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Self-Regulation in Multiple Sclerosis: The Role of Illness Cognitions and Coping in Adjustment.

Christy AJ Fergusson-White

Department of Psychology

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Dedication

To my beautiful mother who is always there when I need her. Her wisdom and strength not only inspires me but makes me strive to become half the woman she is. To my kind father, who I can always depend on, who continually supports and guides me with his wise words and gentle nature. To my husband Jonathan, who has not only shown me that some people were just meant to be together but has made me realise how wonderful life in love can be. To my grampa, his fighting spirit and if not slightly eccentric personality has taught me the importance of hard work, dedication and not caring what others think, his generosity and humour never fail to amaze me. In loving memory of my grandmother, her unwavering love, selflessness and devotion to those in her life even now still astounds me, you are dearly missed. To all the wonderful friends who believe in me and can always make me laugh till it hurts. Finally, to my gorgeous dogs Rosie and Tigger who constantly remind me that there is more to life than work, thank you for not only keeping me company everyday but keeping me smiling.

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Abstract

Multiple Sclerosis (MS) is a chronic neurological condition, which affects around 2.5 million people worldwide. At a time when there is yet no recognised cure, it is imperative that MS patients learn to cope and adjust well to living with the illness. However, research has found high rates of psychological distress associated with MS (Minden & Schiffer, 1991). This highlights the need for research to investigate the psychological factors, which make MS patients vulnerable to psychological distress. One popular social cognition model called the Self-Regulation Model (Leventhal et al., 1980) has been found to successfully predict adjustment in a range of chronic illnesses. However, previous research applying the SRM to understand adjustment to MS has been limited. The current research therefore represented the first attempt to successfully apply the full SRM to an MS population prospectively.

The present thesis is comprised of three studies and employed a mixed quantitative and qualitative research design method. Studies 1 (N=103) and 3 (N=150) were both quantitative studies, which applied an extended SRM model to clinical samples of MS patients and assessed indices of psychological distress over time. Study 2 (N=15) however was a qualitative study, designed to investigate MS patients experiences of living with the condition. By combining both quantitative and qualitative methods, the findings provided a fuller understanding of the psychological factors underlying successful adjustment to MS.

Overall the findings provided some support for the utility of the extended SRM in predicting adjustment to MS and highlighted the importance of positive mind states and acceptance for successful adjustment to the condition. The findings also had a number of clinical implications, which are also discussed.

Chapter 1: Review of Multiple Sclerosis

1 Overview

This chapter presents and discusses key information about Multiple Sclerosis (MS). Firstly, it gives a clear definition of what MS is, identifies the prevalence of the illness and considers the different aetiological theories put forward to explain why individuals develop the condition. In addition, this chapter examines the three main diagnostic criteria and highlights some of the difficulties patients encounter in receiving a diagnosis. Furthermore, it discusses some of the possible treatment avenues available to help patients manage their MS. Finally, it provides information regarding both the physical and psychological impact of living with the condition and considers the potential implications of these problems on the patient's quality of life. Overall, this chapter serves as an introduction to the doctorate research, highlighting key information about MS essential for understanding the development, design and implementation of this research.

1.1 Definition of Multiple Sclerosis

Multiple Sclerosis (MS) is defined as a chronic degenerative neurological condition, which creates demyelination (destruction of the neuron's myelin sheath) of the central nervous system (CNS) (brain and spinal cord), resulting in delayed or blocked nervous impulses. The immune system attacks the myelin sheath around the axons (nerve cells) of the CNS, which produces plaques and lesions. The disease is characterised by areas of inflammation in the white matter (myelin rich part) of the brain and spinal cord, leading to swelling (oedema), destruction of myelin (demyelination), scarring and loss of axons. Multiple Sclerosis literally means 'many scars'. Demyelination and neuronal damage result in impaired transmission of the nerve impulses to the muscles and other organs, as a result almost all the functions associated with the CNS can be affected (Mohr & Cox, 2001).

1.2 Prevalence

Currently, there are believed to be around 10,500 MS patients in Scotland, 85, 000 in the United Kingdom (UK) and 2.5 million worldwide. Furthermore, these numbers are rising, with approximately between 10 and 12 individuals per 100,000 being diagnosed with MS every year. At present, Scotland has the highest prevalence of MS in the world. In the UK, there is believed to be a north-south difference between England and Scotland, with a prevalence in England and Wales of between 100 and 120 per 100,000 whereas in Scotland, it is nearer to 190 cases per 100,000 (Multiple Sclerosis Trust, 2004). The reason for this north-south difference remains unknown. Since Scotland currently has the highest rate of MS in the world, research investigating MS in this country is timely and important. Table 1-1 shows the estimated numbers of MS cases in Scotland for 2005. These rates are based on the mid-2005 population estimates by the General Register Office for Scotland (Rothwell & Charlton, 1998).

Table 1-1 Estimated numbers of MS cases in Scotland by health board and gender in 2005.

Health Board	**Male**	**Female**	**Total**
Argyll	224	551	775
Ayrshire	198	488	686
Borders	59	146	205
Dumfries and Galloway	80	197	277
Fife	193	474	667
Forth Valley	154	378	532
Grampian	284	699	983
Greater Glasgow	469	1,154	1,623
Highland	115	284	399
Lanarkshire	301	741	1,042
Lothian	428	1,054	1,482
Orkney	11	26	37
Shetland	12	29	41
Tayside	210	518	728
Western Isles	14	35	49
Scotland	2,751	6,776	9,527

Source: Rothwell and Charlton, 1998.

1.3 Who gets MS?

Research suggests that women are twice as likely as men, to develop MS (Ebers, 1986; Minden & Schiffer, 1991; Mohr & Cox, 2001). MS usually presents itself when patients are in their twenties and thirties, at a time when they are beginning to establish their careers and families (Minden and Schiffer, 1991) However, women tend to develop MS at an earlier age than men (Ebers, 1986; Minden & Schiffer, 1991).

1.4 Aetiology

There is still great controversy over what causes MS. To date, the nature and aetiology of MS remains unknown. Some have argued that the condition is the result of non-specific mild, presumably viral infection (Poser, 1995). However, research has identified a number of factors, which could cause individuals to develop MS. Due to the high prevalence of this condition in Scotland, many people believe that geographic location may be an important factor.

Other people argue that it is caused by the individual's genetic make-up, either that they inherit the condition from someone in their family or that they are genetically predisposed to develop MS. Some blame environmental factors such as pollution, while others put it down to chance or bad luck. However, no specific factor or factors have been identified as the definite cause and without knowing what is responsible for MS the avenues for developing treatments remain limited. Despite the sparse knowledge about what causes this condition and how to cure it, researchers have successfully identified a number of characteristics, which have increased the understanding of this illness.

1.5 Types of MS.

There have been four different types of MS identified, each with different characteristics.

Benign: Between 10 and 20% of MS patients suffer from the benign course of the illness, which is characterised by an abrupt onset and occasional relapses. However, this type of MS does not progress and neurological symptoms remain unaffected long after they have been diagnosed. An individual can only receive a diagnosis of benign MS once they have had little or no disability for a period of 5 to 10 years. Even patients' diagnosed with benign MS experience MS-related problems and a relapse can still occur even after many years of the illness being inactive (Jopson & Moss-Morris, 2003; National MS Society, 2005).

Relapsing-Remitting: Most individuals receive an initial diagnosis of relapsing-remitting MS. This type of MS is characterised by episodes of acute neurological dysfunction (relapses, attacks or exacerbations) followed by a period of remission. Relapses occur when the inflammatory cells attack the myelin of specific nerves, interfering with normal cell function. Relapses can last for days, weeks or even months and can vary in their level of severity. Remission occurs only once the inflammation fades and symptoms calm down. In the earlier stages of this type of MS, it is common for patients to make a complete recovery from symptoms following relapses. However, after several relapses there can be some residual damage to the myelin, consequently patients may only partially recover (Multiple Sclerosis Trust, 2004; National MS Society, 2005).

Secondary-Progressive: On average 65% of those who are initially diagnosed with relapsing-remitting MS, develop this form of the illness within 15 years of their diagnosis. In secondary-progressive MS, patients do not make a full recovery from symptoms after a relapse, they experience an unremitting loss of function and consequently, their level of disability steadily increases and becomes permanent over a period of time. The extent of the condition and rate it develops varies for each individual (Jopson & Moss-Morris, 2003; National MS Society, 2005).

Primary-Progressive: This type of the disease is relatively uncommon with only 10-15% of patients being diagnosed with primary-progressive. It is most prevalent amongst older patients who are in their forties or above. From onset individuals experience a continual worsening of symptoms with no distinct relapses or remissions. In some cases the patient’s symptoms may eventually level off however, in others they may continue to worsen (Jopson & Moss-Morris, 2003; Multiple Sclerosis Trust, 2004; National MS Society, 2005). Men are more likely to suffer from the progressive form of the condition than women (Ebers, 1986).

The effect each of these four types can have on patients’ lives varies markedly. For example, the benign type may enable individuals to live relatively unaffected by the condition. The secondary-progressive course however, is likely to have severe consequences for both the patient and their family. Even patients who have been diagnosed with the same type of MS can be affected differently, since the course of the illness varies depending on the individual. In addition, the type of MS a person has often changes over time. Individuals are therefore faced with high levels of uncertainty. This unpredictability is reinforced by the wide and confusing number of symptoms associated with MS. It is therefore unsurprising, that MS can potentially have a considerable impact of all areas of the patient’s life.

1.6 Diagnostic criteria

Due to the high numbers inflicted with MS worldwide, a number of standardised diagnostic criteria were developed. (Schumacher et al., 1965) created the first set of diagnostic criteria for MS and these have been the basis of all subsequent criteria. The Schumacher criteria relied largely on a neurological examination by the doctor and the patient’s symptom history. They were implemented at a time when Magnetic Resonance Imaging (MRI) techniques and many of the other testing procedures such as Cerebro Spinal Fluid (CSF) testing and Visual Evoked Potentials (VEP) had not yet been developed. MRI scans were employed in 1977 and a new set of criteria called the Poser criteria were developed in 1983. The Poser criteria were much more specific as they recognised the usefulness of MRI scans and spinal taps in the detection of brain and spinal lesions.

For twenty years, both the medical community and researchers have relied on the Poser criteria for diagnosing MS. These criteria are however, insufficient for the new classes of clinical trials and do not reflect the advances in technology for MS detection. In October, 2001 the McDonald criteria were published. These criteria provided further improvement on the requirements for MS diagnosis and placed greater emphasis on using MRI scans, VEPs and CSF testing for detecting MS (Long, 2005). Using the McDonald criteria, the process of diagnosing MS according to the National MS Society (2005) involves a number of stages;

Stage 1. Evidence is taken from a patient's medical history to identify what symptoms, past and present, they have been experiencing. However, a history of the symptoms alone does not indicate MS, since any one or combination of the symptoms could be caused by factors unrelated to MS.

Stage 2. A clinical examination is carried out. This clinical examination may consist of an eye examination, a check of muscle strength, measuring coordination, examination of body surface sensation, a test of vibratory sense and a test of reflexes.

Stage 3. The final stage is one or more laboratory tests. These tests are essential in diagnosing MS. The preferred test is an MRI scan, which can detect plaques or scarring caused by MS. The MRI scan is a diagnostic tool, which uses magnetism instead of radiation and provides a non-invasive, yet sensitive way of imaging the brain. It provides doctors with pictures of any lesions or areas of damage. However, despite the sensitivity of this test an abnormal MRI does not necessarily confirm the presence of MS, as other conditions may cause lesions in the brain, which resemble those caused by MS. In addition, a normal MRI does not mean that MS can be ruled out either. Although a diagnosis of MS may be given based on the history of symptoms, signs and the results of the MRI, there are a number of additional tests, which may be carried out to provide a definite diagnosis that satisfies the McDonald criteria (McDonald et al., 2001). These include evoked potential, cerebrospinal fluid and blood tests.

1.7 Diagnostic difficulties

Despite the development of these improved diagnostic criteria, MS remains a difficult condition to detect since there has not yet been a single definitive test developed. The diagnosis is primarily one of exclusion, depending on identifying multiple central nervous system lesions over time and the exclusion of other causes (Poser et al., 1983). Sufferers often describe a confusing and short-lived array of symptoms, which often cannot be observed directly by health professionals. Furthermore, these symptoms can fluctuate rapidly. This leads to many patients being misdiagnosed, often as suffering from a psychiatric disorder as opposed to a neurological condition. MS patients therefore experience a great deal of psychological distress due to the long period of uncertainty, resulting from multiple testing, doctor’s visits and hospitalisation in pursuit of diagnosis. Patients may feel misunderstood and unsupported. The patient’s doctor and family may in turn be frustrated by their constant complaints about unexplained symptoms (Minden & Schiffer, 1991).

1.8 Treatments

Once individuals receive a confirmed diagnosis of MS they are then faced with the reality that to date, there is no available cure for this condition. However, there have been a large number of drug treatments developed to help manage and alleviate specific symptoms and reduce exacerbations (flare ups of symptoms). One common treatment for MS is beta-1 interferon, which comes in two forms, beta-1a and beta-1b. There are two types of beta-1a interferon, Avonex and Rebif and one beta-1b labelled Betaseron. They aim to decrease the frequency of clinical exacerbations and prolong the accumulation of physical disability. There are also a number of other commonly used treatments for patients with relapsing forms of MS such as Natalizumab, Mitoxantrone and Glatiramer

Acetate (Copaxane), (National MS Society, 2005). A number of drug treatments have also been developed for treating the specific symptoms of MS. For example, Baclofen is often used as muscle relaxant to help treat spasicity and Oxybutin is taken for bladder dysfunction.

Drug treatments for MS therefore, vary in their approach to treating this condition. Those such as beta-1 interferon, aim to reduce exacerbations and delay physical disability as a whole, whereas others have been designed to treat specific symptoms, some on a physical level such as Baclofen and others on an emotional level such as antidepressants. Since there is no recognised cure for MS, there is consequently a large variation in how people choose to treat their condition. Some patients do not take any medication and simply persevere with their symptoms in the hope that a cure will be developed, whereas others can find themselves on a large cocktail of drugs, each with their own side effects. The treatment options available although extensive, do not offer patients a cure. Many of the medications are only suitable for certain types of MS and patients can often experience side effects, which may be worse than the initial symptom being treated. This trial and error process may only lead to further frustration and distress.

1.9 The impact of MS on quality of life

The extent MS can affect each aspect of the patient’s life, including their working, social and home life, is determined largely by both the physical and psychological impact of the condition. The number and severity of physical symptoms experienced places a variety of limitations on the patient’s day to day activities. Furthermore, the psychological impact of living with MS can have considerable implications for their everyday life. In order to assess the impact of this illness on overall quality of life, it is therefore essential that both the physical and psychological impact of the condition be taken into consideration.

1.9. 1 Physical impact of MS

1.9.1.1 Primary symptoms

The symptoms of MS not only vary in nature, they can also fluctuate daily in severity. Fatigue (lack of physical energy) is believed to be the most common and also the most troubling symptom of MS (Fisk et al., 1994; Freal et al., 1984; Krupp et al., 1988) Other common symptoms associated with the condition include cognitive problems (40-60%) (Rao, 1986; Rao et al., 1991), pain, muscle weakness, muscle spasms, numbness, tingling and muscle stiffness, disruptive bladder problems. All of these are considered to be primary symptoms of the condition, since they are all a direct consequence of demyelination (destruction of myelin surrounding the nerve fibres). In addition, MS patients can also experience a number of secondary symptoms.

1.9.1.2 Secondary symptoms

Secondary symptoms are created as an indirect consequence of the primary symptoms or the experience of suffering from a chronic illness. Patients with bladder dysfunction, for example, often experience urinary tract infections. Another example is a loss of muscle tone or poor postural alignment, both of which are secondary symptoms caused by inactivity. Although secondary symptoms can often be treated, neurologists and health professionals often aim to avoid them completely by treating the primary symptoms (National MS Society, 2005).

1.9.1.3 Tertiary symptoms

Primary and secondary symptoms, can lead MS patients to develop what the

National MS Society call ‘tertiary symptoms’. These are the social, vocational and emotional problems, which arise as a result of experiencing the primary and secondary symptoms. MS patients not only experience a range of somatic complaints, they also experience depression, anxiety, hopelessness, and suicide ideation. These can occur as primary, secondary or tertiary symptoms (Sadovnick et al., 1991) and have important implications on the patient’s quality of life. In addition to understanding the physical impact MS can have on the patient’s life, it is also important to appreciate the psychological impact of the condition.

1.9.2 Psychological impact of MS

1.9.2.1 Depression and anxiety

MS patients have been found to experience greater levels of depression than individuals from the general population (Hickey & Greene, 1989; Jean et al., 1997; Minden et al., 1987) and those from other medically ill groups (Hickey & Greene, 1989; Minden et al., 1987; Schubert & Foliart, 1993). Estimates of the current prevalence of depression in MS range from 14 to 57% (Minden et al., 1987). Despite the high levels of depression, there is limited knowledge about the cause of these symptoms. Furthermore, research has shown that the severity of the depressive symptoms experienced in MS is not related to the illness or demographic factors (Minden et al., 1987).

MS patients also suffer from high levels of anxiety, which are greater than those from the general population (Maurelli et al., 1992) and other medical groups such as spinal cord injury patients (MacLeod et al., 1998). Work to date suggests the point prevalence of anxiety in MS patients ranges from 19% to 34% (Minden & Schiffer, 1991; Pepper et al., 1993; Stenager et al., 1994). However, despite these high rates little attention has been given to anxiety associated with MS. In addition, research investigating the point prevalence of anxiety in MS has been criticized because of the small sample sizes used and the lack of consistency in the methods employed across the studies (Mohr & Cox, 2001).

Research has found an overlap in symptoms between MS and psychiatric disorders such as depression and anxiety. This can often to lead to patients intially receiving a psychiatric diagnosis for their condition. However, psychological differences have also been idenitified between depressed MS patients and those with psychiatric disorders such as anxiety and depression. Depression in MS is marked by anger, irritability, worry and discouragement instead of self-criticism, withdrawal and loss of interest associated with psychiatric disorder (Minden et al., 1987). This highlights the need to develop interventions more specific to MS-related depression and anxiety.

1.9.2.2 Hopelessness and suicide ideation

Living with a chronic condition as unpredictable as MS, in the knowledge that there is no cure, can make it difficult for patients to remain hopeful. Hopelessness has been defined as the extent an individual is pessimistic about the future and is thought to be the pernicious link between depression and suicide (seeO'Connor & Sheehy, 2000 for a review). The occurrence of hopelessness in patients with MS is important to take into consideration, since elevated levels of suicide have been identified in this condition (Kahana et al., 1971; Sadovnick et al., 1991; Stenager & Stenager, 1992; Stenager et al., 1992). For example Feinstein, (2002) found that as many as one-third of MS patients have had thoughts of suicide over the course of their lifetime.

Research has identified a variety of factors which are associated with elevated levels of suicide such as early illnes onset, deteriotration of MS, a history of alcohol abuse and social isolation (Feinstein, 2002; Stenager et al., 1992). However, the cause of suicide in MS has not been established (Feinstein, 2002).

1.9.3 Overall impact of MS

MS can profoundly affect individuals on both a physical and psychological level. Physically patients can experience a wide array of primary and secondary symptoms, which lead to a number of social, vocational and emotional problems referred to as tertiary symptoms (see section 1.9.1.3.). The physical symptomology of MS can therefore have profound implications on the patient's everyday life. Research investigating the psychological impact of MS has found a high incidence of anxiety, depression, hopelessness and suicide ideation amongst MS patients (see section 1.9.2) highlighting the need for successful interventions to reduce these levels of distress associated with MS.

