illness representation components each demonstrated only one significant association with outcome, except for the fate causal factor, where its positive relationship with self-esteem was just below the necessary level for statistical significance and therefore should be considered a less accurate result. Unlike the Heijmans' (1998) study where the time-line dimension had many relationships with outcome, within the present study this component was only significantly associated with physical functioning. This therefore suggests that those participants with a more chronic time-line of their MS were more likely to experience lower levels of physical functioning. In addition, those who held a stronger belief in a physical and psychological cause for MS was more likely to experience higher levels of illness intrusiveness and lowered self-esteem respectively.

4.5 Research question 5. Which of the illness representation components are the best predictors of outcome for people with MS?

Within the present study it was found that illness representations were important for explaining the variance in overall outcome. All except two of the illness representation components, that is, the physical and fate causal factors contributed to the explained variance for the outcome variables. This therefore suggests that beliefs concerning the influence of factors, such as a germ or virus, diet, heredity and chance in causing MS were not important for predicting outcome. For each area of outcome a different combination of illness representation dimensions were responsible for the explained variance. Illness intrusiveness had the largest amount of variance explained by illness representations, which included the identity, time-line, consequences, psychological cause and cure/controllability components.

Consequently, the beliefs that the participants held of their MS can be considered to have played an important role in determining how disruptive or intrusive their illness was to their participation in the activities and interests which they valued and enjoyed. Hence, it can be suggested that in addition to the illness-related factors proposed by Devins et al (1992), illness representations also contribute to the level of illness intrusiveness that individuals experience. In contrast, anxiety was the outcome variable with the smallest amount of variance accounted for by illness perceptions, where only the consequences component and the psychological causal factor were significant predictors.

Of all the illness representation components, the consequences dimension demonstrated the most associations with outcome where it positively predicted illness intrusiveness, depression, anxiety and self-esteem and negatively predicted physical functioning. The remaining components each showed fewer associations with the outcome areas. When comparing these findings with those of previous studies some important similarities and differences are apparent. For the present study, the consequences component was demonstrated to be a more important predictor of outcome than was found by Moss-Morris et al (1996). Although the research reported by Heijmans (1998) also indicated that beliefs regarding the consequences of an illness were strongly predictive of a number of areas of outcome. The most significant predictor of overall outcome found by Moss-Morris et al (1996) was the identity dimension, which was also demonstrated by Heijmans (1998) to predict many outcome areas. However, within the present study this component was associated with only two of the five outcome variables, that is, illness intrusiveness and depression. Both of these previous studies failed to find the

time-line component to have any predictive value of outcome, whereas, for the present study it was a negative predictor of illness intrusiveness and depression. This therefore suggests that the belief in a more chronic time-line model was associated with lower levels of illness intrusiveness and depression. The direction of these predictions is an interesting finding, as it would be expected that the relationships should have been positive. It is not clear why this was found. Although, one possible explanation is that holding an accurate view of the time-line of MS is beneficial to and adaptive for the individual as they have realistic expectations about its duration.

On the basis of the findings reported it is therefore apparent that except for the physical and fate causal factors, the illness representation components were important for explaining the variance in outcome for MS. However, unlike the studies conducted by Moss-Morris et al (1996) and Heijmans (1998) no assumptions can be made concerning whether these perceptions were more important than coping for predicting outcome as the investigation of such strategies was not included within the present study.

4.6 Clinical Implications

A number of important implications arise from the present study for the clinical practice of psychologists and other healthcare professionals who provide services to individuals with MS. It is now becoming more widely recognised that illness representations are important for understanding individuals' responses to an illness. Given the same diagnosis of MS, each individual will respond in different ways with some being far less distressed and able to cope with this chronic illness than

others. Also, some individuals will seek help from health professionals when they experience difficulties, where others will try and deal with the physical and psychosocial consequences of their MS alone, often only asking for help in desperation (Freeman, Johnson, Rollinson & Thompson, 1997). These differences in reactions are therefore considered to be due, in part, to variations in individual's illness representations (Moss-Morris & Petrie, 1994) and therefore are of interest to all professionals who are involved with people who are experiencing MS. Consequently, an awareness of the role of illness representations in peoples' responses to MS would help in the development of psychological interventions for those individuals who experience difficulty with managing and living with MS (Pimm & Weinman, 1998).

4.6.1 The nature of clinical interventions for people with MS

Of particular direct relevance for clinical psychologists is how an individual's illness perceptions contribute to and govern the psychological impact of their illness. An important area of a psychologist's work would therefore be to assist individuals in developing beliefs about their MS that would facilitate an adaptive response and minimise the extent of the psychological difficulties that they may experience. The findings that each of the five illness representation components was related to outcome and that certain components predicted specific areas of outcome has important implications for clinical psychologists and indeed, other healthcare professionals. For example, a strong illness identity and the perception of serious consequences were related to impairment in all areas of outcome, where beliefs about limited control also demonstrated many associations. It is therefore necessary

that professionals are aware that such beliefs may render individuals more vulnerable to experiencing difficulties.

In addition, the finding that the consequences component was associated with all areas of outcome provides the indication that changing the beliefs about the seriousness of the consequences of MS would be an important focus for interventions. Interventions aimed at increasing perceptions of personal control over this illness could also be associated with improvements in outcome. In order to provide an indication of the effectiveness of this type of psychological input, the measurement of an individual's illness representations both prior to and following intervention would be beneficial, where any significant changes could be determined.