1.10 Summary

The growing numbers of individuals suffering from MS, highlights the need for research to gain a greater understanding of this condition. Research investigating MS in Scotland is of particular importance, considering this country now has the highest prevalence of MS in the world. At a time when no cure has been developed, the best option for improving quality of life is therefore, ensuring that patients cope and adjust well to living with the condition. Unfortunately, research investigating the psychological impact on MS has shown that many individuals expereince psychological distress. These findings demonstrate the need for interventions to help individuals cope and adjust successfully to living with MS. Psychological research aimed at identifying the factors, which predispose individuals to psychological distress is therefore timely and important. Only by identifying these can successful interventions be designed to improve quality of life.

In psychology, researchers have developed a number of psychological models to help explain how indivduals cope and adjust to illness. By applying these models to a range of illnesses and health behaviours, researchers have been able to identify those factors, which predipose individuals to psychological distress. These psychological models will be the focus of Chapter 2.

Chapter 2: Psychological Models

2 Overview

The aim of this chapter is to review the range of psychological models, which have been developed to explain health behaviour. Firstly, it discusses social cognition and self-regulatory models and then cognitive models of psychopathology. Researchers have used these models as a framework for understanding how individuals adjust to illness. However, a full description of all these models would be extensive and is beyond the scope of this chapter. Therefore key models have been selected, which are useful in understanding adjustment to MS. An outline of the models examined in this chapter, in addition to the key constructs and references of each model are shown in table 2-1 below.

Table 2-1 Psychological models

Name of Model	Constructs	Key Reference
Social Cognitive Theory	Self-efficacy beliefs.	Bandura (1977; 1982; 1986)
Health Locus of Control	Internal locus of control, external locus of control, powerful others, chance.	Rotter (1954; 1966)
Stress and Coping Model	Primary appraisal , secondary appraisal, coping.	Lazarus and Folkman (1984)
Self-Regulation Model	Illness representations (identity, cause, control, timeline, consequences), coping.	Leventhal et al (1980;1984)
Cognitive Model of Depression	Automatic negative thoughts, cognitive schema, negative triad.	Beck (1967), Beck et al (1979)
Learned Helplessness	Lack of control attributed to internal/ external, specific/global and stable/unstable.	Maier and Seligman (1976), Abramson et al (1978)
Hopelessness Theory	Inferred cause, inferred consequence, inferred characteristics about the self.	Abramson et al (1989)

2.1 Development of social cognition and self-regulatory models

Before the first half of the twentieth century, infectious diseases were the main cause of morbidity and mortality in industrial countries (Armstrong et al., 1999). Nowadays however, death is predominantly caused by cardiovascular disease and cancer, illnesses increasingly being associated with health-impairing behaviours such as smoking, drinking alcohol, poor nutrition and lack of exercise (McGinnis & Foege, 1993). The increasing importance placed on the role of lifestyle factors has led psychologists to attempt to develop an empirical and theoretical understanding of the psychological determinants in health behaviour (de Wit & Stroebe, 1995, 2004).

Researchers have distinguished between two types of health behaviours. Firstly, health-impairing behaviours (e.g. smoking, binge-drinking, unprotected sex), which have a negative effect on health and secondly, health-protective behaviours (e.g. exercise, healthy eating), which have a positive effect (Matarazzo, 1984). Health behaviours are viewed as social behaviours and are influenced by a variety of factors. The social-psychological approach to health behaviour emphasizes the role of social-cognitive factors. In particular, this approach focuses on the class of social cognitions, which are associated with beliefs about the consequences of specific behaviours. Beliefs, are socially acquired and shared experiences. They are associated with the thoughts an individual has about the attributes of a specific situation or condition. They also take into consideration the outcomes of performing specific courses of action (de Wit & Stroebe, 2004).

To understand health behaviours researchers developed a number of social cognition and self-regulatory models. These models identify a number of important cognitions and explain the role these cognitions play in the regulation of health behaviours. Social cognition and self-regulatory models examine factors, which predict behaviour and/or behavioural intentions. They also assess why individuals fail to maintain a particular behaviour even when the individual is committed to it (Ogden, 2000).

Conner and Norman (1995) and Conner (1995) have highlighted a number of potential advantages for employing these models in health psychology. First of all, these models give a clear theoretical background to research. They direct the selection of variables to assess and guide the procedures employed to develop reliable and valid measures and explain how these variables combine to predict health behaviour. Secondly, they further our understanding of health and enable us to design effective interventions to change the cognitions underlying healthy behaviours. Finally, they provide us with a description of the cognitive processes, which determine why individuals are motivated to perform different behaviours.

2.2 Different types of social cognition and self-regulatory models

There have been two broad types of these models applied in health psychology (Connor, 1993). Firstly, there are attribution models. These are concerned predominantly with an individual’s casual explanations of health-related events. The second type investigates the various aspects of an individual’s cognitions in order to predict future health-related behaviours and outcomes (Conner & Norman, 1995).

The social cognition and self-regulatory models discussed in this chapter, include the Health Locus of Control Theory (HLC: Rotter, 1954; 1966), Social Cognitive Theory (SCT: Bandura, 1977,1982,1986), the Transactional Stress and Coping Model (Lazarus, 1984) and the Self-Regulation Model (Leventhal et al., 1980; Leventhal et al., 1984b). There are a number of other social cognition and self-regulatory models, which have been used to predict health-behaviours including the Health Belief Model (HBM: Becker, 1974; Rosenstock, 1966) Protection Motivation Theory (PMT: Rogers, 1975,1983,1985; van der Velde & van der Pilgt, 1991), Theory of Reasoned Action/ Theory of Planned Behaviour (Aijzen & Fishbein, 1970; Fishbein, 1967; Fishbein & Aijzen, 1975), the Transtheoretical Model of Change (Prochaska & DiClemente, 1982). However, these will not be discussed as a full description of all these models would be too extensive and beyond the scope of this chapter.

2.3 Social Cognitive Theory

Social Theory Cognitive theory is a Social Learning Theory, developed by the famous psychologist Albert Bandura at Stanford University. He changed the name of his social learning theory to Social Cognitive Theory as a way of emphasising the vital role cognition plays in an individual’s ability to create reality, self-regulate, encode information and perform behaviours (Pajares, 2002). In 1977, Bandura identified the concept of self–efficacy beliefs as a key component, which was missing not only from prevalent learning theories but also from his own social learning theory. First of all this section gives an overview of the core assumptions of Social Cognitive Theory and then focuses more specifically on the role self-efficacy beliefs.

2.3.1 Core assumptions of the Social Cognitive Theory

Based on Social Cognitive Theory human behaviour is a function of the interaction between personal, behavioural and environmental influences (Bandura, 1977,1986). According to this theory, human motivation and action is regulated by forethought. This anticipatory control mechanism involves three kinds of expectancies; 1) situation-outcome expectancies, 2) action-outcome expectancies and 3) perceived self-efficacy.

Situation-outcome expectancies reflect the belief that the world is altered without ones own personal engagement. From this perspective, behavioural outcomes are seen as a result of the environment and occur even without the individual taking personal action. Individuals can sit and wait for things to occur however, illusions about what the future holds can allow people to cope with the threat of a stressful situation. For example individuals can anticipate disease and consequently, may alter their beliefs about the likelihood of it occurring. This response can be referred to as defensive optimism. However, with action-outcome expectancies the outcomes are seen as a result of personal actions. Finally, perceived self–efficacy is associated with the person’s beliefs about their ability to perform a specific behaviour in order to achieve a specific outcome. Action-outcome expectancies and self-efficacy expectancies include the chance to change the world and deal instrumentally with health threats by taking preventative action. These reflect functional optimism (Schwarzer & Fuchs, 1995)

2.3.2 The role of self-efficacy beliefs

Adopting a health promoting behaviour or refraining from a detrimental habit depends on three cognitions 1) the expectancy that one is at risk, 2) the expectancy that the behavioural change will reduce the threat and 3) the expectancy that the individual is capable of performing (health promotion behaviour) or refraining (health risk behaviour) from the behaviour. To initiate and maintain health behaviours it is therefore not only necessary to perceive an action outcome contingency, the individual needs to believe that they have the ability to perform the behaviour (Schwarzer & Fuchs, 1995). This highlights the importance of self-efficacy beliefs in predicting health behaviours.

Perceived self-efficacy is defined as *'peoples judgements of their capabilities to organize and execute courses of action required to attain designated types of performances'* (Bandura, 1986; p. 391). Self–efficacy beliefs determine life choices, motivation levels, quality of functioning, resilience to adversity and vulnerability to stress and depression. These beliefs are developed based on four main sources of influence. The first and most important source is through the individual's previous performance or mastery experiences. By interpretating the results of previous experiences the individual forms beliefs about their ability to perform in subsequent activities and consequently, behaves in accordance to these beliefs. Secondly, self-efficacy beliefs are formed by the vicarious experience of seeing others similar to oneself (referred to as social models) successfully performing tasks. The third way is through social and verbal persuasion. Finally, these beliefs are influenced by assumptions from somatic and emotional states, which indicate personal strengths and weaknesses (Bandura, 1994). A large body of research has investigated the role of optimistic self-beliefs as a predictor of health behaviour change (O'Leary, 1992; Schwarzer, 1992)

2.3.3 The role of self-efficacy in adjustment to illness

Self-efficacy perceptions are believed to play a key role in dealing with chronic illness (Holman & Lorig, 1992) as they determine whether an individual will attempt to initiate health-related behaviours in the first place. Studies investigating the role of self-efficacy in adjustment to illness have found that individuals with strong self-efficacy beliefs experience higher levels of motivation and have the intention to perform specific health behaviours. However, according to Clark and Dodge (1999) when considered within the context of real behaviour results can vary. For example some behaviour associated with illness management such as giving up smoking is maintained by strong habitual factors, which make it problematic for people to change despite their initial levels of confidence. The concept of self-efficacy is associated with the concept of personal control. This is a broader conception of the belief that one can influence ones behaviour, environment and create desired outcomes (de Ridder et al., 1998). Research has found the individuals who believe they can personally control their illness are more likely to adhere to medical regimes (Helgeson, 1992).

The importance of health control beliefs has been recognised by a number of researchers and consequently, has been central to the development of another social cognition model called the Health Locus of Control (HLC) Theory. According to this theory, an individual’s perceptions of control are central to determining health behaviours and in turn adjustment to illness. The following section therefore examines this model in more detail.

2.4 Health Locus of Control Theory

The origin of the Health Locus of Control (HLC) construct can be traced to Julian B. Rotter's (1954) theory of social learning. According to his theory the chance of a behaviour occurring in any situation is determined by two major kinds of 'expectancy'. The first is the individual's expectancy that the behaviour will lead to a specific outcome/reinforcement and the second is the extent he/she values the outcome/reinforcement (Rotter, 1954). Based on this earlier social learning theory Rotter in 1966 developed the construct of HLC. This section examines the core assumptions of the HLC theory to provide a fuller understanding of the constructs of this theory. It describes how this theory has been operationalized in addition, to examining the findings of researchers employing these measures to a range of conditions. Finally, it discusses the limitations of this theory.

2.4.1 Core assumptions of the HLC Theory

The HLC Theory is the extent an individual believes their health is controlled by internal or external factors. The construct, locus of control therefore represents a generalized expectancy about who or what determines the rewards and punishments in a person's life. Locus of control is considered to be either internal or external (Rotter, 1966,1982). Through a learning process individuals develop the belief that specific outcomes are caused by their own actions (internal) or caused by other forces independent of themselves (external) (Rotter et al., 1972). An internal locus of control is the belief that the rewards the person accrues and the control of future outcomes is controlled by oneself.

An external locus of control however, is the belief that positive and negative events are not contingent upon oneself but are governed by outside factors such as powerful other people or fate/chance (Rotter, 1966,1982).

Hannah Levenson (1973) offered an alternative view to Rotters (1966) uni-dimensional (internal to external) conceptualization of locus of control. Levenson's model proposed that there are three independent dimensions: Internality, Chance and Powerful Others. According to this model, an individual can employ each of these components independently or simultaneously (Levenson, 1973).

The HLC theory predicts that individuals with an internal locus of control are more likely to engage in health promoting activities. The assumption is that internality is the most beneficial. However, there are some situations where an external locus of control is considered advantageous. A belief in powerful others may be of greater value for hospitalised individuals with acute illness and a belief in chance locus of control may be more adaptive in situations where individuals have limited opportunity to change their health status.

2.4.2 The role of control beliefs in understanding health behaviour.

The main way the HLC construct has been applied, is as a predictor of preventative health behaviour. The construct locus of control has been used by a number of researchers to explain and predict a variety of health-specific behaviours. It is believed that those with internal locus of controls will take active responsibility for their health and therefore perform health behaviours. However, the evidence for this has been weak overall Wallston (1991; 1992) concluded that the amount of variance explained the HLC construct is low. He argued that health behaviours are complex and multi-determined (Norman & Bennett, 1995). Consequently, Wurtele et al (1985) argued that the HLC theory may simply be too narrow to explain this behaviour adequately. Norman and Bennet (1995) conclude that there is a need to consider variables from other theoretical approaches. This is just one of the limitations of the HLC theory.

2.4.3 Limitations of the HLC Theory

According to Ogden (2000) there are a number of other problems with this theory. Firstly, it is unclear if health locus of control is a state (determined by mood) or a trait (determined by personality) response. For example if it is a trait response then the individual will always have an internal locus of control. It is also unclear whether individuals can be both internal and external. Thirdly, is seeking medical attention for a health condition related to an external locus of control (i.e. “The doctor is a powerful other who can make me better”) or internal (i.e. “I am determining my health status by searching out appropriate treatment”).

2.4.4 Application of the HLC to understanding adjustment to illness

Despite the limitations of this theory, perception of control appears to play a determining role on how individuals cope and adjust to illness. However, the research implies that investigating the role of control beliefs alone may not provide a full understanding of how individuals adjust to illness. Researchers suggested that the concept may be too narrow to explain health behaviour. This highlights the need to take other psychological factors into consideration when investigating adjustment to illness. The final two social cognitions models discussed in this chapter have recognised the importance of control beliefs in health behaviour. However, in addition to taking into account the role of control beliefs they also identify a number of other psychological factors, which may be influential in adjustment to illness. The first of these models is the Transactional Model of

Stress and Coping (Lazarus, 1984).

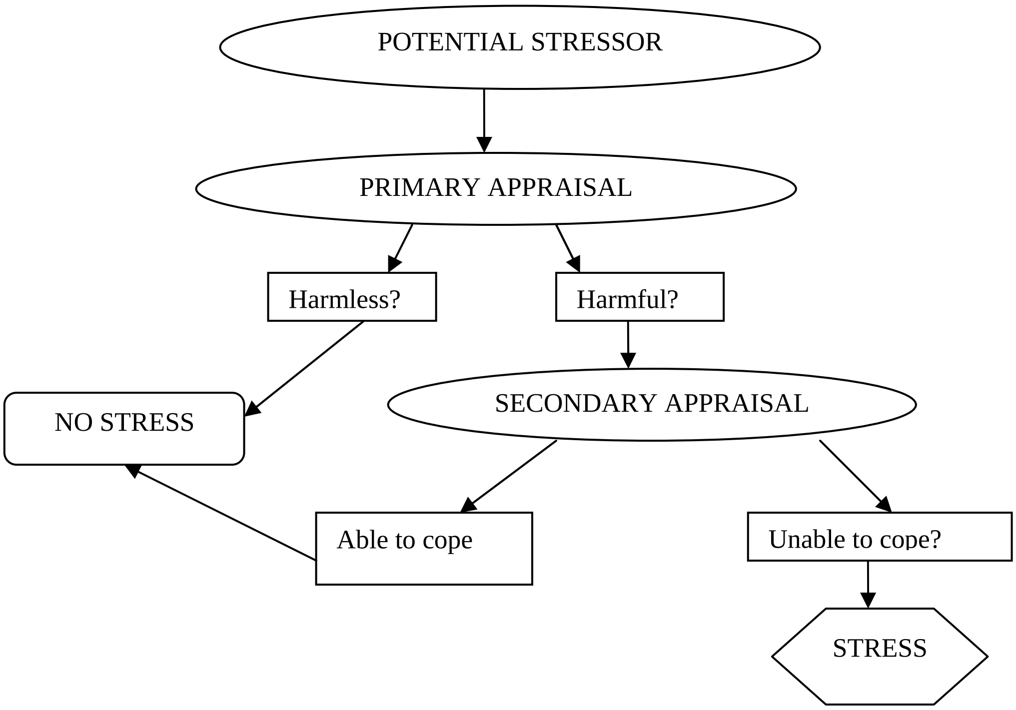
2.5 Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping was developed by Lazarus and Folkman in 1984, as a framework for explaining the processes involved in coping with stressful events. This model represents a novel way of looking at the stress response. Based on this theory, individuals are viewed as psychological beings who appraise the outside world instead of just passively responding to it. When faced with a health threat such as a chronic illness, individuals make an appraisal of the situation in terms of threat, challenge or controllability. The following section discusses this model in detail.

2.5.1 Core assumptions of the Stress and Coping Model

According to this theory, the experience of stress is the result of a transactional process between the individual and their external world (Ogden, 2000).This relationship is mediated by both the individual’s appraisal of the stressor and also the social and cultural resources the individual has access to (Antonovsky & Kats, 1967; Cohen, 1984; Lazarus & Cohen, 1977). Individuals are constantly appraising their transactions with their environment. Cognitive appraisals are defined as evaluative processes, which reflect the person’s interpretation of the event. Events are appraised in terms of threat, challenge and controllability (Lazarus, 1984). Individuals engage in a variety of ever-changing and evolving appraisal processes which have an impact on their emotional reactions to the chronic illness including potential coping strategies. Cognitive appraisal and coping strategies act as mediational processes between the potential stressor and the outcome (Pakenham & Stewart, 1997).

Figure 2-1 A schematic representation of the Stress and Coping Model.



Source: Myer, Newman & Enomoto (2004)

2.5.2 Components of the Stress and Coping Model

As illustrated in the schematic representation of the model, there are a number of key components to this model. As Figure 2-1 shows this process begins when an individual is faced with a potential stressor. Stressors are defined as demands which are made by the internal and external environment that upset balance and therefore influence physical and psychological well-being. They require action in order to restore balance (Lazarus & Cohen, 1977). According to this model, when an individual encounters a potential stressor, they firstly appraise the potential threat in terms of their own well-being. An event can be appraised as irrelevant, benign and positive or harmful and negative. This is referred to as primary appraisal (Myers et al., 2004). If the situation is appraised as a threat, the individual will make a secondary appraisal to decide on the course of action they will take (Cohen, 1984; Ogden, 2000). The type of coping strategy employed is therefore determined by the individual's appraisal of the threat and the resources available to help the individual cope. It aims to reduce the demands placed on the individual and therefore reduce the level of stress (Myers et al., 2004; Petrie & Moss-Morris, 1997).

Coping is defined as those ‘constantly changing cognitive and behavioural efforts (used) to manage specific external and/or internal demands that are appraised as taking or exceeding the resources of the person” (Lazarus and Folkman, 1984, p.141). Coping style refers to the strategies employed by an individual to deal with the demands that are appraised as taxing their resources. Lazarus and Folkman (1984) identified two general types of coping. The first is labelled problem-focused coping, which refers to patients’ efforts to manage the stress by problem solving or doing something to alter the source of the stress (Myers et al., 2004). These strategies include defining the problem, generating alternative solutions and weighting alternative solutions (Folkman & Lazarus, 1980). The second type of coping identified is emotion-focused coping, which involves attempts to reduce or manage emotional distress associated with the situation. (Myers et al., 2004). These strategies include minimization, distancing, selective attention, positive comparisons and wrestling positive value for negative events, self-blame, wishful thinking and avoidance. Folkman and Lazarus (1980) developed a measure called the Ways of Coping Questionnaire to assess the coping component of this model. Since the original development of the scale there have been a number of revisions (Folkman & Lazarus, 1985; Vitaliano et al., 1985). Embedded in this measure is the distinction between problem-focused coping and emotion-focused coping (Myers et al., 2004).