The finding that only a minority of the individuals involved in the present study could be considered as experiencing psychological difficulties of a clinical level challenges the general assumption that people with MS are likely to be psychologically vulnerable. Nevertheless, it is important that psychological services are available to individuals who do encounter such difficulties, in order to prevent long-term and more severe mental health problems developing. The dilemma for clinical psychologists, however, is how to identify individuals with significant psychological difficulties, particularly, as it is widely recognised that following their diagnosis, many people with MS lose contact with health services for many years (Freeman et al, 1997). It is not clear why this should occur and therefore, it is essential that all people with MS are made aware of what services and resources are available to them as soon after diagnosis as possible. In order to encourage

individuals to make use of the services provided by NHS Trusts it is important that they are easily accessible with uncomplicated referral procedures and minimum waiting times. Such services should also be available to the families of people with MS who are also often affected by their close family member's illness.

Furthermore, it would be beneficial to provide education and training for other professionals that have contact with people with MS, for example, general practitioners, consultant neurologists, physiotherapists, occupational therapists and nurses, about the possible psychological effects that individuals with MS may experience and the role that illness representations have to play in these. This would therefore ensure that they were in a better position to identify individuals who had psychological difficulties and who were in need of input from a clinical psychologist.

Not only is it important within clinical practice to recognise particular beliefs that may lead to the development of psychological difficulties and to identify individuals who are already experiencing such problems, but it is also fundamental that interventions for people with MS are aimed at facilitating the formation of illness representations that are accurate and consistent with the actual medical nature of this illness. As noted by Moss-Morris & Petrie (1994), more accurate illness representations are likely to help individuals to keep their illness in perspective and minimise its potential effects. The period following diagnosis is likely to be the time when individuals will be most likely to develop inaccurate beliefs as they strive to make sense of their illness. It is therefore important that interventions are provided for people newly diagnosed with MS with an emphasis on the presentation of

factual information and discussions regarding individual's fears and expectations for the future. Such interventions could either be in the form of psycho-educational groups or individual input. Services for newly diagnosed people with MS would also provide the opportunity for common misconceptions of this illness population to be identified which could serve as a basis for interventions. Although, central to any intervention should be the eliciting and understanding of each individual's personal beliefs as differences between illness representations are inevitable.

4.6.2 Discrepancies in the illness representations of clients and professionals, and clients and their families

Providers of healthcare for people with MS must be aware that discrepancies between their own and their client's personal beliefs about this illness may occur. Such differences in illness representations are of particular importance as they can result in a number of difficulties. For example, compromised communication between the professional and client, reduced adherence to medical advice, greater client dissatisfaction, poorer health outcomes and ceasing contact with services (Hampson et al, 1994; Orbell et al, 1998). It is therefore important that healthcare professionals are sensitive to any differences in illness beliefs that emerge through their contact with clients and are respectful of clients' beliefs even if they are not shared by themselves. Moss-Morris & Petrie (1994) have proposed that client's representations of their illness are often private and if the client is aware that their beliefs are not the same as the professionals' then they are unlikely to discuss them for fear of confrontation. Through developing a trusting relationship and working collaboratively with clients, they may in time, feel able to share their beliefs. It would then be possible to assist them in changing those beliefs which are inaccurate

and inappropriate, and which would be likely to lead to possible difficulties in the future.

Discrepancies in beliefs about MS may also exist between the individual and their family, which also have the potential to cause difficulties. For example, differences may exist between the individual's and family's beliefs about the seriousness and consequences of MS. Conflict could therefore occur if family members believe that MS is a serious illness with many consequences and as a result, become over-protective of the individual. If the individual does not share this view, then they are likely to feel angry and frustrated by this response, particularly, if it leads to their roles within the family being reduced. Alternatively, if the family consider that MS is an illness with few consequences they may assume that the individual's life will be unaffected and expect them to continue with their previous roles, even when experiencing difficulties or an exacerbation of their symptoms. Consequently, if the individual's beliefs were different, then they would be likely to feel unsupported by their family. Clinical psychologists therefore, have an important role to play in educating families about the nature of MS and its possible consequences to reduce the likelihood of them developing beliefs that are markedly different to the individual who experiences it. It would also be necessary for clinical psychologists to provide more specific interventions to families who are experiencing significant difficulties with adjusting to having a family member with MS, which would be aimed at improving understanding and interactions within the family.

4.6.3 Transitions and illness representations

As many people with MS experience a general worsening of symptoms and decline in function over time regardless of the particular type of MS they are considered to experience, changes in illness representations will need to take place. As the physical difficulties of MS become more severe, it will be necessary for individuals to make adjustments to the beliefs they hold about their illness to maintain concordance between their illness representations and illness experience. For those who have the relapse-remitting type of MS, challenges to their beliefs will also occur with each exacerbation. It is at these times that individuals may be vulnerable to psychological difficulties, particularly, if they fail to make changes to their beliefs in response to a possible increase in symptoms and disability after the exacerbation has receded.

Such problems may also be experienced by individuals, who following diagnosis have long periods of relatively few or very mild symptoms and then are faced with an exacerbation. Prior to the relapse, they may have believed that their illness was mild and that they were unlikely to experience the more severe effects that are typical of MS. When the symptom exacerbation occurs, the individual would therefore be confronted with an experience that was not consistent with their illness representations causing confusion and uncertainty which could render the individual psychologically vulnerable. Consequently, it is important that healthcare professionals are aware that these processes take place and that the individual receives appropriate support, and if necessary, formal psychological input. The difficulty, however, is identifying people who are experiencing problems as a result of exacerbations. This is particularly the case when their physical difficulties are not

severe enough for a hospital admission where an individual's psychological distress is likely to be recognised. For those whose relapse results in an admission to hospital it would be beneficial for neurological wards to have a specialist nurse in MS who would have a greater awareness of the both the physical and psychological effects of this illness.

4.7 Methodological weaknesses

There are a number of methodological limitations of the present study which could have had an effect on the results found. These weaknesses will be discussed along with some suggestions for improvements or alternative approaches.

4.7.1 Design

The use of a cross-sectional design and the correlational nature of the data have a number of implications for the inferences that can be drawn from the study's findings. In particular, as correlations only identify relationships between two variables, no assumptions can be made concerning causality. Relationships between two variables may therefore be the result of, or influenced by another variable that is related to both variables in question. Hence, although associations were demonstrated between the different illness representation components themselves and between these components and outcome, they should not be taken as implying causal relationships. It is possible that there is a reciprocal relationship between illness representations and outcome. Such that, the type of beliefs an individual holds of their MS may influence outcome or conversely, outcome, for example, reduced physical functioning or depression resulting from this illness could determine their illness representations.

Cross-sectional designs only provide measures of variables at one point in time and therefore it not possible to ascertain whether individuals' scores on the measures used were typical for each person. In addition, the individuals' psychological status prior to them developing MS was unknown. Therefore it can not be assumed that for those participants who showed higher levels of depression and anxiety, and lowered self-esteem that these difficulties were a process of the experience of this illness. It is also feasible that these difficulties were apparent before they developed MS.

Conducting the present study as a postal survey and using a questionnaire that consisted of a series of specific measures meant that information was collected in a very structured and impersonal way. Although this can be considered a strength of the study, for example, exactly the same data was gathered in a consistent format for each participant, their answers were not subject to the researcher's interpretation and by completing the questionnaire without a researcher present the participants' may have felt able to provide more honest answers, it is also a potential limitation. The use of interviews would have had the benefit of allowing the participants greater flexibility in their responses and to provide more in-depth information which may have facilitated a better understanding of the individuals' illness representations and experience of MS. It could therefore have been useful to have conducted a brief interview with each participant prior to them completing the questionnaire to focus on these particular areas. Although this would have resulted in a smaller number of people being included in the study.

4.7.2 Sample

Although the study sample was fairly large, it may not be representative of the population of people with MS and therefore difficulties arise when generalising the findings more widely. In terms of the number of males and females that completed questionnaires, the proportion was representative of the total number of individuals who were approached to take part in the study. However, it was not representative of the national proportion, where the sample consisted of a greater number of females to males than should be expected. It is therefore apparent that the sample of people that were initially contacted was also not representative of the national gender ratio which suggests that either there were fewer males who had been diagnosed with MS in the region from where the participants were recruited or that fewer males were referred for psychological input following their diagnosis. It is not clear why the latter should have occurred, as all newly diagnosed people should be routinely referred to the psychologist. Although, it is possible that males are more likely to reject the referral and so avoid contact with the psychology department.

As the majority of the sample had received psychological input, it may not reflect the general population of people with MS, as many would be unlikely to have access to such routine and specific psychological services. The input received from the psychologist may therefore have contributed to the accuracy of the illness representations that were found and the overall low levels of psychological distress apparent among the sample. For many individuals, the initial psychological intervention would therefore seem sufficient, as despite the fact that a substantial amount of the participants did not continue to have regular, if any contact with the

psychologist, they did not demonstrate inappropriate illness beliefs or experience significant psychological difficulties.

A further important feature of the sample that may affect the generalisability of the findings was that overall the participants showed high levels of physical functioning. The sample therefore does not reflect the population of people with MS, as many would experience marked disability as a result of their illness. Those individuals with greater levels of physical disabilities, particularly, motor and co-ordination difficulties, and visual problems which would have made it difficult or impossible for them to read and complete the questionnaire would have been unable to participate. However, in an attempt to include individuals with more severe physical disabilities, it was outlined in the participants' information sheet that they could ask either someone they knew or the researcher to help them. Although a small number of people did this, others may have been reluctant to ask a family member, friend or carer to assist them with the questionnaire or discouraged by the inconvenience and extra burden of contacting the researcher. Individuals who had cognitive impairments of a more severe nature would also have been incapable of taking part in the study. In addition, the use of a postal survey may have excluded some potential participants who had difficulties with literacy skills.

It is also important to note that a large proportion of the sample had not been diagnosed with MS for a long period of time and consequently, this may have affected the results. In particular, the failure to find significant relationships between illness representations and length of diagnosis could have been due to the sample consisting of few individuals who had a long-standing diagnosis of MS resulting in

a skewed distribution. The greater number of people more recently diagnosed with MS may have had further implications for the participants' experience of this illness. Although the course of MS varies considerably between individuals, it is a progressive illness and therefore, many will experience an increase in severity and disability over time. Hence, it is feasible that the nature of the illness representations and the levels of outcome found within the present study were influenced by the majority of the sample's MS being less severe and as a result, having lower levels of physical disability. However, an alternative argument is that due to the variability of the progression of MS and the fact that many people experience symptoms for many years before being provided with a definitive diagnosis, length of diagnosis may not provide a good indicator of severity and level of disability and hence, these factors would have had minimal impact on the study findings.

In addition, it is important to note that the type of MS each respondent was experiencing would have been likely to influence their responses on each of the measures included within the questionnaire. However, as this information was not available it was not possible to explore whether the different types of MS affected both the nature of illness representations and levels of outcome. This can therefore be considered a further weakness of the study.

4.7.3 Measures

The IPQ is a relatively new measure of illness representations and therefore its psychometric properties have not been rigorously tested. However, the reliability and validity data that does exist is promising. In the present study, all except the cure/controllability scale showed high internal consistency, although it was still of

an acceptable level. Further tests of the IPQ's psychometric properties, for example, test-retest reliability would have been advantageous, however, this was not possible for practical reasons. In addition, although a revised version of the IPQ identity scale was developed for the present study, the omission of cognitive symptoms, for example, difficulties with memory and concentration places some limitations on the usefulness of this scale. As cognitive difficulties are an important feature of MS, it would therefore have been advantageous to include such symptoms.