The coping responses elicited by the individual will in turn lead to an event outcome (e.g. favourable resolution, unfavourable resolution or no resolution). The process of appraisal, coping and event outcomes also generates emotion. A favourable event outcome is likely to result in a positive emotion and this will end the coping response. However, an unsatisfactory outcome such as an unfavourable resolution or no resolution is likely to lead to distress and further coping.

2.5.3 Support for the Stress and Coping Model

The relationship between cognitive appraisal of illness and psychological distress has been well established (Pakenham & Stewart, 1997). A large number of studies have found an association between high levels of stress, threat appraisal and poorer adjustment (Stanton & Snider, 1993; Thompson et al., 1992). However, evidence for the association between controllability appraisals, challenge appraisals and better adjustment is weaker (e.g. Stanton and Snider, 1993).

Research has shown that coping behaviours differ depending on the individual’s appraisal of the stressful event and the context in which this appraisal occurs. A number of cross-sectional studies with healthy community populations have been carried out by Lazarus and his colleagues (Folkman & Lazarus, 1980; 1985; 1986). These studies revealed that problem-focused coping strategies are employed when the individual views the event as changeable or manageable. However, in instances when the individual assesses the situation as having to be accepted they are likely to use emotion-focused strategies (Folkman & Lazarus, 1980).

Overall the Stress and Coping Model, highlights the importance of the individual’s appraisals or beliefs in determining how they cope with stressful situations, which in turn, determines how they adjust. When considered in the context of a chronic illness such as MS, this model suggests that the way in which the patient views the condition, will affect the types of coping strategies they employ, which in turn, will affect whether they experience psychological distress or a good quality of life. This relationship between illness appraisal, coping and adjustment has also been central to another social cognition model called the Self–Regulation Model (SRM). The SRM focuses more specifically on adjustment to illness as opposed to stress in general or a health threat. In particular this model emphasises the importance of illness appraisals and refers to these illness beliefs as illness representations. This model is discussed in detail in the following section.

2.6 The Self-Regulation Model

This section examines the research and theory behind the Self-Regulation Model of Illness Cognition and Behaviour (SRM; Leventhal et al, 1980). The SRM is the underlying framework upon which the current doctorate research is based. Therefore, the SRM is discussed in more detail than the other models examined in this chapter.

2.6.1 The development of the SRM

The development of the SRM originates from a series of studies on fear communications carried out in the late 60s by Leventhal and his associates (Leventhal, 1970). These studies showed that actions such as stopping smoking only occurred when individuals were exposed to a fear message and an action plan (e.g. a leaflet illustrating the location of the Student Health Center on campus and details of the hours its is open). They found that only the combination of the action plan and fear message led to a change in attitude over a period of days or weeks.

Earlier results had shown that feelings of fear or fear induced attitude change faded with 48 hours. This suggested that the action plan was not associated with the fear itself but in a sense, altered the individual's perception or representations of the health threat. This led Leventhal et al (1980) to the realization that the representation of the health threat in combination with the action plan was the factor, which influenced the individual's coping actions. To investigate this further they began to design studies to define the nature of these representations (Diefenbach & Leventhal, 1996).

Illness representations are defined as a patient's own implicit, common-sense definition of their health threats (Leventhal et al., 1998; 1980; Weinman et al., 1996). The researchers used two different approaches to identify the nature of these illness representations. Firstly, they carried out a series of experimental studies, which assessed how the preparation of noxious experiences affected emotional reactions and coping procedures. Secondly, they focused on patients verbal responses and examined the meaning the patient assigned to somatic stimuli. Based on the findings from the preparation studies they assumed that patients would perceive somatic sensations as indicators of underlying disease.

2.6.2 Core assumptions of the SRM.

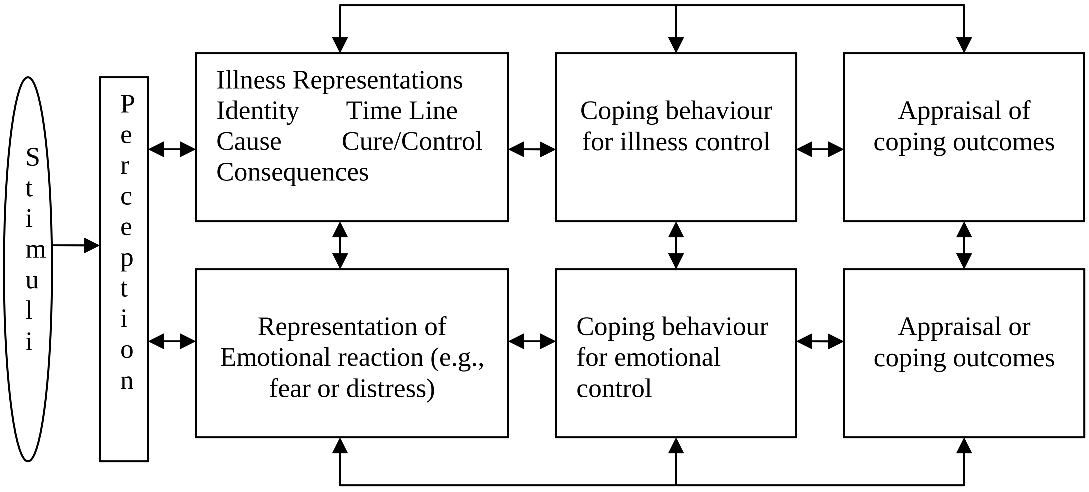
Based on their early studies Leventhal et al (1980) developed SRM, which suggests that illness representations are directly related to coping and via coping, they are related to outcome. This model views illness perceptions as essential in directing the way a patient copes with symptoms, illness and threats to health. In essence, this theory argues that psychosocial adjustment following illness is predicted by mental representations that we possess about an illness (illness representations) and these, in turn, determine our coping strategies. An illustration of the relationships between illness representations, coping and adjustment according to the SRM is shown in Figure 2-2. It consists of four features: the cognitive representation of illness, the emotional response to the illness and treatment, the coping directed by the illness representations and the individual's appraisal of the coping outcome. The model assumes that coping mediates the relationship between illness representations and adaptive outcome(Leventhal et al., 1980).

Leventhal et al (1980) proposed that the SRM is a 'parallel-processing' model. The model views the individual as a problem solver who is faced with two phenomena. The first is the perceived reality of the health threat. The second is their emotional reaction to this threat. Illness representations are therefore, not only made up of cognitive dimensions, but also contain an emotional representation. The individual is therefore involved in parallel-processing, as they make simultaneous cognitive and emotional representations of their illness (Diefenbach & Leventhal, 1996).

The emotional representation of illness has not been as well developed and as a result, the relationship between these two systems has not been fully elaborated (Lobban et al., 2003). It is believed that the emotional aspect will increase or decrease the intensity of illness symptoms and create symptoms. These symptoms can become confused with those caused by the condition. Consequently, the individual may focus on the negative outcomes of the condition, therefore having a reciprocal relationship with the cognitive processing (Leventhal et al., 1984b).

There are three central tenets, which underlie the SRM. Firstly, the individual is perceived as an active problem solver who seeks out information and tests hypotheses about the meaning of their somatic sensations (symptoms) and physical condition. They also assess the relevance of this, in terms of the media and interpersonal messages they receive about health threats. Secondly, illness representations are viewed as the primary cognitive structure, which directs coping efforts and the individual’s appraisal of the action outcomes. Finally, these representations are highly individual and often are not congruent with medical variables (Diefenbach & Leventhal, 1996).

Figure 2-2 A schematic representation of the Self-Regulation Model.



2.6.3 Formation of illness representations

Illness representations are formed at the onset of symptoms. Researchers have identified a number of sources of information, which direct the formation of illness perceptions. Early research with students, carried out by Lau and Hartman (1983) suggests that an individual’s experience of everyday common illness may play a determining role. Most individuals have experienced numerous minor illnesses prior to the development a major one. These teach them how to think, feel and respond to illness. They therefore may try to use their existing schemata or scripts to understand more severe conditions. Lau and Hartman argue that it is a ‘lack of fit’ and ‘failure to match’ their new symptoms with these common sense illness schemas that informs the individual they are suffering from a new (perhaps more severe) condition. As a result they will construct a new illness schema. Although models may be created based on information from the media and others with serious conditions, they argue that pre-existing common sense illness schemas will act as a template for the design of the new schema. This was supported by Meyer et al (1985), who found that hypertensives developed a model, which had strong similarities to prior illness experiences.

Although previous common illness may determine the architecture of the individual’s illness representations, Leventhal and his associates (Leventhal et al., 1980; Leventhal et al., 1984a) identified three basic sources, which guide the individual’s perceptions of their illness. These include information from the general pool of ‘lay’ information, the external social environment and finally their current personal experience of the illness (Diefenbach & Leventhal, 1996). Illness beliefs may therefore change and develop over time with experience of the illness and also from information individuals receive from social messages and the medical profession.

2.6.4 Bi-level (perceptual and conceptual) nature of representations.

Observing individuals behaviour when under stress, studies of the pain system (Egbert et al., 1964; Melzack & Bromage, 1973) and theoretical work investigating the association between language and perceptual categories (Macnamara, 1972), led Leventhal and his colleagues to suspect that illness representations would be represented as concrete perceptual codes and abstract linguistic codes. They found support for this bi-level hypothesis, through a series of studies designed to identify the factors responsible for distress during medical treatments. The findings showed that the attributes of illness representations were both perceptual (i.e. symptoms guiding medication taking) and conceptual (i.e agreement that hypertension label is asymptomatic). The preparation studies they carried out, further revealed that the perceptual level in particular, played a crucial role in determining how individuals responded emotionally.

2.6.5 Levels are linked: The symmetry rule

The data provided by Leventhal and colleagues research, led them to hypothesize that the perceptual and conceptual levels are linked, as a result of pressure to achieve symmetry. This process of linking symptoms with labels follows the ‘symmetry rule’ (Leventhal et al., 1992). For example if an individual experiences symptoms or somatic information (e.g. fatigue) they will search for a recognised diagnosis and label (e.g. Multiple Sclerosis). This proposition has been supported by a number of research studies (Bishop & Converse, 1986). On the other hand, if individuals are given an abstract illness label (e.g. multiple sclerosis) they will find symptoms to match (e.g. fatigue) this label (Croyle & Sande, 1988; Lacroix, 1991; Leventhal et al., 1980; Pennebaker, 1982). Research has also found support for this proposition (Pennebaker, 1982) (Bauman et al., 1989; Meyer et al., 1985; Pennebaker & Skelton, 1981). Overall, these theorists suggest that the way in which an individual perceives and interprets the information provided by the different sources, compels them to construct illness representations via symmetrical conceptual (abstract and prepositional) and schematic (concrete and perceptual) processes.

2.6.6 Support for the five components.

Research has found support for the relationship between illness representations and a range of psychological outcomes as predicted by the SRM. These include coping (Heijmans, 1998; Moss-Morris et al., 1996; Scharloo et al., 1998; Scharloo et al., 2000), mood (Fortune et al., 2000) and functional adaption (Heijmans, 1998,1999; Moss-Morris et al., 1996; Scharloo et al., 1998). Furthermore, research has found that these five components are inter-related with each other. In particular, a belief that MS has serious consequences appears to be dependent on having a strong illness identity (Heijmans, 1998; Moss-Morris et al., 1996; Schiaffino et al., 1998; Vaughan et al., 2003; Weinman et al., 1996). Based on the findings of their meta-analysis, Hagger and Orbell (2003) suggested that the illness beliefs components are not orthogonal but are dependent on one another. Consistent with this Heijmans (1998) suggested that these components should be conceptualised as groups of beliefs or schemata as opposed to single cognitions.

2.6.7 Measurement of illness representations

A number of different methodological approaches have been employed by researchers, measuring illness representations. Early methodological approaches to operationalise illness representations have involved eliciting a patient’s beliefs through open-ended questions. In their original work, Leventhal and his associates used in-depth, semi-structured interviews which focused on the patient’s concrete experiences, in order to elicit their illness representations. In their hypertensive studies Meyer et al (1985) used unstructured interviews to investigate illness representations. Lau and Hartman (1983) in their questionnaire study with undergraduates used open-ended descriptions of illness episodes to assess everyday common sense illness representations.

Other researchers (Lacroix, 1991) have developed questionnaires for measuring illness representations, however these have been criticised (Weinman et al., 1996) for not being theoretically derived or only evaluating one type of patient group.

In 1986 Turk, Rudy and Salovey developed a 45-item Implicit Models of Illness Questionnaire (IMIQ), which includes questions to measure the components of illness representations outlined by the SRM. Factor analyses revealed four dimensions of illness representations referred to as seriousness, personal responsibility, controllability and changeability.

Schaffino and Cea (1995) did not find support for the original ‘generic’ four-factor structure proposed by Turk et al (1986) instead they identified a four-factor structure, which they argued displayed a number of similarities to the components of the SRM. They identified a 14-item factor concerned with the curability of the illness, which they felt reflected the cause and cure components of the model. This factor also referred to the timeline of the condition by defining it as not chronic or permanent and going away on its own. The second 14-item factor involved an individual's personal responsibility for the condition. There was a 10-item factor for symptom variability, which also reflected the timeline component with respect to viewing the symptoms of the illness as controllable and changeable and a 6-item factor, which involved the serious consequences of the condition and accounted for the beliefs about illness identity.

One of the main limitations of the measure was that it failed to reflect the five core dimensions of the SRM and therefore has questionable validity (Jopson & Moss-Morris, 2003). Turk et al's (1986) initial study was administered to diabetic educators, diabetic patients and college students. The scale was therefore based on the ratings of contrasting illnesses by patient, student and nursing samples instead of using the patient's own representations of illness (Weinman et al., 1996). However, to address the limitations of earlier illness representation measures a group of researchers devised a quantitative measure of illness representations called the Illness Perception Questionnaire (Weinman et al., 1996). This measure is based on the five factor structure of illness representations identified by the SRM.

Illness Perception Questionnaire

The Illness Perception Questionnaire was developed by Weinman et al (1996) to provide a theoretically derived quantitative assessment of the five components of illness representations - identity, cause, timeline, consequences and cure/control proposed by the SRM. It became a popular measure and was used by researchers to measure illness representations in a wide variety of illnesses including heart disease (Petrie et al., 1996; Steed et al., 1999), rheumatoid arthritis (Murphy et al., 1999; Pimm & Weinman, 1998; Scharloo et al., 1998), psoriasis (Fortune et al., 2002; Scharloo et al.), chronic pulmonary disease (Scharloo et al., 1998), chronic fatigue syndrome (Heijmans, 1998; Moss-Morris et al., 1996), diabetes (Grivia et al., 2000), Addison's disease (Heijmans, 1999) and depression (Fortune, 2004).

Illness Perception Questionnaire - Revised

Following the success of the IPQ, Moss-Morris et al (2002) identified a need to revise key areas of the core IPQ components. Their aim was to improve the measurement properties of the existing subscales, in addition to extending the scope of the IPQ (Moss-Morris, 2002). The IPQ scale was modified to further separate the causal and identity subscales from the rest of the scale. Instead of measuring the frequency of each symptom the IPQ-R (Moss-Morris et al, 2002) requests that the patient identifies the symptoms they experience first and then indicate which of these they believe are related to their condition. In addition, the casual scale extended the range of available causal items.

The revised inventory also expanded the original IPQ to include measures of illness coherence and emotional representations. The identity component in the original IPQ scale did not assess what the condition meant to the individual or whether they had a good understanding of the condition (Hagger & Orbell, 2003). To assess these beliefs, the revised version includes an illness coherence scale, which enables researchers to assess if the condition 'makes sense' to the patient. A further problem with the original IPQ was that it only assessed the individual's cognitive representations and was therefore, limited in its ability to describe the patient's response to illness. One important improvement of the revised inventory was therefore the inclusion of a measure of emotional representations.

Leventhal, (1994) proposed that individuals develop both cognitive and emotional representations of their health threats. Despite this, previous measures of illness representations have neglected the emotional response to illness. To address this, the IPQ-

R included a six-item emotional representations scale, which enabled researchers to assess the way an emotional representation of a condition can affect how a patient copes and adjusts to illness.

The IPQ-R has also enhanced the ability of the researcher to measure the patient's beliefs about the timeline of their condition. It has increased the reliability of the original acute/chronic timeline and included a measure of cyclical timeline beliefs. The original timeline component has been subdivided into two subscales. The acute/chronic timeline subscale measures the patient's beliefs about the chronicity of the illness and the cyclical timeline subscale measures their beliefs about the fluctuation of symptoms and temporal changeability of illness.

The control/cure dimension has also been subdivided in revised inventory. Horne (1997) argued that this dimension could be separated into personal and treatment components. As a consequence, the cure/control component was differentiated into beliefs about the patient's personal ability to control the condition and the efficacy of the treatment or recommended advice to cure or manage the illness. The new subscales were labelled, personal control and treatment control respectively.

The reliability and validity of the IPQ-R has been supported by evidence provided by Moss-Morris et al (2002) who investigated a variety of chronic and acute conditions. In particular the control/cure and timeline scales, which had lower reliability and validity than the other dimensions using the original IPQ, were found to show good internal reliability. However, despite the good reliability and validity of the IPQ-R one of the main limitations of this measure is its length. The questionnaire has over 80 items and consequently, may not be suitable for patients who are very ill or in situations where there is limited time for assessment. Consequently, researchers recently developed a shorter measure of illness beliefs called the IPQ-Brief.

Illness Perception Questionnaire-Brief

The Illness Perception Questionnaire –Brief (Broadbent et al., 2006) was designed to use a single-item scale approach to assess illness perceptions on a continuous linear scale. This is an alternative format to the IPQ and IPQ-R, which employ a multifactorial Likert scale approach. Since this measure is considerably shorter, it is more suitable for a wider range of patients groups and may be more useful in situations when illness beliefs are being measured alongside a number of other psychological constructs.

The IPQ-Brief measures patients cognitive and emotional representations of illness including consequences, timeline, personal control, treatment control, identity, coherence, concern, emotional response and causes. This scale has been shown to be a reliable and valid measure of illness perceptions in a range of illness groups (Broadbent et al., 2006).

2.7 Application of social cognition and self-regulatory models to understanding illness.

Research suggests that self-efficacy beliefs and health locus of control beliefs may play an important role in determining how an individual will cope and adjust to living with a chronic condition. However, research suggests that the HLC construct may be too narrow for explaining such a multi-determined behaviour as adjustment to illness (see section 2.4.2). This highlights the need for research to incorporate a range of other psychological variables in explaining adjustment to illness.

Two models which address this limitation are the Stress and Coping Model (Lazarus and Folkman, 1984; see section 2.5) and the SRM (Leventhal et al, 1980; see section 2.6). Both of these models were developed to include the construct of perceived control, in addition to a range of other psychological variables. These models have been successfully applied to a variety of medical conditions and provide evidence for the role of the patient's beliefs in determining how they cope and adjust to illness.

The SRM in particular, demonstrates how an individual’s cognitive representation of their illness can predict how they cope and adjust to living with the condition. This model identifies a number of core beliefs, which individuals develop at the onset of illness (see section 2.6.3). Together these beliefs create a cognitive representation of the condition. Unlike the other models discussed in this chapter, the SRM has been extensively developed to investigate how individuals adjust to illness (see section 2.6.6). Consequently, the SRM provides a framework for the design of the current doctorate research.