The ADL Scale used was a newly developed measure and therefore also has limited data available on its psychometric properties. Analysis conducted by its authors has shown it to be a one-factor scale and to have very high internal consistency. This level of internal consistency was further demonstrated in the present study. However, further analyses by other researchers are necessary before its psychometric properties are confirmed.

Prior to the completion of the present study, the ADL Scale had only been used previously in a study with people with end-stage renal disease and therefore, it was not known whether it would be as suitable for individuals with MS. The data gathered from the scale suggested that it was an appropriate measure, although there are potential difficulties with the interpretation of the participants' responses for two of the items. Unlike many of the scale's items, it can not be assumed that individuals who responded 'not at all' to the 'do you manage your own garden' and 'do drive a car' items did not perform these activities due to the physical constraints of their MS. Practical reasons, that is, they had not acquired a driver's license and lived in a property without a garden could also account for this response. It may therefore have been beneficial if the scale included a 'not applicable' option.

Although, this would have implications for the scoring, where a mean score would have to be used instead of an overall total score to account for the possibility of different numbers of items being answered by each individual.

Despite the HADS being developed to exclude the physiological symptomology of anxiety and depression which can often be experienced as part of physical illnesses, item 8, 'I feel as if I am slowed down' can be considered to reflect a symptom of MS, where fatigue is a common experience. In fact, nearly a half of the sample obtained the highest score for this item, which is likely to indicate their physical experience of MS rather than a symptom of depression. In addition, participants' responses to item 10, 'I have lost interest in my appearance' may have been confounded by individuals' physical disabilities which would prevent them from maintaining their appearance in the way that they used to when they were physically more able.

It is important to note that certain factors that could have potentially influenced the content of illness representations and the individual measures of outcome were not examined within the present study. For example, there was no indication of the stage of each participant's MS, where it was not known whether they were experiencing an exacerbation or relapse at the time when they completed the questionnaire. There was also no measure of recent significant life events, for example, bereavement which would have been likely to affect scores on the HADS and RSE.

4.7.4 Data analysis

Although stepwise multiple regression was considered the most appropriate of the multiple regression methods for examining how the illness representation components predicted each of the outcome measures, it has a number of potential limitations. In particular, the inclusion criteria for the independent variables into the equation are statistical rather than theoretical. Variables are therefore only entered if they meet the criteria stipulated by the statistical package being used. However, with the simultaneous multiple regression approach, where all the independent variables are entered into the equation initially and are not subsequently removed, variables can be included according to the theoretical model being used.

4.8 Suggestions for future research

The present study has provided valuable insight into the illness representations of people with MS and how these beliefs are related to and predict outcome. However, it also highlights some possibilities for future research within this area.

The use of prospective and longitudinal designs would allow the associations between illness representations and outcome to be explored in more detail with an emphasis on establishing causal relationships. It may therefore be possible to determine whether certain illness beliefs lead to particular outcomes, such as, increased psychological distress. Such research designs would also be useful for investigating how the illness representations of people with MS change over time. The different components of illness perceptions could therefore be assessed repeatedly at different stages in the illness process to provide an indication of how individuals' beliefs change in response to the experience of their illness. Assessing

illness representations following diagnosis would also be useful for investigating whether early beliefs are predictive of later outcome. In addition, the use of longitudinal and prospective designs would make it possible to explore the important assumption of the self-regulation model that the three processing stages of representation, coping and appraisal are recursive with a longitudinal design. Hence, providing an understanding of how this feature of the model relates to MS.

Although the present study provided evidence to suggest that the illness representations of MS were related to outcome, the possible role of coping in this process was not explored. It would be useful for future research with people with MS to further study the relationships between illness representations and outcome, as well as, associations between illness representations and coping, and coping and outcome. The findings of previous studies that suggest that coping is not a mediating factor between illness representations and outcome could therefore be investigated further. Hence, providing the opportunity to ascertain whether this finding can be replicated for MS. Research regarding coping would also be important for exploring the types of coping strategies that people with MS use and to determine how such styles may change with symptom exacerbations and relapses.

A final suggestion for further research is the comparison of the present findings with a sample of people with MS who have not received psychological input for their illness. The current sample was drawn from a NHS Trust where there was a routine psychology service for all people newly diagnosed with MS. Comparing the illness representations and levels of outcome of the present study with those of individuals from regions where no such service is available would enable the

contribution of psychological input to these factors to be investigated. This may

therefore provide support for the important role that clinical psychologists have in

working with people with MS and the development of psychology services for this

illness population nationwide.

5. Conclusion

On the basis of the present study, it can be concluded that the illness representations held by people with MS have important relationships with outcome. Illness identity and the perceived consequences that this illness has for individuals' lives demonstrated relationships with all areas of outcome. Although, the consequences component was the most important for predicting overall outcome. It can also be concluded that people with MS generally have accurate and realistic beliefs about their illness and, on the whole, do not experience significant psychological difficulties as a result of their illness experience.

These findings have important clinical implications for all healthcare professionals that have contact with people with MS, where the role of clinical psychologists can be considered as central to the services provided to this illness population. Understanding the beliefs that individuals have of their MS and their relations to outcome, such as, emotional well-being and physical disabilities provides valuable insight into the type of illness perceptions that may lead to difficulties in these areas. It also allows individuals to be identified who may be at risk of developing problems with managing and living with their MS. Clinical psychologists therefore, have a fundamental part to play, not only in the development and provision of interventions for people with MS who experience psychological difficulties, but also in educating other healthcare professionals about the importance of illness representations for this illness.

Further investigation of the illness representations of people with MS is necessary to broaden understanding in this area. In particular, research using prospective and

longitudinal designs is needed for exploring the way in which the beliefs of this

illness population change over time and with the progression of MS. Such studies

would also be useful for providing an indication of the nature of the possible causal

relationships between illness representations and outcome.

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APPENDICES

Appendix A: Letter to participants' General Practitioners

Dear Dr

I am proposing to contact the following patient(s) of yours for their consent to be included in a survey of people with M.S:

All the people in the survey have been seen or given the opportunity to see a clinical psychologist following their diagnosis of M.S. This is part of the routine service provided by the Neurology Department at Gloucestershire Royal Hospital.

The survey aims to find out more about the beliefs that people with M.S have about their illness and the consequences that M.S has had on their lives. The results will be very useful in helping us improve the services currently provided to people diagnosed with M.S and their families.

The research is being carried out as part of a Doctorate in Clinical Psychology and is being conducted under the supervision of Leslie Morrison, Chartered Clinical Psychologist, Department of Health Psychology, GRH.

I am planning to send patients an information sheet, a letter requesting their participation in the project and a consent form for them to return to the Health Psychology Department (see attached copies).

If people are happy to be involved in the project, I will send them a questionnaire through the post and I am available to help them complete it if they anticipate having any difficulties.

The questionnaire will be completely confidential and the completed forms will only be seen by the Researcher.

People's participation or not in the survey will in no way interfere with their access to the services provided at GRH either currently or in the future.

If you have any concerns about us contacting your patients or any questions about the research project, please contact Rachel Vaughan at the Health Psychology Department, GRH on (01452) 394448.

If I do not hear from you within two weeks, I shall assume that you are happy for us to contact your patients.

Thank you for your help.

Yours sincerely

Rachel Vaughan
Psychologist in Clinical Training/Researcher.

Appendix B: Participants' initial invitation letter

Dear

You may remember that as part of the routine service provided by the Neurology Department you were given the opportunity to meet with someone to discuss the impact of the diagnosis of M.S and how you were coping with it.

I am contacting you again to ask if you would be willing to take part in a research project. The aim of the research is to find out more about the beliefs people have about their illness and the consequences that M.S has on their lives. The results will be very useful in helping us improve our services to people diagnosed with M.S and their families.

The research is being conducted by a clinical psychology trainee, under my supervision and is part of the requirements for her Doctorate in Clinical Psychology. I am enclosing an information sheet and consent form.

If you were able to help, this would be very much appreciated, however, you are in no way obliged to do so. Your decision to participate or not would not in any way interfere with your access to our service either currently or in the future.

If you have any questions or would like any further information about the project, please contact Rachel Vaughan (Researcher) at the Health Psychology Department, Gloucestershire Royal Hospital on (01452) 394448. If you get an answerphone, then please leave a message, which will be responded to promptly.

Yours sincerely

Leslie Morrison
Chartered Clinical Psychologist – Neurology
Department of Health Psychology

Enc.

MULTIPLE SCLEROSIS SURVEY

PARTICIPANTS' INFORMATION SHEET

We are conducting a research project into the beliefs that people with Multiple Sclerosis (MS) have about their illness. We are also interested in the consequences of MS and the ways in which this illness may interfere with day-to-day life. This information will be useful for helping us improve the services that we provide for people with MS and their families.

As someone who has been diagnosed with MS, we would greatly value your participation in this study. Your views are important, as they will help increase our understanding of how people see their MS and the affect that it has on their lives.

If you agree to participate in this survey, you will be sent a questionnaire which should take between 20-30 minutes for you to complete. In order to let us know whether or not you would like to take part, please complete the enclosed consent form and return it in the stamped addressed envelope provided by **Friday 27 November 1998**.

Due to the physical effects of MS, some people may experience difficulty with filling in the questionnaire. If you feel that this applies to you, then please ask someone you know to help you. Alternatively, Rachel Vaughan (Researcher), will be able to arrange to complete the questionnaire with you.

Please note:

• All of the information that you provide will be treated in **strictest confidence** and your anonymity will be assured.

• Your decision whether or not to participate in the project will not affect your access to services for people with MS.

- Your answers to the questionnaire will not interfere in any way with the services you are currently receiving and will only be seen by the Researcher.

- You have the right to withdraw from the study at any time.

Thank you in anticipation of your help with this survey.

Rachel Vaughan	Psychologist in Clinical Training - Researcher (Dept of Health Psychology, GRH/University of Leicester)
Dr G Fuller	Consultant Neurologist (GRH)
Dr D Stevens	Consultant Neurologist (GRH)
Leslie Morrison	Clinical Psychologist - Neurology (Dept of Health Psychology, GRH)

If you would like any further information about this project, please contact Rachel Vaughan on (01452) 394448. If you get an answer-phone, please leave a message, which will be responded to promptly.

Appendix D: Participants' consent form

MULTIPLE SCLEROSIS SURVEY

PARTICIPANTS' CONSENT FORM

To let us know whether or not you would like to be included in this survey, please complete and return this consent form in the stamped addressed envelope provided by_____1998.

I am / am not (please delete as applicable) willing to participate in the research project as outlined on the Participants' Information Sheet.

I will / will not (please delete as applicable) need help from the Researcher to complete the questionnaire.

Name: _____   Signature:_____

Address:_____

_____

_____

_____

Telephone Number: _____

ID NO_____

Appendix E: Section of questionnaire covering demographic details

> **About you and your Multiple Sclerosis**

The following questions ask for details about you and your Multiple Sclerosis (M.S).
For each question, place a tick in the box opposite the response that best applies to
you or where required, write your answer in the box provided.

1) Are you...

☐ Male
☐ Female

2) How old are you?

☐ years

3) Are you...