The SRM, Stress and Coping Model, Social Cognitive Theory and HLC Theory are all fundamentally health psychology frameworks, designed to assist in developing an understanding of how individuals with medical conditions adjust to their illness. However, the application of social cognition and self-regulatory models to understanding adjustment to illness is a relatively new area of investigation. Traditionally researchers relied on models of psychopathology to explain why some individuals with chronic conditions experience psychological distress. Unlike social cognition and self-regulatory models, which investigate the psychological determinants behind health behaviours, these models were developed to explain the psychological mechanisms behind depression, anxiety, helplessness and hopelessness. Furthermore, they focus primarily on negative states of mind and have been widely accepted as providing frameworks for understanding the underlying causes of psychological distress. Therefore, to fully understand the psychological factors, which may lead MS patients to depression, anxiety, hopelessness and suicide it is important to take into consideration these models of psychopathology. Consequently, these models will be the focus of the remainder of Chapter 2.

2.8 Models of psychopathology

There are three main types of models of psychopathology; biological, behavioural and cognitive. Psychological research has predominantly focused on the role of cognitive factors to explain why individuals experience psychological distress. These cognitive models of psychopathology are the focus of the follow section. In particular, three of the most common cognitive models; the Cognitive Theory of Depression, the Learned Helplessness Theory and the Hopelessness Theory are discussed.

2.9 Cognitive Theory of Depression

The Cognitive Theory of Depression is the most empirically supported model for understanding depression. According to this model, an individual's beliefs determine how they act and feel. The most influential researcher to develop this theory was Aaron Beck. Beck's principal argument was that depression is caused by the individual having a negative view of him or herself instead of this negative view being caused by depression.

2.9.1 Core components of the model

Beck (1967) and Beck et al, (1979) identified three core components, which determine whether an individual will experience depression. The first is referred to as the cognitive triad, which is a pattern of depressive thoughts comprised of a negative view of the self, negative view of the world and a negative view of the future. The second concept is cognitive errors, which refers to faulty thinking and the third component is schemas, which are adaptive or maladaptive beliefs activated when life becomes stressful.

According to this model, individuals create dysfunctional attitudes or beliefs in early childhood, referred to as maladaptive schema. Schemas are defined as deep-seated beliefs about oneself and others, which develop during childhood (Young, 1999).

Individuals develop ‘self-schemas’ to understand and explain their own experiences in specific contexts. The individual’s schemas may be ‘inactive’ at times. The type of input received from their surroundings can quickly ‘energize or de-energize’ the individuals schemas. According to this theory, schemas are triggered by critical incidents such as stressful events, and if maladaptive can lead to typical negative automatic thoughts about oneself, the world and the future. These negative thought patterns not only cause psychological distress but help to maintain low and anxious moods associated with the physical symptoms of depression and anxiety. These symptoms, in turn, reinforce more negative thoughts (Beck 1967; Beck et al., 1979; Ingram, 2003). Individuals suffering from depression experience a number negative schemas, including cognitive-conceptual, affective, physiological, motivational, behavioural schemas.

2.10 The Learned Helplessness Theory of Depression

The Learned Helplessness Theory of Depression was developed by Martin Seligman in the 1960s as a framework for explaining depression. Based on this learned helplessness has been defined as ‘the hopelessness and resignation learned when a human or animal perceives no control over repeated bad events’ (Myers, 2002). Seligman developed this theory of helplessness by accident, while studying the effects of inescapable shock, on active avoidance learning in dogs. According to Seligman and colleagues, learned helplessness in animals was analogous to human depression. This theory was therefore extended to humans, providing a framework for understanding depression. However, researchers identified a number of difficulties with using an animal model to explain human depression. Some researchers argued that learned helplessness displayed by animals was not be related to depression in humans and consequently, they have provided a number of alternative interpretations. One competing theory argued that Seligman’s dogs were acting more like trauma victims, than depressed people (Pratt, 1980).

In 1976, Maier and Seligman not only attempted to refute competing theories, they also acknowledged the theoretical confusion caused by the learned helplessness phenomenon. As a result they abandoned the animal model altogether two years later (Abramson et al., 1978). They consequently introduced the ‘reformulated learned helplessness model of depression’. This reformulated model was developed from attribution theory (Jones et al., 1972), which focuses on how individuals attribute causality to events. According to this reformulated theory, depressed individuals are more likely to think pessimistically about the bad events, than non-depressed individuals. Seligman referred to this as ‘explanatory style’ a notion borrowed from attribution theory. According to this new model, depression and helplessness is caused by the individual causally attributing bad events to themselves (see Hahner, 1989 for a full discussion on the development of this theory).

The reformulation of the theory has generated a large amount of empirical work on depression (see Sweeney et al., 1986 for a meta-analysis of 104 studies). Some reviewers have argued that the theory has strong empirical support (Peterson & Seligman, 1984), while others have claimed that it has weak empirical foundations (Barnett & Gotlib, 1988; Coyne & Gotlib, 1983). Moreover, others (Abramson et al., 1988; Brewin, 1985) have argued that it has never been adequately used to predict learned helplessness or depression, in either a range of patient populations or situations

2.10.1 Criticisms of the Reformulated Learned Helplessness Model

Despite the wide application of the model, this theory has received a number of criticisms. Firstly, the features of the theory are not applicable to everyone in all situations (Comer, 2004). The hopeless self-blamer and the hopeful self-blamer both internalise the causes of their behaviour and feelings. Attributing causes internally can lead to positive psychological states such as optimism as opposed to pessimism.

According to Hahner's (1989) review, this model is the same as Aaron Beck's (1964, 1979) cognitive model of depression. Although the researcher who developed this theory of helplessness (Abramson et al., 1988) acknowledged that Beck's and their perspective are compatible they do not believe they are the same. They still ascertain that their animal based research is the basis of their formulated model.

Hahner (1989) also identified a number of weak links in this theory and questioned its construct validity, arguing that although the measurement of the theory may be precise it is unclear what the model is actually measuring. The researchers behind the formulated model recognised these limitations of the theory and demonstrated that this model did not present a clearly articulated theory of depression. Instead they felt that they had provided an attributional account of depression, which only briefly dealt with the implications for depression. To address the limitations of the Reformulated Model of Learned Helplessness they developed the Hopelessness Theory of Depression (Abramson et al., 1989). This is the focus of the following section.

2.11 Hopelessness Theory of Depression

The Hopelessness Theory of Depression was developed by Abramanson and colleagues in 1989 and is a revision of the 1978 Reformulated Model of Learned Helplessness and Depression (Abramson et al., 1978). The hopelessness theory represents a theory-based approach to the classification of depressive disorder and proposes the existence in nature of an unidentified subtype of depression, referred to as hopelessness depression. The researchers argue that the evolution of helplessness to a hopelessness theory is consistent with Mandler's (1964; 1972) view that hopelessness, not helplessness is the underlying cause of the symptoms of depression.

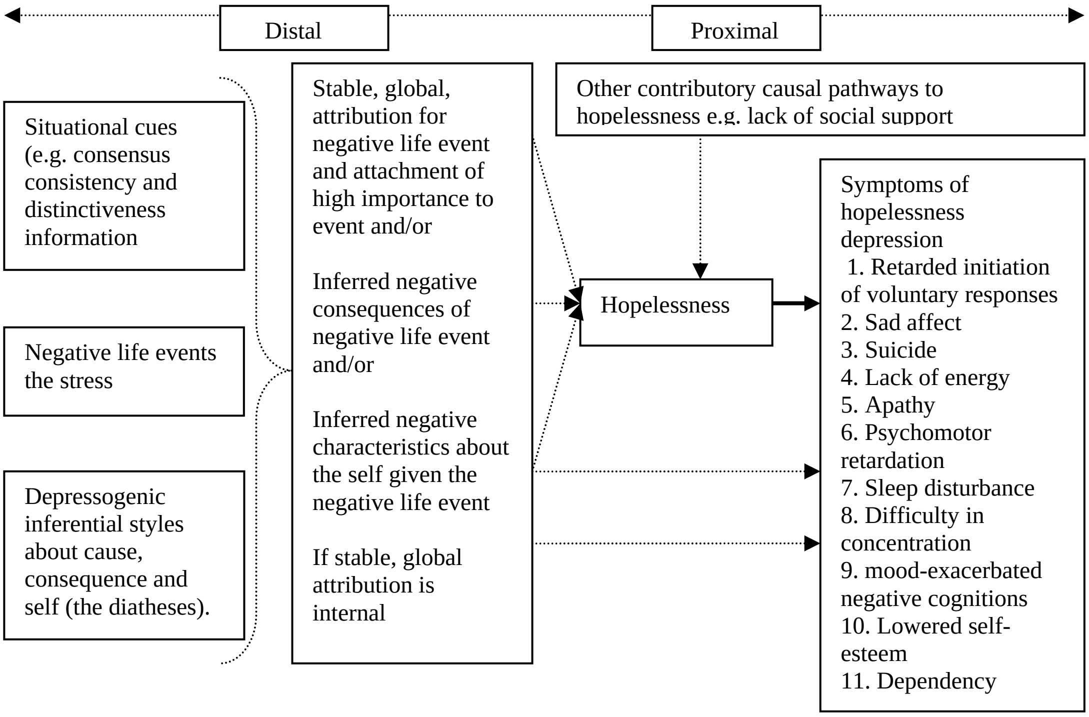
2.11.1 Core assumptions of the Hopelessness Theory of Depression

According to this theory, symptoms of hopelessness depression are caused by a combination of the following; 1) the expectation that highly desired outcomes will not occur whereas highly aversive outcomes (negative outcome expectancy) will 2) the expectation that they are helplessness (helplessness expectancy). Therefore hopelessness is a subset of helplessness.

There are three inferences individuals make that determine whether they become hopeless and in turn develop symptoms of hopelessness depression; 1) inferences about why the event occurred (i.e. inferred cause or causal attribution, 2) inferences about consequences that will result from the occurrence of the event (i.e. inferred consequences) and c) inferences about the self given that the event occurred (i.e. inferred characteristics about the self). See Abramson et al, 1989 for a full description of this model.

These inferences which the individual makes will determine the cognitive style they adopt. If they attribute the negative event to stable and global causes they are adopting what is referred to as a depressogenic inferential style. This type of cognitive inferential style can make them vulnerable to depression and hopelessness. This is illustrated in the schematic representation of the Hopelessness Model provided below in Figure 2-3.

Figure 2-3 A schematic representation of the Hopelessness Theory of Depression.



Source: Abramson et al (1989) (Arrows with solid line indicate sufficient causes. Arrows with broken lines indicate contributory causes).

2.11.2 Recent developments in understanding the role of hopelessness.

Research has operationalised hopelessness almost exclusively via the Beck Hopelessness Scale (Beck et al., 1974). This is a 20-item, true/false forced choice questionnaire with higher scores indicating greater levels of hopelessness. This measure remained virtually unchallenged for many years and consequently, some argued that hopelessness lacked conceptual clarity (MacLeod et al., 1997). MacLeod and Colleagues argued that hopelessness appears to be central to the suicidal behaviour. Despite this, little research had addressed the question of what hopelessness actually was and the term had been used in different ways (MacLeod et al., 1993). The new hopelessness theory explains depression to some extent on the basis of pessimistic expectations about the future. MacLeod and his colleagues became curious about whether the pessimism associated with hopelessness was characterized by negative expectation of the future, or the inability to think positively about the future, or whether these two representations were the same. As a result McLeod and Colleagues developed a personal future fluency task called the future thinking task (MacLeod et al., 1997). This is an instrument measuring the extent an individual can generate positive and negative future thoughts. Studies using this task (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004) suggest that non-suicidal individuals can be differentiated from suicidal individuals by their positive future thoughts (they have fewer positive future thoughts and they do not differ in negative thoughts). This highlights the need for research to take into account an individual’s future thoughts in addition, to hopelessness when investigating the development of psychological distress.

2.12 Application of models of psychopathology in understanding illness

Models of psychopathology focus primarily of negative mind states to explain the development of psychological distress. The cognitive theory of depression emphasises the role of maladaptive schemas in creating psychological distress. When an individual is faced with a chronic illness this critical event will trigger the schemas they have about themselves. If the individual has dysfunctional attitudes or faulty thinking they are likely to trigger maladaptive schemas. These will typically lead to negative thought pattern causing psychological distress. In addition, to forming self-schemas they may also for an illness schema, which enables them to explain their experience of that illness. Therefore in addition to making generalization about themselves they may also do so about their illness. Their illness schema is formed through the evaluations made about their condition by themselves, their physician, their loved ones and societal views. These illness schemas may have an affect on the beliefs they have about their illness such as how serious the condition is, how long it will last and even what a caused it. These illness schemas may be similar to the cognitive representations of illness that the SRM postulates.

The learned helplessness and hopelessness theory can also be easily applied to understanding psychological distress experienced by individuals with chronic conditions. When someone has been diagnosed with a chronic condition such as MS which has no cure they may begin to feel that they no longer have control over their lives. According to the theory, as a result of this lack of perceived control the individual would rely on others for help and consequently, learn to be helpless. This helpless state would lead to psychological distress.

Overall, models of psychopathology suggest that psychological factors such as cognitive distortions, learned helplessness and hopelessness play an important role in the development of depression. In addition, further examination into the role of hopelessness has identified the role of future thinking as a predictor of suicide intention. This represents a move away from the traditional explanation of psychological distress by taking into consideration the role of positive mind states.

2.13 Summary

The psychological models examined in this chapter highlight a number of key psychological factors, which may lead MS patients to experience psychological distress. Furthermore, they provide useful frameworks for understanding how individuals adjust to MS. Consequently, researchers investigating MS have successfully applied these to models to understand how MS patients adjust to their illness. Chapter 3 presents and discusses this research, in hope that the findings will provide information about the psychological factors, which make MS patients vulnerable to psychological distress. These findings will be used to inform the design of the current doctorate research.

Chapter 3: Application of Psychological Models to Multiple Sclerosis

3 Overview

Health psychology has developed a number of social cognition and self-regulatory models to explain health behaviour. These models, which were the focus of Chapter two, have provided a grounding for the research investigating how individuals adjust to MS. Researchers have also applied cognitive models of psychopathology to identify the psychological factors, which make MS patients vulnerable to psychological distress. The aim of this chapter is to examine the research applying the psychological models discussed in Chapter 2, to individuals with MS. This provides an insight into the psychological factors, which are important for successful adjustment to this condition.

3.1 Social cognition/self-regulatory models and MS

Social cognition and self-regulatory models were developed to identify the psychological factors, which make individuals adopt different health behaviours (see Chapter 2 section 2.1.). This section examines the research, which has successfully applied these health behaviour models to understand adjustment to MS.

3.2 Self-Regulation Model

3.2.1 The role of illness representations in adjustment to MS

Researchers developing the SRM (see Chapter 2 section 2.6 for a full description of the model) highlighted the importance of illness representations in predicting adjustment to illness. These are defined as a patient's own implicit, common-sense beliefs about their illness (Leventhal et al., 1998; Leventhal et al., 1980; Weinman et al., 1996). There have been a number of research studies, which have investigated the role of illness beliefs in determining how well individuals adjust to MS. The following section, examines both early and more recent research carried out in this area. Since these studies form the basis for the current doctorate research, they are discussed in greater detail than the other research, examined in this chapter.

3.2.1.1 Early MS research investigating illness representations

One of the earliest studies investigating the role of illness beliefs in MS was conducted by (Pavlou & Coute, 1983). However, this study only employed one standard measure, the Personal Orientation Inventory (Shostrum, 1963), all of the other measures used in the study were original instruments. The content validity and convergent validity of the scales designed for the study are therefore unknown. Moreover, this study was carried out at a time when there were no universal items or other types of instruments developed to tap into the same dimensions.

The first study to assess MS patients' illness beliefs, using a recognised standard measure was published in 1995 by Schiaffino and Cea. They employed the Implicit Models of Illness Questionnaire (Turk et al., 1986) to assess undergraduate students and patients assessments of: MS, Rheumatoid Arthritis (RA) and Human Immunodeficiency Virus (HIV). The findings of this study provided evidence that the IMIQ may be useful in assessing illness representations. It also revealed that illness perceptions vary depending on the illness and the sample. However, this study did not assess the role of illness representations on adjustment to illness. In order to address this limitation Schiaffino and colleagues (Schiaffino et al., 1998) used the scales identified in the earlier study to investigate the relationship between illness representations and psychological adjustment in patients with MS and RA. They carried out a longitudinal study with data being collected in two waves, each four months apart.

Illness representations were found to influence MS patients' current psychological adjustment. The findings showed that individuals who believed their MS had serious consequences experienced greater concurrent illness severity and disability. However, those individuals who believed their MS could be cured experienced lower levels of concurrent illness severity.

Illness representations were not found to be associated with concurrent depression in MA or RA. However, MS patients' initial beliefs in symptom variability lead to significant increase in depression over time. The study also found evidence for the inter-relationships between illness representations. For both RA and MS, a belief that the condition was curable, was associated with a belief that the patients had some responsibility for the occurrence of their illness.

These two early studies (Schiaffino & Cea, 1995; Schiaffino et al., 1998) investigating illness representations in MS have received a number of criticisms. In these studies, illness representations were assessed using the IMIQ, which is believed to have 'questionable validity' as it fails to reflect the five core dimensions of illness representations (Jopson & Moss-Morris, 2003). Moreover, the structure of illness representations this measure is based on, has not been used in other research, preventing the findings from being compared directly to other studies of illness representations (Vaughan et al., 2003). The latter study also only measured one area of adjustment. Two recent studies (Jopson & Moss-Morris, 2003; Vaughan et al., 2003) have addressed these limitations.

3.2.1.2 Recent research investigating illness representations in MS

In 2003, two studies investigating the role of illness beliefs in adjustment to MS were published. They aimed to address the limitations of the earlier studies by Schiaffino and colleagues (1995, 1998), by operationalising adjustment through a range of variables and using well-validated measures of illness representations, the Illness Perception Questionnaire (Weinman et al., 1996) and the IPQ-R (Moss-Morris et al., 2002) (see Chapter 2, section 2.6.7 for a description of these scales).

In the first of these studies, Jopson and Moss Morris (2003) investigated the impact of illness representations on adjustment, in 168 MS patients using the IPQ-R (Moss-Morris et al., 2002). Their findings revealed that patients' illness representations were the most significant predictors of social dysfunction, fatigue, anxiety, depression and self-esteem. Furthermore, they predicted adjustment to MS on a range of outcome variables, even when illness severity is controlled for.

Another study published in the same year by Vaughan et al (2003) also investigated the relationship between illness representations and adjustment to MS. This study even employed two of the same measures as Jopson and Moss-Morris (2003) including the HADS (Zigmond & Snaith, 1983) and the Self-Esteem Scale (Rosenberg, 1995) however, instead of the IPQ-R (Moss-Morris et al., 2002) they used the original IPQ (Weinman et al., 1996). The findings of this study also showed that negative beliefs such as strong illness identity and a belief that MS has serious consequences are related to poorer adjustment, whereas more positive beliefs such as a greater sense of personal control are associated with better outcomes. In addition to investigating the relationship between illness representations and adjustment, this study also examined the inter-relationships between each of the illness representations. The findings were consistent with Heijmans (1998) view that illness representations should be conceptualized as groups of beliefs rather than single cognitions. They found that believing MS is a chronic condition is associated with believing MS is an uncontrollable, incurable condition with serious consequences. The results suggested that how long individuals believe their condition will last influences how well they feel they can manage the condition. Moreover, they found support for the association between a strong illness identity and serious consequences reported by other studies (see Chapter 2, section 2.6.6)

A further study, investigating the role of illness representations in MS was carried out by Sousa and Periera (2003). Although only the abstract of this study has been published, the findings support the results of earlier studies (Jopson & Moss-Morris, 2003; Schiaffino et al., 1998; Vaughan et al., 2003) that illness representations affect adjustment to MS. In terms of illness representations, they found those with a greater illness severity tended to believe that their condition had more serious consequences, was out of their control and could not even be controlled by treatment.