☐ Single
☐ Married
☐ Living with partner
☐ Living away from spouse/partner, e.g. in residential care
☐ Separated/Divorced
☐ Widowed

4) What is your occupation?

☐ Employed – Full-Time
☐ Employed – Part-Time
☐ Self-Employed
☐ Unemployed
☐ Unemployed/On Sick Leave due to MS
☐ Retired
☐ Housewife
☐ Student

5) What year were you diagnosed with M.S?   ☐

6) What year did you first experience your symptoms?   ☐

7) Apart from your MS, do you have any other medical or health problems?   ☐ Yes
☐ No

If YES, please describe...   ☐

8) Did you have help to complete the questionnaire?   ☐ Yes
☐ No

BEST COPY NOTE

THE FOLLOWING PAGES
ARE STUCK IN SUCH A
MANNER THAT
FILMING IS IMPEDED

Your views about your Multiple Sclerosis

Please circle the number that best describes how often you experience each of the following symptoms as part of your Multiple Sclerosis.

	All the time	Frequently	Occasionally	Never
1. Pain and discomfort	1	2	3	4
2. Urinary frequency and/or urgency	1	2	3	4
3. Numbness and/or tingling	1	2	3	4
4. Heavy feeling in arms and legs	1	2	3	4
5. Fatigue	1	2	3	4
6. Visual problems	1	2	3	4
7. Difficulties with balance and/or co-ordination	1	2	3	4
8. Loss of fine movement in hands	1	2	3	4
9. Soreness in muscles	1	2	3	4
10. Sleep difficulties	1	2	3	4
11. Muscle cramps and/or spasms	1	2	3	4
12. Loss of strength	1	2	3	4

We are interested in your own personal views of how you now see your Multiple Sclerosis (MS). Please indicate how much you agree or disagree with the following statements about your MS by circling the appropriate number.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
1. A germ or virus caused my MS	1	2	3	4	5
2. Diet played a major role in causing my MS	1	2	3	4	5
3. Pollution of the environment caused my MS	1	2	3	4	5
4. My MS is hereditary – it runs in my family	1	2	3	4	5
5. It was just by chance that I became ill	1	2	3	4	5
6. Stress was a major factor in causing my MS	1	2	3	4	5

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
. My MS is largely due to my own behaviour	1	2	3	4	5
. Other people played a large role in causing my MS	1	2	3	4	5
. My MS was caused by poor medical care in the past	1	2	3	4	5
. My state of mind played a major part in causing my MS	1	2	3	4	5
. My MS will last a short time	1	2	3	4	5
. My MS is likely to be permanent rather than temporary	1	2	3	4	5
. My MS will last for a long time	1	2	3	4	5
. My MS is a serious condition	1	2	3	4	5
. My MS has had major consequences on my life	1	2	3	4	5
. My MS has become easier to live with	1	2	3	4	5
. My MS has not had much effect on my life	1	2	3	4	5
. My MS has strongly affected the way others see me	1	2	3	4	5
. My MS has serious economic and financial consequences	1	2	3	4	5
. My MS has strongly affected the way I see myself as a person	1	2	3	4	5
. My MS will improve with time	1	2	3	4	5
. There is a lot which I can do to control my symptoms	1	2	3	4	5
. There is very little that can be done to improve my MS	1	2	3	4	5
My treatment will be effective in curing my MS	1	2	3	4	5
Recovery from MS is largely dependent on chance or fate	1	2	3	4	5
What I do can determine whether my MS gets better or worse	1	2	3	4	5

te: The scoring for this version of the IPQ is the reverse to that stated by Weinman et al (1996) which was used in this nat for the data collection stage only.

Appendix G: Summary of factor analysis for the IPQ cause scale

Item	Component		
	1	2	3
8. Other people played a large role in causing my MS	.871[a]	.158	-.105
10. My state of mind played a major part in causing my MS	.766[a]	-.159	.230
6. Stress was a major factor in causing my MS	.740[a]	9.135	4.108
7. My MS is largely due to my own behaviour	.533[a]	.191	.492
1. A germ or virus caused my MS	-8.197	.787[b]	-.125
2. Diet played a major role in causing my MS	.245	.752[b]	.104
3. Pollution of the environment caused my MS	.245	.716[b]	.111
5. It was just by chance that I became ill	.118	-.199	.735[c]
4. My MS is hereditary – it runs in my family	-.158	.380	.608[c]
9. My MS was caused by past poor medical care in the past	.384	2.672	.392[c]

[a] Component 1: psychological cause   (24.90% of variance)
[b] Component 2: physical cause   (19.69% of variance)
[c] Component 3: fate   (14.10% of variance)

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Appendix H: Illness Intrusiveness Ratings Scale (IIRS)

> **How your Multiple Sclerosis affects your life**

The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. For each item, please <u>circle</u> the number that best describes your current life situation. If an item is not applicable, please circle the number 1 to indicate that this aspect of your life is not affected very much.