As this section shows, recent research has found that the way in which an individual views their MS has important implications on how well they will adjust to the condition. Examining the findings of each study individually would only provide limited information about the role of each illness representation component in predicting adjustment. Therefore to have a full understanding of which components lead to a good quality of life and which lead to psychological distress, it is beneficial to compare the findings of each of the studies. The following section will therefore examine each illness representation component individually and assess the findings from each of the studies discussed above, in terms of that component.

3.2.1.3 Patterns of illness representations in MS

Early research found that patients’ cluster their beliefs about their illness around five coherent themes or components. Together these components create the individuals’ perception of their illness (Leventhal et al., 1984a). These components give MS patients a framework to make sense of their symptoms and direct coping and action (see Chapter 2, section 2.1.8.). Based on previous research of these five components, MS patients appear to have a dominant view of their illness comprising of a strong illness identity, external attributions for their condition and pessimistic beliefs about the course, consequences, time-line and possibilities of cure. The research discussed so far in this section found that these beliefs affect on how MS patients adjust to their condition as suggested by the SRM. To demonstrate more clearly the role of illness representations on adjustment to MS it is important to examine the research in terms of each illness representation component individually.

Illness Identity Component

Illness identity or the tendency to attribute a wide range of symptoms to MS was found to be related to higher levels of depression and anxiety, greater illness intrusiveness, greater impairment in physical functioning (Vaughan et al, 2003) and greater anxiety and fatigue (Jopson & Moss-Morris, 2003). Jopson and Moss Morris (2003) suggested that illness identity could be closely associated with the process of internal somatic focus. MS patients who focus more on the sensations in their body may experience a wider variety of symptoms. One study found a greater internal somatic focus lead to higher subjective fatigue in MS (Vercoulen et al., 1996). Based on the SRM individuals are inclined to move towards symmetry. Consequently, when patients experience symptoms they are motivated to discover a label to explain them and those who have been given a label are inclined to find symptoms which reinforce that label (see Chapter 2, section 2.1.8.7.). There are a wide array of symptoms experienced by MS patients, which can fluctuate daily (see Chapter 1, section 1.9.1), consequently, it is difficult for patients to identify which symptoms are caused by their condition and those which are not. As a result, patients may misattribute symptoms such as headaches to their MS. The experience of symptoms can also lead individuals to believe that the condition is progressing, creating anxiety and depression.

Patients may cope with this by reducing their social interaction with others.

Timeline Component (Acute/Chronic)

The timeline component measures whether patients perceive their condition as acute or chronic. MS is a chronic neurological condition, however surprisingly some MS patients perceive their condition as being acute. Individual beliefs about whether their MS is acute or chronic can have important implications for how well they adjust to this illness. The belief that MS is acute has been found to lead to greater depression (Vaughan et al, 2003). The inability to accept that MS is a chronic illness creates greater distress for individual. This highlights the importance of patients recognising that MS is a chronic condition. Schiaffino and Cea (1995) identified this recognition as a crucial step in coping with the condition.

Consequences Component

MS can affect many aspects of patients' lives. The severity of the symptoms and unpredictable nature of the condition can have devastating consequences on many different areas of patients' lives. Research has found that believing MS has serious consequences leads to poorer outcomes, lower self-esteem, higher levels of depression (Jopson & Moss-Morris, 2003; Vaughan et al., 2003) and anxiety, greater illness intrusiveness, poorer physical functioning (Vaughan et al., 2003) and greater mental fatigue (Jopson & Moss-Morris, 2003). The patient's perceptions of the consequences of this condition therefore, have a significant impact on their quality of life.

Illness Coherence Component

There are many aspects of MS, which can make it difficult for patients to feel they have a good understanding of the condition. There are numerous theories about what causes MS (see Chapter 1, section 1.4). The illness itself is characterised by a confusing array of symptoms, which not only vary between individuals but can fluctuate daily (see Chapter 1, section 1.9.1.). In addition, there has been no cure developed and the physiological aspects of the condition can be confusing. However, in terms of what we do know about MS, many patients believe they have a reasonable understanding of the condition. The research emphasises the importance of this belief on patients' adjustment, since lack of a coherent model or understanding has been found to be associated with poorer psychosocial functioning, stronger emotional representations and lower self-esteem. A poor understanding has also been found to predict levels of anxiety in patients (Jopson & Moss-Morris, 2003).

Causal Component

Another illness perception, which has been found to have implications for adjustment to MS, is patients' beliefs about what causes the condition. Despite their being no recognised cause (see Chapter 1, section 1.8) individuals tend to form their own ideas about the underlying cause of their MS. Vaughan et al (2003) found that 35% of patients attributed the cause of their MS to a germ or virus, 21% identified stress as the main cause, 8% believed heredity factors lead to their condition and only 7% felt an altered immunity was responsible. This study found that the majority of patients identified chance (44.4%) and stress (43.4%) as the main causes of the condition however, the research found that these beliefs have no effect on any of the outcome variables. However, Jopson & Moss-Morris (2003), found that attributing the condition to a psychological factor lead to poorer psychosocial functioning, stronger emotional representations, anxiety and low self-esteem. Other research by Eklund and MacDonald (1991), found that MS patients who had come to accept why they had developed the condition adjusted better. Those who questioned why it had happened to them, were found to experience greater levels of depression. Their data suggests that what they believed caused their MS can have a different impact on their adjustment to the condition at different times. Following the initial diagnosis, it is more beneficial for patients to attribute their MS to a controllable factor such as too much responsibility and stress. However, as time passes they adjust better if they attribute their condition to an outside factor such as pollution. Their findings showed that those MS patients with greater self-esteem were more likely to attribute their MS to outside factor.

Control Component

Living with a serious chronic condition generates unusual psychological burdens for patients, as they attempt to balance their desire to maintain a sense of mastery over their lives, with the need to surrender the treatment of their condition to health care professionals (Reid, 1984). MS is a highly uncontrollable condition. The illness is characterised by an unpredictable and variable course with varying types of neurological symptoms, fatigue, cognitive disabilities and pain (see Chapter 1, section 1.9.1) (Paty & Poser, 1984). To date no cure or treatment has been identified and there are limited options for regulating MS. The uncertain nature of MS highlights the importance of examining control constructs in this population.

Current understanding of the relationship between control beliefs and adjustment in chronic illnesses such as MS where individuals have little control over their illness, face a unique test. There have been two predictions formulated, which are only partly compatible. One perspective is that surrendering control to powerful others is adaptive in situations where there are limited opportunities available for personal control and maintaining a belief in personal control would result in problems with coping. Another perspective is that individuals look for the aspects of the situation, which have remained controllable and exert control over those parts. In addition, there are adaptive benefits to using such selective control (Affleck et al., 1987).

Research investigating illness perceptions in MS has found that individuals with MS who believe they have greater control over their illness, experience lower depression and higher self-esteem (Vaughan et al, 2003; Jopson and Moss Morris, 2003). These findings have been supported by past research on learned helplessness in MS, which has found a strong association between low perceived control and increased depression (Shnek et al., 1995; van der Werf et al., 2003). Beliefs about how much MS patients have control over their illness has also been found to be negatively related to illness intrusiveness and poorer physical functioning (Vaughan et al., 2003). Jopson and Moss Morris (2003) found that personal control was related to an increase in mental fatigue and treatment control was related to a decrease. They provide a justification for these findings, suggesting that the increase in mental fatigue may be the result of the mental effort involved in having to maintain a strong sense of personal control over an unpredictable illness. Believing that the treatment may control their MS however, may place the control to an external source removing the responsibility from the individual.

The inclusion of the control component in these studies, is based of the theory of self-regulation. There have however, been a number of other studies, which have been carried to examine the role of control cognitions in MS based on the health locus of control (HLC) theory. These will be the focus of section 3.4 Although these studies do not include the other illness perception components identified in the SRM they can provide important insight into the role of control cognitions in adjustment to MS.

3.2.1.4 Implications of illness beliefs findings

The research investigating the role of illness representations on adjustment to MS (e.g. Vaughan et al 2003; Jopson and Moss Morris, 2003) has identified a pattern of beliefs, which lead to poor adjustment to MS. Their findings suggest that those who strongly identify with their MS, who believe that MS is an acute, uncontrollable condition with serious consequences, which they do not understand and which is caused by a psychological factor are likely to experience greater levels of psychological distress. However, the findings from these studies only provide information about one part of the SRM. None of them, included a coping measure to assess the role of coping on adjustment. Therefore, to fully understand how patients adjust to MS and to give a clearer picture of the mechanisms involved in creating the psychological distress associated with the condition, it is important to examine the literature investigating role of coping in MS.

3.2.2 The role of coping on adjustment to MS

According to the SRM, coping mediates the relationship between illness representations and adjustment. However research examining the role of illness representations in MS, do not include coping measures and therefore, do not provide any insight into which coping strategies lead to better adjustment in this condition. There has however, been a number of other studies, which have examined the relationship between coping and adjustment, as suggested by the SRM. Consequently, these studies are the focus of this section.

3.2.2.1 The importance of effective coping

Living with MS forces the patients to live in a state of constant uncertainty. The variable nature of the illness course, along with the wide variety of fluctuating symptoms can make everyday activities seem exhausting. As a result, MS patients often experience many changes to their roles at home, in their working life and also in their social circle. Their psychological well-being is dependent on how well they deal with the adversity they are faced with. Since this illness has no identifiable cause or cure (see Chapter 1, sections 1.4 and 1.8) it is likely that patients will feel their lives are out of their control. Research discussed previously showed that this perception of a lack of control can lead to greater psychological distress (see section 3.2.1.3). It is therefore important to examine why individuals with MS adopt different coping strategies from each other to deal with the same objective situations and assess the influence these different strategies have on how well they adjust.

Research has suggested that coping strategies are the strongest predictor of both objective and subjective domain on quality of life in MS (McCabe & McKern, 2002). Those who are unable to cope are more likely to experience suicidal thoughts and experience disruption in their marital, family and social relationships and are less likely to display positive affect and positive self-esteem (Eklund & MacDonald, 1991). Brooks and Matson (1982) carried out a longitudinal study of coping with MS. Their findings revealed that acceptance was associated with self-concept 7 years later, whereas those relying on religion or seeking family support had poorer-self-concepts.

The findings of these research studies highlight the important role coping plays in adjustment to MS. Those unable to cope effectively are more likely to experience psychological distress. According to SRM, the way an individual copes determines how well they will adjust. Researchers investigating the ways in which people cope with various situations in their life have identified a number of coping strategies which fall into two broad categories. These are classified in the literature as either problem–focused or emotion-focused coping (see Chapter 2, section 2.5.2.) The following section will examine which type of strategies (problem-focused or emotion focused), the research has found leads to a better overall quality of life and which leads to greater psychological distress in MS.

3.2.2.2 Emotion-focused versus problem-focused coping

In the literature emotion-focused coping has been shown to be more ‘robustly and consistently’ related to poorer psychological adjustment than problem-focused coping (Arnett et al, 2002). MS patients who use more emotion-focused coping have been found to experience greater psychological and emotional distress (Aikens et al., 1997; Arnett et al., 2002; Beatty et al., 1998; Foley et al., 1987; Jean et al., 1997; Jean et al., 1999; Kroenecke et al., 2001; Lynch et al., 2001; Pakenham, 1999; Schwartz, 1999; Warren et al., 1991), poorer adjustment to their condition (Kroenecke et al., 2001; McCabe et al., 2004; Pakenham, 1999; Pakenham & Stewart, 1997) and poorer quality of life (McCabe & McKern, 2002). These findings suggest that it may beneficial for MS patients to rely on more problem-focused coping strategies. Indeed, some research on individuals with and without chronic physical illness has found that problem-focused coping is associated with well-being (Folkman & Lazarus, 1986; Pakenham, 1999). However, the results of other research has been inconsistent (Mischel & Sorenson, 1991).

The relationship between problem-focused coping and adjustment to MS is also not clear (Mohr & Cox, 2001). A number of studies have found that problem-focused coping is positively related to lower levels of depression (Aikens et al., 1997; McCabe et al., 2004; Mohr et al., 1997), higher self-esteem (O'Brien, 1993) and predicted future subject health status (Pakenham, 1999). However, a number of studies have been unable to find a relationship between problem-focused coping and better adjustment (Sullivan et al., 2004). Moreover, other studies have found that this kind of coping has no impact on reducing depression (Jean et al., 1999; Lynch et al., 2001) and has little association with the patient's quality of life (McCabe & McKern, 2002). Arnett et al (2002) found that active coping, which is classed as a subset of problem-focused coping was associated with lower levels of depression however, the effect was relatively weak. Aikens et al (1997) found planful problem solving lead to lower depression at 6 months but not 12 months. In addition, limited support (Pakenham & Stewart, 1997) and no support (Jean et al., 1997; Sullivan et al., 2004) was found for a positive relationship between problem-focused coping and current adjustment to MS. Infact the study by Sullivan et al (2004) found that neither coping style (problem-focused or emotion focused) contributed to patients adjustment to MS.

3.2.2.3 Identifying specific coping strategies

Although the distinction between problem-focused and emotion-focused coping may be a useful heuristic for investigating coping (Arnett et al., 2002) researchers have started to recognise that these broad categories involve a number of different kinds of strategies, some of which may be more useful than others. For example, some emotion-focused coping responses involve denial, some involve positive reinterpretation of events and others involve seeking out social support. All of these responses vary greatly and as a result may have a number of different implications on how successfully individuals cope. Problem-focused coping also involves a number of distinct activities: planning, taking direct action, seeking assistance, screening out other activities and sometimes forcing oneself to wait before acting (Carver et al., 1989). Instead of considering a range of strategies within the broad categories of emotion-focused and problem focused, it is important to identify the individual strategies and determine which are useful for MS patients. Closer examination of the research findings reinforces this.

The research has found a persistent relationship between poorer psychological adjustment and the passive emotion-focused coping strategies of self-blame, escape avoidance (Aikens et al., 1997; Arnett et al., 2002; Eklund & MacDonald, 1991; McCabe et al., 2004; Mohr et al., 1997) and wishful thinking in MS patients (McCabe et al., 2004), (McCabe & McKern, 2002). However, according to Pakenham (1999) the more constructive forms of emotion-focused coping including positive reinterpretation and growth (Folkman & Lazarus, 1980), emotional approach coping (Stanton et al., 1994) and acceptance (Carver et al., 1989) may be more useful in helping individuals adjust to MS. Eklund and MacDonald (1991) found that MS patients who employed positive reappraisal (Lazarus, 1984) or adaptive denial (Meyerowitz, 1980) when they were initially diagnosed, experienced better long term adjustment. Cognitive reframing of the problem has been found to lead to lower levels of depression in MS (Mohr et al., 1997). This research demonstrates the importance of examining the role of specific coping strategies in determining adjustment to MS instead of investigating problem-focused and emotion-focused coping as broad categories. Overall, the research findings support the relationship between coping and adjustment as suggested by the SRM. They demonstrate that to fully understand why some individuals with MS experience psychological distress, while others experience a good quality of life, it is pivotal that the role of coping be examined.

3.2.2.4 Limitations of the coping research

Coping measures employed

One of the first limitations of the coping research is the measures used to assess patients coping. The majority of research employed either the COPE (Carver & Scheier, 1985) or the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) which have received criticisms for their ability to reliably measure MS patients coping strategies. First of all, none of the instruments were specifically designed to measure MS. Secondly, the Ways of Coping questionnaire in particular has been criticised for the items included in the scale (Carver et al., 1989). For example the scale does not include the kinds of emotion-focused coping strategies that may lead to better adjustment (Pakenham, 1999). Thirdly, they ask patients how they cope with stress in general. Previous research (Jean et al., 1997; 1999) has found that MS patients employ different coping strategies to deal with MS-related stressors compared to the strategies they use to deal with everyday stressors.

These limitations were recognised by Dr Pakenham and his Colleagues, who attempted to address them by developing the Coping with Multiple Sclerosis Scale (CMSS). Instead of separating coping into two broad categories of problem-focused and emotion-focused coping the CMSS identified seven core coping strategies; problem solving, physical assistance, acceptance, avoidance, personal health control, energy conservation and emotional release. In addition, the measure was designed based on interviews with MS patients and is therefore MS-specific. Furthermore, this instrument enables researchers to assess how MS patients coping with one specific disease-related stressor instead of measuring stress un-related to their condition.

Using the CMSS, Pakenham et al (2001) found that when people with MS use passive avoidant coping strategies their ability to adjust to the stressor was poorer. Those with MS who focused on the actual problem, (e.g. with problem solving or personal health control coping), and/or dealt directly with their emotional distress (e.g. using emotional release or acceptance coping), adjusted more successfully. In addition, to the limitations of the measures employed by the coping research previous studies also did not measure patients' illness perceptions.

Lack of illness cognitions measures

According to the SRM, coping mediates the relationship between illness representations and adjustment. However, as discussed in section 3.2.1.4, to our knowledge no published research has investigated the role of illness perceptions, coping and adjustment. However, some coping research has recognised the importance of patients perceptions on coping with MS. Research has found that that during times when patients were experiencing elevated levels of psychological distress they emphasized more emotion-focused strategies (Aikens et al., 1997; Beatty et al., 1998; Jean et al., 1997; Jean et al., 1999). Consistent with these findings, other studies have shown that MS patients with greater self-esteem use more problem-focused coping, whereas those with poorer self-esteem employ more emotion-focused coping (O'Brien, 1993)

These findings demonstrate the importance of patients' perceptions on the types of coping strategies, which they employ. This could mean that individuals who feel that their MS is out of their control may employ more emotion-focused strategies whereas those who believe they can control their MS will be more likely to employ more problem-focused strategies. Although this research suggests that their may be some relationship between illness perceptions and coping as specified by the SRM further research assessing both illness representations and coping is needed before any conclusions can be drawn.

3.2.2.5 Implications of the coping research

Research investigating the role of coping in adjustment to MS has identified a number of strategies, which predict adjustment on a range of variables. The majority of the research has found a persistent relationship between emotion-focused coping and greater psychological and emotional distress. However, the research investigating the role of problem-focused coping is less clear (see section 3.2.2.2.). Recently researchers have began to recognise that each of these categories contain a large number of different strategies some of which may be more important than others (see section 3.2.2.3.).

3.2.3 Application of the SRM to MS

Research applying the SRM to individuals with MS has provided evidence for a relationship between illness beliefs and adjustment (see section 3.2.1.). However, this research is limited by its cross-sectional nature and its absence of a coping measure (see section 3.2.1.4). Other research has investigated the relationship between coping and adjustment to MS as proposed by the SRM (see section 3.2.2.). However, this research also has a number of limitations. The first limitation of these studies is the measures they employ to assess coping and the second limitation, is that they do not take into account the role of illness beliefs (see section 3.2.2.4). Therefore no published research has fully operationalised the SRM and investigated the relationship between illness representations, coping and adjustment in MS. The limitation of the previous research highlights the need for further research to apply the SRM to MS patients prospectively, using a disease-specific coping measure.

The role of illness representations in understanding adjustment is a relatively new area of investigation in MS. In addition, illness perceptions are just one type of psychological variable, shown to be associated with psychological distress. In order to develop a fuller understanding of the underlying mechanisms in adjusting to MS, researchers have identified the need to take other psychological variables into consideration. The following sections therefore examine the research, which has investigated the role of illness cognitions based on other self-regulation and social cognition models discussed in Chapter 2. The focus of the following section is to examine the research, based on the stress and coping model. This model is similar to the SRM as it also recognises the importance of how individuals perceive or appraisal their illness on how they cope and adjust to their condition.

3.3 Transactional Model of Stress and Coping

"The application of stress and coping theory is a powerful tool for unravelling the complexities of long-term adjustment in MS'' (Aikens et al., 1997). This model has been identified as the recommended paradigm for guiding research into psychological adjustment to MS (e.g. Vanderplate, 1984). Pakenham et al (1997) claimed that until recently, the majority of MS research has concentrated on psychopathology and examined MS using more traditional psychiatric constructs. The stress/coping model is similar to the SRM, as it de-emphasises psychopathology and places its focus on coping. It also views coping as playing a key role in the relationship between an individual's perception of their condition and how well they adjust (for a full description of this model see Chapter 2, section 2.5). Unlike the research applying the SRM to MS, some of the studies applying the stress and coping model have investigated both illness appraisals and coping with adjustment to MS. The illness appraisals identified by the stress and coping theory vary from the illness perceptions components identified by the SRM. However, this research still provides important evidence for the role of illness cognitions in coping and adjustment to MS. As these studies demonstrate the way an individual views their situation/condition has important implications for how they cope and adjust. This is the essence of both the stress and coping theory and the SRM.

3.3.1 The role of illness appraisals in MS

The following three studies provide evidence for the successful application of stress and coping in to MS. The first study was carried out by Wineman et al (1994) to compare the coping behaviours of 433 MS patients with 257 Spinal Injury Cord (SCI) patients. When patients appraised the situation as dangerous, emotion-focused coping was employed to manage the threat and when they appraised it as an opportunity, problem-focused coping was favoured. The appraisal of a situation as more dangerous was also to lead to greater emotional disturbance. One limitation of this research is the cross-sectional nature of the data, the findings therefore may not be consistent over time.

Although Wineman et al's (1994) study measured the illness appraisals of MS patients, it did not focus on the relationship between these and adjustment to the condition. The first published study to investigate this was carried out in 1997 by Pakenham and his colleagues. They assessed the role of appraisal and coping strategies in adjustment to illness related stressors in 122 MS patients and 69 MS carers. Patients took part in a semi-structured interview, which was used to identify their main MS-related problem. The findings suggested that threat appraisal may be related to some dimensions of adjustment in MS when the main illness-related stress is psychosocial and unrelated when the stressor is physical. They suggest that the severity and intrusiveness of MS symptoms may override any impact that threat appraisal has on some of the dimensions of adjustment. The controllability and challenge appraisals were found to be only weakly associated with adjustment. However, this study was limited by the cross-sectional nature of the results. They were, therefore, unable to determine whether appraisal and coping play a causal role in adjustment to MS, or whether appraisals and coping behaviours are a result of psychological distress. To address this limitation, Pakenham (1999) investigated 122 MS patients at time 1 and 12 months later. This study assessed the same predictors and adjustment outcome variables as this earlier study (Pakenham & Stewart, 1997). In addition, the role of stressful life events in predicting adjustment was also assessed. From the cross-sectional data, they found that illness appraisals were related to emotional distress and social adjustment. Threat appraisals were positively associated with most adjustment domains at time 1. However, appraisal was not related to adjustment 12 months later and challenge/controllability appraisals were not related to time 1 or 2 adjustment. According to the researchers, the latter finding is consistent with previous research by Folkman and Lazarus (1986), which revealed that challenge and controllability appraisals are unrelated to psychological and somatic outcomes in community samples. Moreover, Pakenham et al (1999) accounts for the lack of association between threat appraisal and subsequent adjustment by referring to the threat appraisal measure they used. They relied on anecdotal reports from patients, which may have only assessed threat related to the individual’s current MS problems as opposed to their MS in general.

3.3.2 Application of the Stress and Coping Theory to MS

The stress and coping model highlights the importance of an individual’s illness appraisals, in determining how they cope and adjust to MS. The role of controllability appraisals measured in these studies, is of particular importance for the current research, as it is similar to the control component of the SRM. However, the findings from the studies discussed in this section only provide limited support for the role of controllability appraisals (Pakenham, 1999; Pakenham & Stewart, 1997). These findings contradict Jopson and Moss-Morris (2003) and Vaughan et al’s (2003) (see section 3.2.1.2) research, which found that the greater perceived control an individual has, the better they adjust to MS. Further examination of research investigating the role of control cognitions in adjustment to MS, may provide more consistent findings. As mentioned in section 3.2.1.3, there have been a number of studies which have investigated the role of control on adjustment to MS based on the health locus of control theory. This research is discussed in the following section.

3.4 The Health Locus of Control Theory

Research applying the theory of Health Locus of Control (HLC) demonstrates how the patient's perception of control is a determining factor in whether or not they experience psychological distress, as a result of their condition. This section will examine the research which has successfully applied the HLC to investigate the role of control beliefs in adjustment to MS.

3.4.1 Research investigating the role of control beliefs

In an early study, Yabroff (1984) found that midrange HLC scores were predictive of adjustment to the condition. Published in the following year Halligan and Rezinikoff (1985) found that patients who reported an internal HLC orientation experienced lower levels of depression and a greater perceived body image. In a further study, investigating control beliefs, Wassem (1991) using the Health Locus of Control Scale (Wallston et al., 1975) found that MS patients who were more internally orientated experienced a milder course of MS, had higher levels of knowledge of MS and practiced more self-care than those who were externally orientated. However, this study was limited by the sample used. The MS sample was taken from a support group and therefore it was not confirmed that individuals had received a formal diagnosis of MS. The findings, therefore, may not be generalisable to a wider MS population

Wassem (1991) and Halligan and Reznikoff's (1985) findings suggest that an internal locus of control is associated with better adjustment to MS. These findings are consistent with the results of Hickey and Greene's (1989) study, which found that internal HLC was related to lower levels of hopelessness in both males and females. This study also found that individuals who believed powerful others controlled their health experienced lower levels of hopelessness however, this was only in females. Unlike the previous studies discussed in this section, this study takes into account gender differences They found that males were more likely than females to believe that powerful others were in control of their health. Furthermore, this study also investigated the relationship between health control beliefs and coping with MS. The HLC theory predicts that individuals with an internal locus of control will engage in health promoting activities (see Chapter 2 section 2.4.1). Engaging in these types of activities can also be classed as a type of problem-focused coping. It is therefore expected that internality would be related to problem-focused coping. However, this study found that problem-solving coping was not related to internality of HLC as predicted, but instead tended to be positively related to an external HLC. In addition, they found that chance HLC was associated with lower levels of problem-focused coping in females and lower levels of emotion-focused coping in males. To our knowledge, this study is the only published study to investigate the relationship between health control beliefs and coping with MS. However, this study only assessed control beliefs in 41 MS patients and is therefore limited by the size of the sample used.

As discussed in Chapter 2 (see section 2.4.1) the core assumption of this theory, is that an internal orientation of control is the most beneficial. The findings of the research, discussed in this section are consistent with this prediction. They suggest that MS patients who attribute control internally, will adjust better to their condition. Other research however, has provided contradictory evidence for the relationship between internality and adjustment.

MacLeod and MacLeod (1998) found that internality was not related to lower levels of psychological distress in either SCI patients or MS. However, the correlation between externality in patients HLC and level of depression did approach significance and a slightly stronger relationship (although also non-significant) between internality and depression in MS was identified. The researchers, although unable to drawn any firm conclusions, suggest that their results imply that an internal HLC in MS may not necessarily be maladaptive. It is worth noting that this study had a number of limitations, which may have influenced the findings. In addition to the small sample size, the measures used were not validated for an MS population. The limitations of this study may account for the inconclusive findings about the relationship between internality and adjustment to MS.

The final study which will be discussed in this section was carried out by Gerald Devins and his colleagues. They have carried out a number of studies investigating the relationship between illness intrusiveness and adjustment to MS patients (Devins, 1994; Devins et al., 1993; Devins et al., 1996). Although illness intrusiveness plays a key role in adjustment to MS and other chronic illness, Devins and colleagues have studied the role of this psychological variable extensively and therefore, it will not be assessed in present research. However, the research carried out by Devins and his associates has also provided support for the importance of perceived control in adjustment to chronic illness, including MS. Devins et al (1993) found that personal control was associated with greater positive psychological well-being, after controlling for disease characteristics and illness intrusiveness.

3.4.2 Application of HLC Theory to MS

Overall, the research discussed in this section, provides evidence for the importance of health control beliefs in successful adjustment to MS. According to the HLC theory, an internal locus of control is beneficial (see Chapter 2 section 2.4.1.). The findings provide support for this proposition. The studies found that an internally orientated locus of control was related to lower levels of depression, hopelessness, disability, fatigue, illness intrusiveness, a milder MS course and increased psychosocial well-being. This research highlights the importance of taking into account the role of control beliefs in order to fully understand the psychological mechanisms behind successful adjustment to MS. However, as discussed in Chapter 2 (section 2.4.2 and 2.4.3) the HLC theory alone may be too narrow to explain adjustment to illness. In addition, to control beliefs other psychological factors need to be taken into consideration. Another illness cognition, which is closely related to health control beliefs is self-efficacy beliefs. The role of self-efficacy beliefs is a central component of Social Cognitive Theory (Bandura, 1977,1986). This theory will be the focus of the following section.

3.5 Social Cognitive Theory

Psychological research often examines the role of negative mind states in adjusting to illness. However, there is increasing recognition in the role of positive psychological states. Social Cognitive Theory proposes that human behaviour is a function of the interaction between personal, behavioural and environmental influences. Based on the proponents of Social Cognitive Theory, research has been developed to investigate positive psychological cognitions and adjustment to MS. This research has primarily focused on the role of the patient's self efficacy and optimistic beliefs in helping them cope and adjust (for a full description of the Social Cognitive Theory see Chapter 2, section 2.3). This research gives further insight into the role of patient's illness cognitions in determining their quality of life.

3.5.1 The role of self-efficacy

The role of self-efficacy beliefs is a key component of Bandra's Social Cognitive Theory (see Chapter 2 sections 2.3.1 and 2.3.2). Consequently, the construct of self-efficacy has received increased attention from MS investigators.

One of the earliest studies was carried out by Walsh and Walsh (1987) who found that self-esteem was adversely affected by poor physical functioning and a negative adaptive attitude. In a more recent study Shnek et al (1995), found that lower self–efficacy was significantly related to depression. However, self-efficacy only accounted for a small portion of the variance in depression and had no significant effect when helplessness was controlled for. Their findings did however show that self-efficacy may influence coping behaviour. Individuals with low self-efficacy were impaired in their ability to formulate coping strategies. These results however, need to be interpreted with caution as this study had a number of limitations with the measures used. The psychological measures employed had previously been used with RA patients and were modified for use with MS by changing the wording from ‘arthritis’ to ‘MS’. The reliability and the validity has therefore not been established. Furthermore, the study was also limited by the cross-sectional nature of the design.

Barnwell and Kavanagh (1997) carried out the first published research to investigate self-efficacy in MS using a longitudinal design (two months). Self-efficacy was found to predict performance of mood control and social activity at two months. Contrary to Walsh and Walsh’s (2001) findings Barnwell and Kavanagh (1997) did not find a relationship between disability and self-esteem. However, self-efficacy for their ability to take part in social activities predicted their self-esteem (extent we value ourselves) two months later. Self-efficacy did not predict depression or the patient’s self-reported disability. They claimed that this was caused by the stability of depression and disability, over the two month period. The follow-up period was relatively short and as a result, their findings may have only focused on short term changes.

In the most recent study to date, Wassem and Dudley (2003) employed a 4 year longitudinal design to investigate the effectiveness of a nursing intervention in promoting adjustment and symptom management in individuals with MS. They did observe that treatment influenced self-efficacy scores at 6 months however, scores varied between 60 to 70 for the remaining data collection points. This study was however, limited by its small sample size and patients were aware whether they had been assigned to the treatment or control group, which could have affected their responses. Furthermore, many individuals in the control group had commented that they enjoyed completing the self-efficacy measure it therefore acted as a weaker form of the intervention.

In addition to Shnek et al's (1995) study, other research has shown that self-efficacy has an influence on the coping strategies individuals with MS employ. O'Brien (1993) found that self-esteem was related to problem-focused coping. They found that the four kinds of coping strategies employed most often were all problem-focused. They all reflected strategies to maintain control. The study also found an inverse relationship between self-esteem and emotion-focused coping. Although this study found a link between self-esteem and problem-focused coping, the correlation was low. Further research is required to explain how self-esteem influences this type of coping. It may be possible that this relationship varies depending on the level of disability.

Riazi et al (2004) used Schwartz et al's (1996) Multiple Sclerosis Self-Efficacy Scale (MSSE function and control scale) to assess the predictive value of self-efficacy on self-reported health status in 89 MS patients. Their findings revealed that when the sample of patients from both the rehabilitation and steroid treatment groups were combined both the baseline and improvement in self-efficacy were strong and independent predictors of patients' improvements in self-reported outcomes. They also found similar results within each of the treatment groups. However, for the rehabilitation group the baseline self-efficacy scores did not predict how well patients' health status improved. These results do not support Barnwell and Kavanagh's (1997) study, which found that self-efficacy did not predict self-reported disability. However, they employed a MS specific measure of self-efficacy, which showed a medium to large effect size. They argue that their own analysis must be interpreted with caution because of the small sample size (N=50). In addition, to the small sample size this study also had a number of other limitations. The regression models only accounted for a maximum of 49 % of the variance. This suggests that further research is needed, including additional variables such as coping, which may explain greater variance.

In addition to the research investigating the role of self efficacy beliefs, other research has investigated the role of optimistic self-efficacy beliefs.

3.5.2 Optimistic self-efficacy beliefs

Research with a variety of patient groups has found that optimistic self-efficacy beliefs play a direct and indirect role (via coping) in the adjustment to chronic illness. Research investigating the relationship between optimism and illness has identified a relationship between optimism and physical and psychological well-being (Brenner et al., 1994; Carver et al., 1993; Carver & Scheier, 1985). Optimistic patients with rheumatoid arthritis (Brenner et al., 1994; Holman & Lorig, 1992), Parkinson’s disease (Shifren, 1996) breast cancer (Carver et al., 1993) or HIV infection (Taylor et al., 1991) experience greater psychosocial and physical functioning. The research highlights that optimism may act as a buffer against psychological distress and enable patients to adjust to their condition better than if they had not adopted an optimistic disposition (Gold-Spink et al., 2000).

There have been a range of studies which have investigated the role of optimistic self-efficacy beliefs in MS. Fournier et al (1999) found optimistic MS patients experienced lower levels of depression and depending on the dimension of optimism, the impact on depression was mediated by emotion-orientated coping. Following on from this study

Fournier and colleagues (Fournier et al., 2002a,2002b) carried out further research to assess the role of optimistic beliefs in adjustment to three different chronic illnesses taking into account the role of control. Their findings revealed that optimism led to lower levels of depression, anxiety and physical functioning both directly and indirectly through coping. Consistent with the SRM their findings suggest that coping may act as a mediator.

3.5.3 Application of Social Cognitive Theory to MS

Components of the Social Cognitive Theory have been successfully applied to understanding adjustment to MS. As discussed in this section, research applying this theory to MS has investigated the role of self-efficacy beliefs. In particular it has focused on the role of optimistic self–efficacy beliefs. The findings of the research provide evidence for the importance of self-efficacy in successful adjustment to the condition. Those who have more confidence in their ability to cope with the illness, are likely to engage in more problem-focused coping strategies, social activities and are better at controlling their mood. Furthermore, feeling positive about being able to maintain an optimistic outlook on their condition will determine how individual will cope and adjust. Overall these findings highlight the importance of taking into consideration the role of optimism and self-efficacy beliefs when investigating the psychological factors, which lead to psychological distress in MS.

3.6 Application of social cognition and self-regulatory models to MS

Social cognition and self-regulatory models have provided researchers with a framework for investigating the psychological factors, which lead to successful adjustment to MS. The key model discussed in Chapter 2 was Leventhal’s Self-Regulation Model (see Chapter 2, section 2.6). As this chapter discussed MS research has found support for the relationship between illness beliefs and adjustment to MS (e.g. Vaughan et al 2003; Jopson and Moss Morris, 2002) (see section 3.2.1) and also between coping and adjustment to MS (see section 3.2.2). However, no published research has fully operationalised the SRM in predicting adjustment to MS

Research applying the SRM and Stress and Coping Model to individuals with MS, has highlighted the importance of illness beliefs and coping in predicting adjustment to MS (see section 3.3.2). In addition, to illness representations and coping, research based on the Health Locus of Control theory (see section 3.4.2) and Social Cognitive Theory (see section 3.5.1) has suggested that health control beliefs and self-efficacy beliefs also play a determining role in how individuals cope and adjust to MS. Their findings highlight the need for research to take into account these factors when investigating adjustment to this condition.

The Stress and Coping Model, Social Cognitive Theory, HLC Theory and the SRM in particular, are all fundamentally health psychology frameworks designed to assist in developing the understanding of how patients with medical conditions adjust to their illnesses (Petrie & Moss-Morris, 1997). Aikens (2003), highlighted the need to determine how well illness representations explain adjustment to MS, compared to more current-reigning constructs such as cognitive models of psychopathology. Three of the most influential cognitive models of psychopathology are the Cognitive Model of Depression, the Learned Helplessness Theory (see Chapter 2, section 2.10) and its revised Hopelessness Theory (see Chapter 2, section 2.11). As discussed in Chapter 2 (see section 2.8) these models were developed to explain why individuals experience psychological distress. It is therefore important to examine the research applying these models to individuals with MS, to fully understand the psychological mechanisms which lead some MS patients to become psychologically distressed. Consequently, this research is the focus of the following section.

3.7 Cognitive models of psychopathology

Cognitive models of psychopathology were designed to identify the psychological factors behind depression, anxiety and suicide ideation. Chapter 2 examined three influential cognitive models of psychopathology - Cognitive Theory of Depression, Learned Helplessness Theory and the Hopelessness Theory of Depression (see Chapter 2 section 2.9, 2.10 and 2.11 for a full description of these models).

3.8 Cognitive Theory of Depression and Learned Helplessness Theory

Three cross-sectional studies (McGuiness, 1996; Shnek et al., 1995; van der Werf et al., 2003) and one longitudinal study have measured the role of helplessness in adjustment to MS. In addition, Shnek et al (1995) also investigated the role of cognitive distortions in adjustment to MS.

Shnek et al (1995) found that although greater cognitive distortions were significantly related to depression. Only helplessness predicted depression when these variables were measured simultaneously. Helplessness significantly accounted for 27.2% of the variance in depression in 80 of patients with a clinically definite diagnosis of MS and made biggest contribution towards predicting depression compared to self-efficacy and cognitive distortion, even after controlling for demographic and disease-related variables.

Although a number of other studies have investigated the role of learned helplessness in MS, to date this is the only published study investigating the relationship between cognitive schema and psychological distress in the population. However, as discussed in section (3.5.1.) this study was limited by the psychological measures employed and the cross-sectional design. This highlights the need for additional research to investigate the role of cognitive schema in adjustment to MS using a prospective design.

In addition to Shnek et al's (1995) research, three other studies have investigated the role of learned helplessness in adjustment to MS. McGuiness (1996) found that those who felt more helpless experienced greater disease severity and tended to perceive their condition as more active. Greater levels of helplessness were found to be related to more severe functional disability and more severe social disability. In 2001, Evers and colleagues investigated the role of helplessness in developing and testing the Illness Cognitions Questionnaire (ICQ). Helplessness was found to be moderately to relatively highly related to lower levels of optimism, extraversion and physical and psychological health status and greater levels of neuroticism. Greater helplessness was primarily related to an increase in disease activity, functional disability, physical complaints and impact of the disease on daily life 12 months later. However, it should be noted that due to the uniform pattern of criterion measures, in both MS and RA, samples were calculated together.

Using the ICQ developed by Evers et al (2001), Van der Werf et al (2003) also investigated the role of helplessness in MS. They found that greater emotional instability and neurological impairment was significantly related to greater helplessness, which in turn led to higher fatigue severity and depressed mood in 87 outpatients with a definite diagnosis of MS.