How much does your illness and/or its treatment *interfere* with your:

1.   **HEALTH**

   Very little   1   2   3   4   5   6   7   Very much

2.   **DIET (i.e. the things you eat and drink)**

   Very little   1   2   3   4   5   6   7   Very much

3.   **WORK**

   Very little   1   2   3   4   5   6   7   Very much

4.   **ACTIVE RECREATION (e.g. sports)**

   Very little   1   2   3   4   5   6   7   Very much

5.   **PASSIVE RECREATION (e.g. reading, listening to music)**

   Very little   1   2   3   4   5   6   7   Very much

6.   **FINANCIAL SITUATION**

   Very little   1   2   3   4   5   6   7   Very much

7.   **RELATIONSHIP WITH YOUR SPOUSE/PARTNER**

   Very little   1   2   3   4   5   6   7   Very much

How much does your illness and/or its treatment *interfere* with your:

8.   **SEX LIFE**

Very little   1   2   3   4   5   6   7   Very much

9.   **FAMILY RELATIONS**

Very little   1   2   3   4   5   6   7   Very much

10. **OTHER SOCIAL RELATIONS (e.g. friends)**

Very little   1   2   3   4   5   6   7   Very much

11. **SELF-EXPRESSION/SELF-IMPROVEMENT**

Very little   1   2   3   4   5   6   7   Very much

12. **RELIGIOUS EXPRESSION**

Very little   1   2   3   4   5   6   7   Very much

13. **COMMUNITY AND CIVIC INVOLVEMENT**

Very little   1   2   3   4   5   6   7   Very much

Appendix I: Activities of Daily Living Scale (ADL Scale)

> **The impact of your Multiple Sclerosis on your ability to complete daily activities**

Below are listed a series of activities grouped into categories (*Mobility*, *In the kitchen* etc). For each activity, please select the response which best applies to you by circling the appropriate number. If your symptoms vary, then choose the response that best reflects your ability on an average day.

Mobility	Not at all	With help	Alone with difficulty	Alone easily
Do you:				
O **walk around outside?**	0	1	2	3
O **climb stairs?**	0	1	2	3
O **get in and out of bed?**	0	1	2	3
O **get in and out of a car?**	0	1	2	3
O **cross roads?**	0	1	2	3
O **travel on public transport?**	0	1	2	3

In the kitchen				
Do you:				
O **manage to feed yourself?**	0	1	2	3
O **manage to make yourself a hot drink?**	0	1	2	3
O **do the washing up?**	0	1	2	3
O **make yourself a hot meal?**	0	1	2	3

Domestic tasks

Do you:	Not at all	With help	Alone with difficulty	Alone easily
O manage your own money when you are out?	0	1	2	3
O wash small items of clothing?	0	1	2	3
O do your own shopping?	0	1	2	3
O do a full clothes wash?	0	1	2	3

Self-care

Do you:

	Not at all	With help	Alone with difficulty	Alone easily
O manage to dress yourself?	0	1	2	3
O manage to bath yourself?	0	1	2	3
O manage to use the toilet?	0	1	2	3

Leisure activities

Do you:

	Not at all	With help	Alone with difficulty	Alone easily
O read newspapers or books?	0	1	2	3
O use the telephone?	0	1	2	3
O write letters?	0	1	2	3
O go out socially?	0	1	2	3
O manage your own garden?	0	1	2	3
O drive a car?	0	1	2	3

Appendix J: Hospital Anxiety and Depression Scale (HADS)

> **About how you feel**

Emotions play an important part in most illnesses. This questionnaire is designed to find out about how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the **past week.**
Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. Please tick only one box in each section.

1. I feel tense or 'wound up'

Most of the time □
A lot of the time □
Time to time, Occasionally □
Not at all □

2. I still enjoy the things I used to enjoy

Definitely as much □
Not quite so much □
Only a little □
Hardly at all □

3. I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly □
Yes, but not too badly □
A little, but it doesn't worry me □
Not at all □

4. I can laugh and see the funny side of things

As much as I always could □
Not quite so much now □
Definitely not so much now □
Not at all □

5. Worrying thoughts go through my mind

A great deal of the time □
A lot of the time □
From time to time but not too often □
Only occasionally □

6. I feel cheerful

Not at all □
Not often □
Sometimes □
Most of the time □

7. I can sit at ease and feel relaxed

Definitely □
Usually □
Not often □
Not at all □

8. I feel as if I am slowed down

Nearly all the time
Very often
Sometimes
Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

10. I have lost interest in my appearance

Definitely
I don't take so much care as I should
I may not take quite as much care
I take just as much care as ever

11. I feel restless as if I have to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

12. I look forward with enjoyment to things

As much as ever I did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. I get sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

14. I can enjoy a good book or radio or TV programme

Often
Sometimes
Not often
Very seldom

Appendix K: Rosenberg Self-Esteem Scale (RSE)

> Your feelings about yourself

Here is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement by <u>circling</u> the appropriate number.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. On the whole, I am satisfied with myself.	1	2	3	4
2. At times I think I am no good at all.	1	2	3	4
3. I feel that I have a number of good qualities.	1	2	3	4
4. I am able to do things as well as most other people.	1	2	3	4
5. I feel I do not have much to be proud of.	1	2	3	4
6. I certainly feel useless at times.	1	2	3	4
7. I feel that I'm a person of worth, at least on an equal plane with others.	1	2	3	4
8. I wish I could have more respect for myself.	1	2	3	4
9. All in all, I am inclined to feel that I am a failure.	1	2	3	4
10. I take a positive attitude toward myself.	1	2	3	4

GLOUCESTERSHIRE
HEALTH AUTHORITY

VICTORIA WAREHOUSE
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Our Ref: IPD/bke/wglrec/study no 98/21W

Please ask for: Beryl Elliott

19th October 1998

Miss Rachel Vaughan
Psychologist in Clinical Training

Dear Miss Vaughan

Re Study No 98/21W: The Illnesss Representations of Multiple Sclerosis

Thank you for your letter of 22nd September enclosing the information requested. I apologise for the delay in responding. We are now able to give you full approval to proceed with the study on condition that you remove the last sentence of Paragraph 3 of the Participants' Information Sheet - "If we do not hear from you by then, we will assume that you are happy to be included and send you the questionnaire".

The Committee draws your attention to:

a)   The responsibility of the investigator to notify the LREC immediately of any information received by him/her of which he/she becomes aware which would cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the LREC and/or which would raise questions about the safety and/or continued conduct of the research.

b)   The need to comply with the Data Protection Act 1984.

c)   The need to comply, throughout the conduct of the study, with good clinical research practice standards.