Overall the research applying the Learned Helplessness Theory of Depression provides support for the relationship between learned helplessness and depression.

As discussed in Chapter 2 (see section 2.11) the Learned Helplessness Theory was revised in 1989 to a broader theory of hopelessness. Research based on this hopelessness model has identified hopelessness as the pernicious link between depression and suicide (see Chapter 2, section 2.11.2). Consequently, due to the high rates of suicide in MS patients (see Chapter 1, section 1.9.2.2.) it is important to examine the research which has investigated the role of hopelessness in adjustment to MS.

3.9 Hopelessness Theory of Depression

Patten and Metz (2002) found that hopelessness was higher amongst those with secondary-progressive MS patients than those with relapsing-remitting. Depression was found to be strongly related to hopelessness in both types of MS. However, it was not possible to determine if hopelessness could be regarded as a cognitive distortion which is caused by depression. According to the researchers another possibility was that increased hopelessness could reflect activation of specific cognitive schema by illness-related stressors, which in turn could lead to depression. This study provided no data on the role of hopelessness in relation to suicide in MS, as the number of suicides and suicide attempts in this study was insufficient to support the analysis. Furthermore, they did not include a measure of suicide ideation. This study represented the first prospective evaluation of hopelessness in persons with MS. However, these results were derived from clinical trials and consequently, may not be generalisable to the general population of individuals with MS. This highlights the need for further research to investigate the role of hopelessness in predicting suicide intention in a more representative sample of MS patients.

As discussed in Chapter 2, section 2.11.2, recent developments in the Hopelessness Theory of Depression identified the construct of future thinking. To date, only one published study has investigated the role of future thinking in MS. Moore et al (2006) investigated how MS patients with relapsing forms of MS anticipated their future using the FTT. They employed a mixed design comparing depressed MS patients to non-depressed MS patients and health controls. They found that the MS depressed group anticipated reduced future positive experiences, but no increase in negative future thoughts compared to non-depressed and health controls. One of the main limitations of this study was the small sample size. Only 42 adults took part in the study, these were split into three groups with the smallest group (MS depressed) having only 14 participants. Furthermore, this study only assessed levels of anxiety and depression in MS. Therefore to date, no research has investigated the future thinking in predicting suicide ideation in this condition.

3.10 Application of cognitive models of psychopathology to MS

Cognitive models of psychopathology were developed to identify the psychological factors underlying depression, anxiety and suicide ideation. Research applying these models to understand adjustment to MS highlights the need for further research to investigate the role of cognitive schema, hopelessness and future thinking in predicting adjustment to MS. Although the research found some support for these constructs in predicting psychological distress, the limitations of these studies highlight the need for future research to investigate these relationships further.

3.11 Summary

This chapter examined the research which has applied the psychological models discussed in Chapter 2, to understand adjustment to MS. Firstly, it investigated the research which has been designed based on social cognition and self-regulatory models. It then assessed those studies derived from cognitive models of psychopathology. The current doctorate research was designed based on the findings and limitations of previous research applying social cognition models, self-regulatory models and cognitive models of psychopathology. The development and design of the present research is focus of Chapter 4.

Chapter 4: Rationale for Thesis

4 Overview

The aim of this chapter is to summarise the rationale behind the current doctorate research. Firstly, it gives an overview of the background theory and research presented in the first three chapters. Based on the previous research findings (Chapters 1-3), a number of key research questions are proposed and the overall aim of the current doctorate research is discussed. Furthermore, a schematic model of the relationships being measured by the current research is presented and based on the findings of previous research a number of hypotheses are proposed.

4.1 Background to thesis

In Chapter 1, the need for research to investigate the psychological factors, which make those with MS vulnerable to psychological distress was highlighted (see Chapter 1, see section 1.9.3.). Research investigating the psychological impact of the condition emphasises the need for the development of interventions to help individuals cope and adjust successfully to living with MS (see Chapter 1, section 1.9.2).

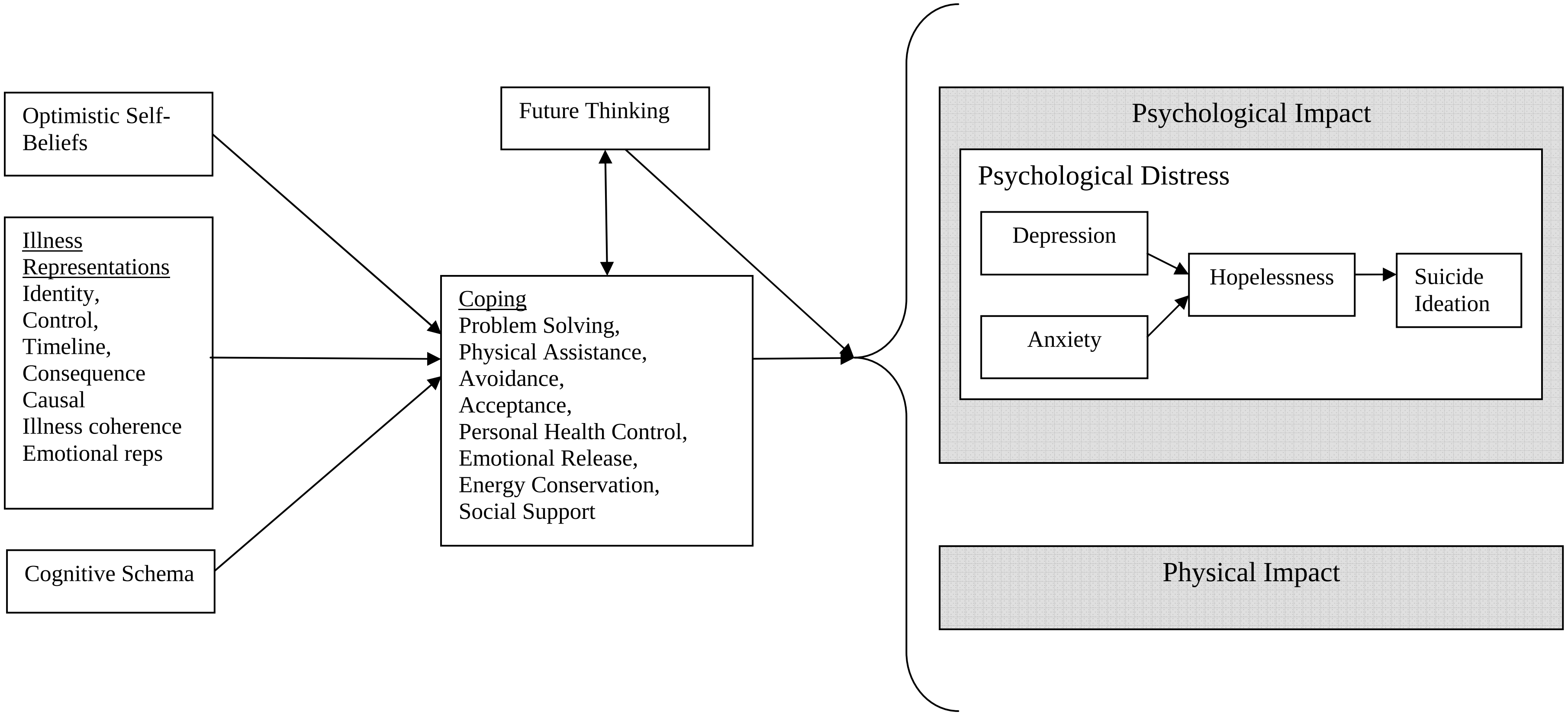
In psychology, researchers have developed a number of psychological models to help explain how individuals cope and adjust to illness. These models were the focus of Chapter 2. In particular, Chapter 2 identified three types of psychological models, which researchers have employed to understand human behaviour - social cognition models, self regulatory models and cognitive models of psychopathology (see Chapter 2 for a full description of these models).

Previous research applying these psychological models to MS identified a number of key illness cognitions, which influence how individuals adjust to living with MS. Research based on social cognition and self-regulatory models has emphasised the role of health beliefs such as illness representations, health control beliefs and optimistic beliefs, in addition to coping in determining successful adjustment to MS. Furthermore, cognitive models of psychopathology have identified the role of cognitive schema, helplessness/hopelessness and future thinking in predicting depression, anxiety and suicidal ideation. However, to our knowledge no published research has investigated the relationship between all of these variables. The current research will, therefore, investigate the relationship between each of these factors and examine which illness cognitions (illness representations, optimism, cognitive schema, future thinking) and coping strategies lead to successful physical and psychological adjustment and which precipitate psychological distress.

4.2 Aim of the current doctorate research.

The main aim of the current doctoral research is, therefore, to identify the psychological factors, which predict quality of life and psychological distress in MS. To do so, the current research aims to apply psychological models to samples of MS patients and assess indices of quality of life and psychological distress over time. The model in Figure 4-1 illustrates the relationships, which will be investigated during the doctoral research. This research will, therefore, increase theoretical knowledge about the psychological factors, which lead to a better quality of life and those, which lead to psychological distress. It will also provide a foundation on which to build interventions, which will hopefully, aid healthcare professionals in the early identification of MS patients vulnerable to the development of psychological distress. This will enable them to intervene at an early stage to improve the patient’s quality of life.

Figure 4-1 A schematic representation of the proposed relationships investigated in the current research.



4.3 Research Questions.

In order to test the proposed model in Figure 4-1 the following research questions were developed.

4.3.1 Question 1 (i), (ii) & (iii) – What is the relationship between the illness representation components in MS ? (Studies 1 & 3)

Previous research (Vaughan et al, 2003) has found that MS patients' illness beliefs are related to each other. However, this latter study did not investigate the relationship between the different illness representation components over a period of time or whether MS patients' illness representations changed over time. Furthermore, no research has investigated the relationship between illness beliefs and the other illness cognitions such as dysfunctional attitudes, optimism and future thinking in MS. The current doctorate research, therefore, investigated:

(i) What is the relationship between the different illness representation components?

(ii) Do illness representations change over time?

(iii) What is the relationship between illness representations and the illness cognitions, dysfunctional attitudes, optimism and future thinking?

4.3.2 Question 2 (i), (ii) & (iii) – What is the relationship between illness representations, coping and concurrent and prospective adjustment in MS? (Studies 1 & 3)

The aim of the current research was to examine the efficacy of the SRM framework in predicting adjustment to MS over time. Previous MS research has investigated the relationship between illness beliefs and adjustment (see Chapter 3, section 3.2.1), while others have assessed the role of coping on adjustment to MS (see Chapter 3, section 3.2.2). However, no published research has investigated the relationship between all the SRM components in an MS sample. This research, therefore, addressed the following questions;

(i) What is the relationship between illness representations and coping?

(ii) What is the relationship between illness representations and concurrent and prospective adjustment to MS?

(iii) What is the relationship between coping and concurrent and prospective adjustment to MS?

4.3.3 Question 3 (i) & (ii) – Do illness representations and coping predict adjustment to MS? (Studies 1 & 3)

According to the SRM (Leventhal et al 1980), illness representations predict coping, which in turn, predicts outcome. However, no published research has fully applied the SRM to understanding adjustment to MS, over time. To this end, the current research addressed the questions:

(i) Do illness representations and coping predict concurrent and prospective adjustment to MS?

(ii) Do illness representations directly predict concurrent and prospective adjustment to MS or is coping a mediating factor?

4.3.4 Question 4 (i) – What is the relationship between dysfunctional attitudes, optimism, future thinking, coping and adjustment to MS? (Studies 1 & 3)

The model proposed in Figure 4-1 was based on the SRM framework, however it has been extended to include the role of cognitive schema (dysfunctional attitudes), optimism and future thinking. This model proposes that dysfunctional attitudes, optimism and future thinking are related to how an individual copes, which in turn influences how well they adjust. However, no previous research has investigated the relationships between each of these cognitions in MS. This research, therefore, examined:

(i) What is the relationship between these illness cognitions?

4.3.5 Question 5 (i), (ii) & (iii) – Do dysfunctional attitudes and coping predict adjustment to MS? (Study 1)

According to Beck's Theory of Depression, maladaptive cognitive schemas lead to the development of psychological distress. Despite the high rates of depression and anxiety in MS, there has been limited research investigating cognitive schema in adjustment to this condition. The current research, therefore, investigated the questions:

(i) What is the relationship between dysfunctional attitudes, coping, concurrent and prospective adjustment to MS?

(ii) Do dysfunctional attitudes and coping predict concurrent and prospective adjustment to MS?

(iii) Do dysfunctional attitudes directly predict concurrent and prospective adjustment to MS or is coping a mediating factor?

4.3.6 Question 6 (i) (ii) & (iii) – Does future thinking and coping predict adjustment to MS? (Studies 1 & 3)

Previous research has identified future thinking as an important predictor of psychological distress (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004; O'Connor & Sheehy, 2000). However, only one study has investigated the role of future thinking in MS (Moore et al., 2006). The current research, therefore, investigated the questions:

(i) What is the relationship between future thinking, coping, current and prospective adjustment to MS?

(ii) Does future thinking and coping predict concurrent and prospective adjustment to MS?

(iii) Does future thinking directly predict concurrent and prospective adjustment to MS or is coping a mediating factor?

4.3.7 Question 7 (i) (ii) & (iii) – Does optimism and coping predict adjustment to MS? (Study 3)

Previous research suggests that optimistic self-beliefs may protect MS patients from becoming vulnerable to psychological distress. Using the SRM framework, this research investigated the role of optimism in relation to coping and adjustment over time. The current research, therefore, addressed the following questions:

(i) What is the relationship between optimism, coping, current and prospective adjustment to MS?

(ii) Does optimism and coping predict concurrent and prospective adjustment to MS?

(iii) Does optimism directly predict concurrent and prospective adjustment to MS or is coping a mediating factor?

4.3.8 Question 8 (i) – Does hopelessness mediate the relationship between depression/anxiety and suicide ideation in MS? (Study 3)

Previous research suggests that hopelessness is the pernicious link between depression and suicide(O'Connor & Sheehy, 2000). However, no published research has investigated this in MS. Study 2 therefore addressed the question:

(i) Does hopelessness mediate the relationship between depression/anxiety and suicide ideation in MS?

4.4 Design of the current doctorate research

The current doctorate research has been designed to address the research questions outlined in section 4.3. To this end, it investigated the relationships illustrated in the schematic model proposed in Figure 4-1, prospectively. Furthermore, the current research employed mixed qualitative and quantitative research methods. Previous research investigating the role of illness beliefs on coping and adjustment to MS has only employed quantitative research methods. However, according to Casebeer and Verhoef (1997) the combined, sustained and complementary use of qualitative and quantitative research methods will advance our knowledge of chronic diseases. The current research, therefore, included both quantitative and qualitative research measures. This provided a greater insight into the role of illness beliefs on coping and adjustment to MS.

4.5 Summary

Previous research has highlighted the need for further research to investigate the psychological factors, which make some MS patients more vulnerable to psychological distress. Based on the findings of previous research applying psychological models to MS, the model in Figure 4-1 was developed. The overall aim of the current doctoral research was, therefore, to test the proposed model in Figure 4-1, in order to identify the psychological factors, which predict successful adjustment to MS over time. Based on the SRM framework, the proposed model extends the SRM to include cognitive schema, future thinking and optimism. Using mixed quantitative and qualitative design methods, the current research investigated the relationships outlined by the proposed model and addressed the research questions outlined in section 4.3. A fuller discussion of the design and methods employed by the current research will be the focus of Chapter 5.

Chapter 5: General Methodology

5 Overview

Having discussed the fundamental aims and rationale underlying this research, the following chapter discusses the methodology used in the current doctorate research. Firstly, gives an outline of the thesis, by providing a description of how each study was designed. In addition, this chapter presents information about the individuals who took part in the research, including details of their recruitment, their response rates and the inclusion/exclusion criteria on which their selection for research was based. Furthermore, it discusses each of the quantitative psychological measures employed and gives a description of the semi-structured interview used in the qualitative study. This chapter also gives an outline of the overall procedure used. Finally, it discusses the ethical considerations, which were addressed when carrying out the current research.

5.1 Outline of thesis

For the current thesis, both quantitative and qualitative research methods were combined. This research therefore included two quantitative prospective studies and one qualitative research study. Quantitative research is defined as ‘the numerical representation and manipulation of observations for the purpose of describing and explaining the phenomena that those observations reflect’ (Babbie, 1992). Qualitative research however, is described as ‘the non-numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships’ (Babbie, 1992). Quantitative research often begins with pre-specified objectives focused on testing preconceived outcomes whereas, qualitative research begins with open-ended observation and analysis, attempting to identify patterns and processes that explain ‘how and why’ questions. A combination of these two methods produces a fuller understanding of the psychological factors involved in adjusting to MS (Casebeer & Verhoef, 1997). Due to the differences in the design of each study, this section discusses each the studies individually.

5.1.1 Study 1

This is a prospective study, in which MS patients (N = 105) completed a range of psychological measures, at two time points. These recognised measures assessed future thinking, illness perceptions, dysfunctional attitudes, physical/psychological impact, depression/anxiety and coping. Participants were then asked if they would be willing to take part in short telephone interview, answering questions about how they were adjusting to MS, two months later. Those who agreed were telephoned two months later for the second interview.

5.1.2 Study 2

This is a qualitative study, in which MS patients (N=15) took part in a semi-structured interview investigating their experience of living with MS from the insider's perspective. The interview questions focused on the individual's beliefs about their MS, how they coped with the condition and how much they felt it affected their quality of life.

5.1.3 Study 3

This is a prospective study, in which MS patients (N = 150) completed a range of psychological measures, at three time points. These recognised measures assessed depression/anxiety, hopelessness, suicide ideation, physical/psychological impact, optimism, illness perceptions, future thinking and coping. Participants were then asked whether they would be willing to complete a small number of measures of adjustment (depression/anxiety, hopelessness, suicide ideation, physical/psychological impact) 4 and 8 months later. Those who agreed were telephoned 4 and 8 months later for follow-up interviews.

5.2 Participants

This section provides information about the participant recruitment sources and the exclusion criteria employed. However, a full description of how participants were recruited, the response and follow up rates and the procedures employed for data collection are given in each of the study chapters.

5.2.1 Recruitment of participants

All participants who took part in the current doctorate research had been clinically diagnosed with Multiple Sclerosis (MS). They were recruited from the following three sources:

1) The Forth Valley Area Rehabilitation Team (FVART) which operated from both Stirling Royal Infirmary and Falkirk and District Royal Infirmary

2) The Fife Physical Rehabilitation Service (FPRS) which operated from Cameron Hospital in Fife.

3) The Southern General Hospital in Glasgow.

Both the FVART and FPRS were established to provide assessment and rehabilitation to those aged 16-64, who suffer from physical disabilities or brain injury caused by trauma or progressive disease. As estimated by Rothwell and Charlton (1998) (see Chapter 1, table 1-1) in 2005 the estimated prevalence of individuals with MS in Fife was 667 in Forth Valley it was 532 and in the greater Glasgow area they estimated a total of 1, 623. These rates could be considered in terms of the estimated total of 9,527 cases in Scotland in 2005. This gives some indication of the target population for the current research. All MS patients treated by the FVRT, FPRS and Southern General Hospital, with exception of those who met exclusion criteria detailed below, were eligible to take part in the research.

5.2.2 Exclusion and inclusion criteria

All participants had to have received a formal diagnosis of MS by a neurologist to be eligible to take part. In order to be as inclusive as possible the research included patients with all forms of MS (relapsing-remitting, primary-progressive, secondary-progressive and benign). Furthermore, only a few specific exclusion criteria were employed, which were as follows;

(i) Any patient staff at the recruiting hospital felt may not be able to participate due to severe emotional difficulties. The FVART and FPRS members and a consultant neurologist from the Southern General Hospital screened participants and informed the researcher of those not deemed suitable to participate;

(ii) Any patient for whom English was not their first language. One of the measures (the future thinking task) was developed for English speaking participants;

(iii) Any patient who was particularly cognitively impaired (who scored less than 25/30 in the MMSE).