Chairman: Chris Creswick   Chief Executive: Jeff James

NHS
1948 - 1998

d)   The need to refer proposed amendments to the protocol to the LREC for further review and to obtain LREC approval there to prior to implementation (except only in cases of emergency where the welfare of the subject is paramount).

e)   The requirement to furnish the LREC with details of the progress of the research project periodically (usually annually) and **failure to do this could result in approval to continue with the study being withdrawn.** Please also inform us of the conclusion and outcome of the research project and inform the LREC should the research be discontinued or any subject withdrawn altogether

A list of the members of the West Gloucestershire LREC may be supplied if required.

Yours sincerely

Beryl Elliott

I P Donald MA FRCP
Chairman, West Gloucestershire LREC

Appendix M: Summary of *t*-test for gender differences - means and standard deviations

Variable	Sex	N	Mean	Standard Deviation
Identity	Male	21	9.29	3.24
	Female	73	10.52	1.91
Time-line	Male	24	3.97	0.97
	Female	76	4.30	0.72
Consequences	Male	24	3.60	0.94
	Female	76	3.53	0.72
Physical cause	Male	24	2.31	0.86
	Female	76	2.32	0.78
Psychological cause	Male	24	2.41	0.84
	Female	77	2.35	0.80
Fate	Male	24	2.25	0.72
	Female	74	2.21	0.59
Cure	Male	23	2.77	0.75
	Female	75	2.80	0.58
Illness Intrusiveness	Male	24	47.79	17.03
	Female	74	41.53	17.28
Physical Functioning	Male	23	45.96	21.59
	Female	71	51.94	17.69
Depression	Male	24	6.88	5.06
	Female	79	6.09	3.91
Anxiety	Male	24	8.25	5.53
	Female	77	8.66	4.42
Self-esteem	Male	23	23.83	7.34
	Female	77	23.03	5.78

Appendix N: Summary of one–away ANOVA for age differences – means and standard deviations

Variable	Age-group	N	Mean	Standard Deviation
Identity	21-30	7	9.43	2.82
	31-40	26	10.00	2.50
	41-50	35	10.37	2.37
	51-60	22	10.32	2.03
	61-70	3	11.67	.58
	71-80	1	12.00	.
	Total	94		
Time-line	21-30	6	4.33	.37
	31-40	27	4.21	.94
	41-50	36	4.25	.77
	51-60	26	4.26	.73
	61-70	4	3.42	.50
	71-80	1	5.00	.
	Total	100		
Consequences	21-30	6	3.12	.61
	31-40	27	3.55	.77
	41-50	36	3.50	.79
	51-60	27	3.68	.78
	61-70	3	4.10	.79
	71-80	1	3.00	.
	Total	100		
Physical cause	21-30	7	1.86	.72
	31-40	27	2.63	.84
	41-50	34	2.27	.75
	51-60	27	2.14	.74
	61-70	4	2.33	1.05
	71-80	1	3.00	.
	Total	100		
Psychological cause	21-30	6	2.17	.56
	31-40	27	2.32	.85
	41-50	35	2.42	.75
	51-60	28	2.36	.87
	61-70	4	2.13	1.01
	71-80	1	3.50	.
	Total	101		
Fate	21-30	6	1.94	.71
	31-40	27	2.17	.60
	41-50	32	2.26	.60
	51-60	28	2.25	.67
	61-70	4	2.58	.42
	71-80	1	1.67	.
	Total	98		

Variable	Age-group	N	Mean	Standard Deviation
Cure	21-30	6	3.00	.30
	31-40	26	2.99	.59
	41-50	35	2.75	.71
	51-60	27	2.66	.57
	61-70	3	2.44	.59
	71-80	1	2.50	.
	Total	98		
Illness Intrusiveness	21-30	7	32.14	11.75
	31-40	26	42.46	18.70
	41-50	34	41.38	15.36
	51-60	26	47.42	19.20
	61-70	4	51.50	17.06
	71-80	1	45.00	.
	Total	98		
Physical Functioning	21-30	7	60.86	13.58
	31-40	24	54.75	18.42
	41-50	35	51.63	17.91
	51-60	23	43.48	19.39
	61-70	4	40.75	23.88
	71-80	1	35.00	.
	Total	94		
Depression	21-30	7	4.14	3.80
	31-40	27	5.11	3.53
	41-50	36	6.44	4.33
	51-60	28	7.39	4.65
	61-70	4	7.25	2.22
	71-80	1	11.00	.
	Total	103		
Anxiety	21-30	7	7.71	3.90
	31-40	27	8.04	4.16
	41-50	35	8.11	4.25
	51-60	27	9.89	5.85
	61-70	4	9.25	4.92
	71-80	1	6.00	.
	Total	101		
Self-Esteem	21-30	7	22.14	4.06
	31-40	25	22.32	5.74
	41-50	35	23.00	5.93
	51-60	28	24.21	7.16
	61-70	4	25.25	8.02
	71-80	1	24.00	.
	Total	100		

Appendix O: Correlation coefficients calculated using Pearson's r for the associations between the illness representation components and length of diagnosis

	Length of diagnosis
Identity	.04 $p = 0.68$ N = 94
Time-line	.05 $p = 0.65$ N = 100
Consequences	.13 $p = 0.19$ N = 100
Physical cause	.21 $p = 0.04$ N = 100
Psychological cause	.17 $p = 0.09$ N = 101
Fate	.11 $p = 0.29$ N = 98
Cure/Controllability	-.25 $p = 0.02$ N = 98

Bonferroni adjustment for multiple correlations indicated a significance level of $p < 0.007$