5.3 Measures.

5.3.1 Documentation and cognitive assessment.

All the studies required an information sheet, invitation letter, consent form and questionnaire collecting patients' demographic and illness details. The invitation letter, in addition to inviting them to take part, also provided them with the researchers contact information. This was sent to participants along with an information sheet. The information sheet provided details about the nature of the studies, in particular it explained what participation involved and any issues they needed to take into consideration before volunteering to take part. Prior to the interview participants completed a consent form, short questionnaire and a cognitive assessment. The consent form, which presented a series of statements, required them to initial several boxes and then give their name, signature and the date at the bottom. The questionnaire asked them for their basic demographic details, illness characteristics and past medical history. This documentation varied slightly with each of the studies. The *Mini-Mental State Exam (MSSE: Folstein et al., 1975)* was used to systematically assess participants' mental status. It is an 11-question measure that tests five areas of cognitive function: orientation, registration (immediate memory), attention and calculation, recall and language. The maximum score is 30. A score between 25-30 out of 30 is considered normal, 18-24 indicates mild to moderate impairment and scores of 17 or less indicates severe impairment. It has been validated and extensively used in clinical practice. This can be seen in Appendix 2. In addition to the MMSE a range of other measures were used depending on the study. The following table provides a summary of all measures used in Study 1 and 3.

Table 5-1 Summary of Assessment Tools

Measure	**Authors**	**Study measure is employed in.**
Future Thinking Task	MacLeod et al (1998)	Study 1 & 2
Illness Perception Questionnaire- Revised	Moss-Morris et al (2002)	Study 2
Illness Perception Questionnaire-Brief	Broadbent et al (2006)	Study 1
Dysfunctional Attitudes Scale	Weissman & Beck (1978)	Study 1
Life Orientation Scale-Revised	Scheier & Carver (1985)	Study 2
Coping with Multiple Sclerosis Scale	Pakenham (2001)	Study 1 & 2
Multiple Sclerosis Impact Scale	Hobart et al (2001)	Study 1 & 2
Hospital Anxiety and Depression Scale	Zigmond & Snaith (1983)	Study 1 & 2
Beck Hopelessness Scale	Beck et al (1979)	Study 2
Suicide Probability Scale (suicide ideation subscale)	Cull and Gill (1988)	Study 2

5.3.2 Quantitative predictor measures

5.3.2.1 Future thinking

The Future –Thinking Task (FTT; MacLeod et al., 1998) was used to measure participants' thoughts about the future. It has been widely used in published research (MacLeod & Byrne, 1996; MacLeod et al., 1997; O'Connor et al., 2004). For this task participants were asked to think about potential future experiences. The task has two conditions. In the one condition, the participants are required to list all the things that they were looking forward to or felt positively about (positive future thinking). In the other condition, they are asked to list all the things that they are worried about or not looking forward to (negative future thinking). In each condition (positive and negative), participants are required to think of potential future experiences over three time periods – the next week (including today), the next year and the next five to ten years. For each time period the participant is given one minute to say aloud as many responses as possible. Order of completion of the positive and negative conditions (valence) is counterbalanced, such that half the participants complete the positive condition first, while the other half are required to complete the negative condition first. Order of presentation of items within each condition was constant (i.e. next week, next year, 5-10 years). Participants were informed that the items they generate could be trivial or important however, they did need to be things which they thought would happen or were reasonably likely to happen within the given time period. The items generated were recorded by the researcher, scored and summed across each time period (next week; next year; next 5 to 10 years) for both positive and negative conditions separately. Participants were also told to keep trying to generate responses until the time limit was up. Before administration of FTT, all participants completed the standard verbal fluency task (Lezak, 1976) – to control for general cognitive fluency – in which they had to generate as many words as possible using three letters (F, A and S), with one minute allowed per letter.

5.3.2.2 Illness representations

Illness Perceptions Questionnaire –Brief (IPQ-Brief: Broadbent et al., 2006) was used to measure the individuals' illness perceptions (see Appendix 3) and has been found to have good test-retest reliability and predictive validity (Broadbent et al., 2006). The items were developed by forming one question that best summarised the items contained in each subscale of the IPQ-R. It is therefore a self-report measure containing eight new items, in addition to the causal scale previously used in the IPQ-R. All the items with the exception of the causal question, were rated using a ten-point Likert-type scale (0 = no affect at all and 10 = severely affects my life) indicating the strength of agreement with each item. Five of the items measure cognitive illness representations: consequences (item 1), timeline (item 2) personal control (item 3), treatment control (item 4) and identity (item 5). Two items measure emotional representations: concern (item 6) and emotions (item 8). One item measures illness comprehensibility (item 7). Measurement of the causal representation is by an open ended response item adapted from the IPQ-R. It asks patients to list three most important casual factors of their illness (item 9). Responses to the causal item will be grouped into the categories stress, lifestyle, hereditary, viral, chance. Categorical analysis will be performed to assess this component. The ninth statement refers to the casual component and requires participants to list three responses ranking them in order of importance. As with the IPQ-R the items are coded so that high scores represent strong beliefs on the particular dimension. Consequently, high scores on the identity, consequences and timeline items reflect negative beliefs about the number symptoms related to MS, the severity of the consequences and the chronicity of the illness. High scores on the control and coherence dimension represent more positive beliefs about how controllable patients feel their MS is and how well they feel they understand their condition. High scores on the emotional representations question indicated a strong negative emotional response to their condition.

The Illness Perception Questionnaire--Revised (IPQ-R: Moss-Morris et al., 2002) was used to measure the individual's illness perceptions (see Appendix 4). It has been found to have good construct, criterion and known-groups validity across several illness groups (Moss-Morris et al., 2002). The IPQ-R is divided into two sections. The first section consists of eight subscales that assess patients' cognitive representations of their condition, while the second consists of a single subscale assessing patients' emotional representations or responses to their condition. In agreement with Leventhal et al's SRM, the components of cognitive representation in this scale include identity, control, consequences, timeline and cause. The consequences scale measures patients' beliefs about how serious their illness is. The timeline dimension is divided into a timeline acute/chronic subscale, which examines whether they see their illness as chronic in nature or a timeline cyclical subscale, which assesses whether suffers see their illnesses as cyclical in nature. The control dimension is separated into the personal control subscale, which refers to beliefs about ones own ability to control symptoms and treatment control, which refers to beliefs that treatment will be effective in controlling the illness. A new dimension, illness coherence measures the degree to which they feel they have a coherent understanding or model of their illness.

All the items are rated on a five point Likert-type scale, which ranges from strongly agree to strongly disagree with the exception of the identity dimension. The illness identity scale measures the number of commonly experienced symptoms such as fatigue, headaches and loss of strength that the sufferer believes to be related to his/her condition. This dimension asks participants to rate on a yes/no scale whether they believe a list of commonly occurring symptoms are related to their illness.

Items are coded so that high scores reflect strong beliefs on the particular component. Consequently, high scores on the identity, consequences and timeline subscales represent negative beliefs about the number symptoms related to MS, the severity of the consequences and the chronicity of the condition. High scores on the control and coherence components indicate more positive beliefs about how controllable patients feel their MS is and how well they feel they understand their condition. High scores on the emotional representations subscale indicates a strong negative emotional response to the condition.

5.3.2.3 Cognitive schema

The Dysfunctional Attitudes Scale (DAS: Weissman & Beck 1978) was used to measure participants' cognitive schema (see Appendix 5). The DAS assesses the extent to which an individual endorses general attitudes and underlying assumptions. It was hypothesized by cognitive theory that dysfunctional attitudes are associated with depression. It presents 40 statements of dysfunctional beliefs (e.g "Taking even a small risk is foolish because the loss is likely to be a disaster"). Participants are required to indicate on a 7-point Likert scale how strongly they are in agreement or disagreement with each statement ranging from totally agree (1) to totally disagree (7). The DAS has been shown to distinguish clinically depressed from non-depressed psychiatric patients and from normal controls.

5.3.2.4 Optimism

Life Orientation Test (LOT: Carver & Scheier, 1990) was used to measure participants' levels of optimism and pessimism (see Appendix 6). The LOT includes four positively worded items (e.g. I always look on the bright side of things), four negatively worded items (e.g. if something can go wrong for me it will), and four filler items (e.g. It is easy for me to relax). For this doctoral research (Study 3) the Life Orientation Test – Revised version (Scheier et al., 1994) was used. The LOT-R consists of six items (e.g. "I am always optimistic about my future") and four filler items (e.g. "I enjoy my friends a lot"). Participants are required to indicate on a 5 point Likert scale ranging from disagree a lot (0) to agree a lot (4).

5.3.2.5 Coping

The Coping with Multiple Sclerosis Scale (CMSS; Pakenham, 2001) is a self-report measure of coping specific to MS (see Appendix 7). The CMSS has three sections and was used to explore how participants' cope with their MS. Firstly, respondents were asked to describe their main MS-related problem that they have been experiencing over the last month. Responses to this question will be grouped into categories such as mobility, bladder/bowel problems, fatigue etc. Categorical analysis will then be performed to assess patients' responses. Secondly, the measure asked participants to rate on a seven point Likert scale how stressful this MS-related problem has been for them in the past month (1= not stressful at all to 7 = extremely stressful). This rating measures participants' appraised stress concerning the problem with a higher score reflecting higher levels of appraised stress. In the third section, the scale presents statements of coping strategies and asks the participants to rate on a 5-point scale (0 = does not apply/never to 4 = very often) how often they have employed each of the coping strategies (e.g. I try to get information about the problem) to deal with their main MS-related problem over the past month. The scale has seven subscales (Pakenham, 2001) physical assistance (e.g. I use assistive equipment such as a wheel chair….), acceptance (e.g. I accept the fact that it happened), problem solving (e.g. I plan ahead what I need to do), emotional release (e.g. I let my feelings out), avoidance (e.g. I put it to the back of my mind), personal health control (e.g. I use exercise programs such as hydrotherapy…) and energy conservation (e.g. I conserve my energy for example……). The subscales have been shown to have adequate reliabilities (ranging from 0.56 to 0.74) and convergent and predictive validity (Pakenham, 2001).

5.3.3 Quantitative outcome measures

5.3.3.1 Depression and anxiety

Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) was used to measure participants' symptoms of depression and anxiety (See Appendix 8). The scale only includes non-somatic symptoms of depression and anxiety it is not confounded by reports of physical symptomology. It is a self-rating questionnaire which contains fourteen items, seven corresponding to the depression subscale (e.g. I still enjoy the things I used to enjoy) and seven corresponding to the anxiety subscale (e.g. "Worrying thoughts go through my mind"). Items are rated on a 0-3 point scale indicating the degree to which they have been experienced over the previous week. The total scores can range between 0 and 21 for the anxiety subscale and also the depression subscale. Total scores are then calculated for the two subscales with higher scores reflecting greater levels of depression and anxiety in MS patients.

5.3.3.2 Physical and psychological impact

The Multiple Sclerosis Impact Scale (MSIS-29; Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001) was used to measure the physical and psychological impact of MS on participants (see Appendix 9). It is a disease specific, self-report measure which contains 29 items and measures both the physical and psychological impact of MS. Participants are asked their views about the impact of MS on their day-to-day life during the past two weeks. There are 20 items, which measure physical impact (e.g. ‘In the past two weeks, how much MS has limited your ability to do physically demanding tasks?’) and 9 items for psychological impact (‘In the past two weeks how often have you been bothered by lack of confidence?’).They are required to rate on a 5 point scale (1 = not at all and 5 = extremely) the extent each statement describes their situation. The highest score on the physical scale is 100 and highest score on the psychological impact scale is 45. The psychological and physical impact scores can be reported as a total scale however, the evidence indicates that the two scales are measuring related but distinct constructs (inter correlations between scales = 0.62; factor analysis supports two dimensions) (Hobart et al., 2001). This research will therefore, sum the scores measuring the psychological impact of MS from the physical impact. This measure has been found to be a reliable, valid and responsive patient-based outcome measure (Hobart et al., 2001).

5.3.3.3 Hopelessness

Beck Hopelessness Scale (BHS: Beck et al., 1979) was used to measure participants’ levels of hopelessness (see Appendix 10). The BHS is a 20-item measure of patients’ negative expectations regarding the future. Participants were asked to indicate either agreement or disagreement with statements that assess pessimism for the future (e.g. I might as well give up as there is nothing I can do to make things better for myself). The scale employs a dichotomous (true/false) response format to produce a total score with higher scores indicating greater levels of hopelessness. The maximum score is 20. This is a reliable and valid measure that has been shown to predict eventual suicide (Beck et al., 1974).

5.3.3.4 Suicide ideation

Suicide Ideation subscale of the Suicide Probability Scale(SPS: Cull & Gill, 1988) was used to measure participants' suicide ideation (see Appendix 11). The subscale is comprised of 8 items related to suicidal cognitions, negative affect and the presence of a suicide plan (e.g. "I feel people would be better off if I was dead"). Participants' are asked to indicate how often they feel the statement applies to them on a 4-point Likert scale ranging from none or a little of the time (0) to most or all of the time (3).

5.3.4 Semi-Structured interview.

The interview schedule was developed to investigate the patient's experience of living with MS. The schedule began by focusing on participants beliefs about their condition (e.g Tell me your ideas about your illness?) and the progressed onto how they felt it had impacted their life (e.g. how do you feel it has affected your overall quality of life?). Typical questions within the schedule focused around illness beliefs, coping and adjustment to the condition.

5.4 Procedure

5.4.1 Recruitment of participants

Before each study was conducted both ethics approval from the relevant ethics committees (Fife and Forth Valley Ethics Committee and Greater Glasgow and Clyde

Ethics Committee) and research and development approval from the relevant research and development offices for each of the hospitals was applied for.

Following approval, a letter was sent in collaboration with the Forth Valley Area Rehabilitation Team (FVART), Fife Physical Rehabilitation Service (FPRS) or Southern General Hospital to suitable participants enclosing the information sheet and inviting them to participate. The information sheet detailed the project, and the involvement required by the participants. On receipt of the initial contact letter, participants were given 3 weeks to respond. Participants were given a contact name, telephone number and email address should they wish to discuss the research further. They were informed in the information letter that they may contact the researcher or hospital should they wish to discuss any issues, without obligation. The information sheet also clearly explained that they could raise any concerns during their participation and obtain support from those responsible for their treatment.

Those participants wishing to volunteer contacted the researcher by email or telephone. Once a participant had agreed to take part, the first interview was arranged at a date and time suitable for the participant. Given that people with MS may have mobility difficulties, it seemed more appropriate to give them the option to have the interview in their home to minimise their inconvenience. However, some people can find this invasive. Potential participants were therefore given the option of where they preferred the interview to be carried out. They could either be seen at home or at the University of Stirling, depending, on which they preferred. Once recruited participants information was anonymised using a coding system.

A letter was sent to the participant's GP to inform them of the study (in Study 3 this was done following consent by the participants, as requested by the ethics committee). In addition, they were also sent a copy of the information sheet and the research protocol which detailed the design of the study.

5.4.2 Data collection

Before the interview began participants were asked to sign a consent form. The consent form required participants to initial several boxes, and sign and date the form. The researcher helped in the administration of this task. Once informed consent had been taken participants were asked a number of questions regarding their demographic details and illness characteristics such as type of MS, duration of illness etc. Participants then completed the Mini-Mental State Exam (MMSE; see section 5.3.1) to screen for those who were significantly cognitively impaired. This procedure was the same for all three studies.

For Study 2 the semi-structured interview was then carried out. These interviews were all recorded on audio tape following the participants' consent and were transcribed in order for them to be analysed.

For Studies 1 and 3 however, this was followed by the Verbal Fluency test and Future Thinking Task (FTT; see section 5.3.2.1). Due to the nature of MS, many individuals suffering from the condition experience symptoms such as tremors and poor eyesight which could make the task of completing questionnaires difficult. Consequently, the researcher read out the questions from each of the psychological measures and participants were asked to give a response from one of the available options on the response card. Following completion of the first interview, participants were asked to keep the response card for the follow up. The psychological measures at all time points were all counter balanced to prevent any confounding effects from some of the questionnaires. In Study 1 these psychological measures assessed depression/anxiety, future thinking, illness perceptions, coping, physical/psychological impact and dysfunctional attitudes. In Study 3 all the same measures as Study 1 were included except for dysfunctional attitudes and additional measures of optimism, hopelessness and suicide ideation were included. Participants were then asked whether they would be willing to take part in a telephone interview two months later (Study 1) or four months and eight months later (Study 3). The follow up interviews were conducted over the telephone at a prearranged day and time suitable for the participant. Participants were asked to use the response card given to them during the first interview to answer the questions. The researcher read out the questions and marked the participants' responses onto the questionnaires. In Study 1 they were asked questions taken from a number of measures of adjustment (depression/anxiety, physical/psychological impact) and a measure of illness representations. This follow up interview took place two months after the initial interview. In Study 3 they were asked questions taken from a number of measures of adjustment (depression/anxiety, physical/psychological impact, hopelessness and suicide ideation) four and eight months later. Following the interviews a brief review of medical information from the patients' hospital medical records was carried out to gain information about the patients diagnosis of MS, the type of MS they were suffering from, steroid history, prior and current medications, other medical conditions past and present, which they suffer or have suffered from and if there has been any family history of MS.

5.5 Ethical considerations

5.5.1 Participants comfort and well-being

At all stages of the research process, potential participants were made aware of the nature of the research and what was required of them. Throughout the testing sessions, it was made clear that participation was entirely voluntary, that they were free to withdraw at any stage without explanation, that they did not have to answer questions they did not wish to and non-participation did not affect their existing or future treatment protocols. Every effort was made to respect the participants' need for comfort and rest periods were incorporated if necessary. The difficulties, which arise as a result of this condition, were also taken into consideration when designing this research. As discussed in section 5.4.1, due to the mobility problems associated with MS, we offered individuals the option of having the interview in their home. Furthermore, some of the symptoms of MS can make it difficult for some individuals to fill in questionnaires. Therefore as discussed in section 5.4.2, the researcher provided participants with response cards, read each of the questions out and marked down the responses given. These measures were taken in hope that participation in the research would have no adverse physical or psychological affects on those taking part.

5.5.2 Identification of mood disorders

Although participants were in current contact, or had had recent contact with hospitals, there was a chance that some people may have a previously unidentified mood disorder (clinically significant depression or anxiety) or reveal suicidal ideation that requires treatment. If participants reported feelings of depression, anxiety or suicide ideation during the interviews they were advised to contact the hospital and their GP so they could have the opportunity to receive appropriate treatment.

5.5.3 Confidentiality and anonymity

All participants were informed in the patient information sheet that any information given would be confidential. Some of the material people provided during the interviews, in addition, to information taken during the case note review was sensitive in nature. However, steps were taken to ensure confidentiality by using an anonymising coding system and the information gathered was securely stored. For the qualitative studies all participants taking part were given a pseudonym, so that they could not be identified from their transcripts. These pseudonyms have also been used to ensure anonymity when quoting participants directly from transcripts.

5.6 Summary

The aim of this chapter was to present and discuss the methodology used in the current doctorate research. This was done by providing an overview of the research design, presenting information about the participants, describing the range of psychological measures employed, discussing the overall procedure and finally highlighting the ethical issues taken into consideration when designing the research. However, a fuller description of methods used for each of the three studies, is given in the corresponding study chapters which follow.

Chapter 6: A Two Month Prospective Study Investigating the Role of Illness Cognitions and Coping in Adjustment to Multiple Sclerosis.

6 Overview

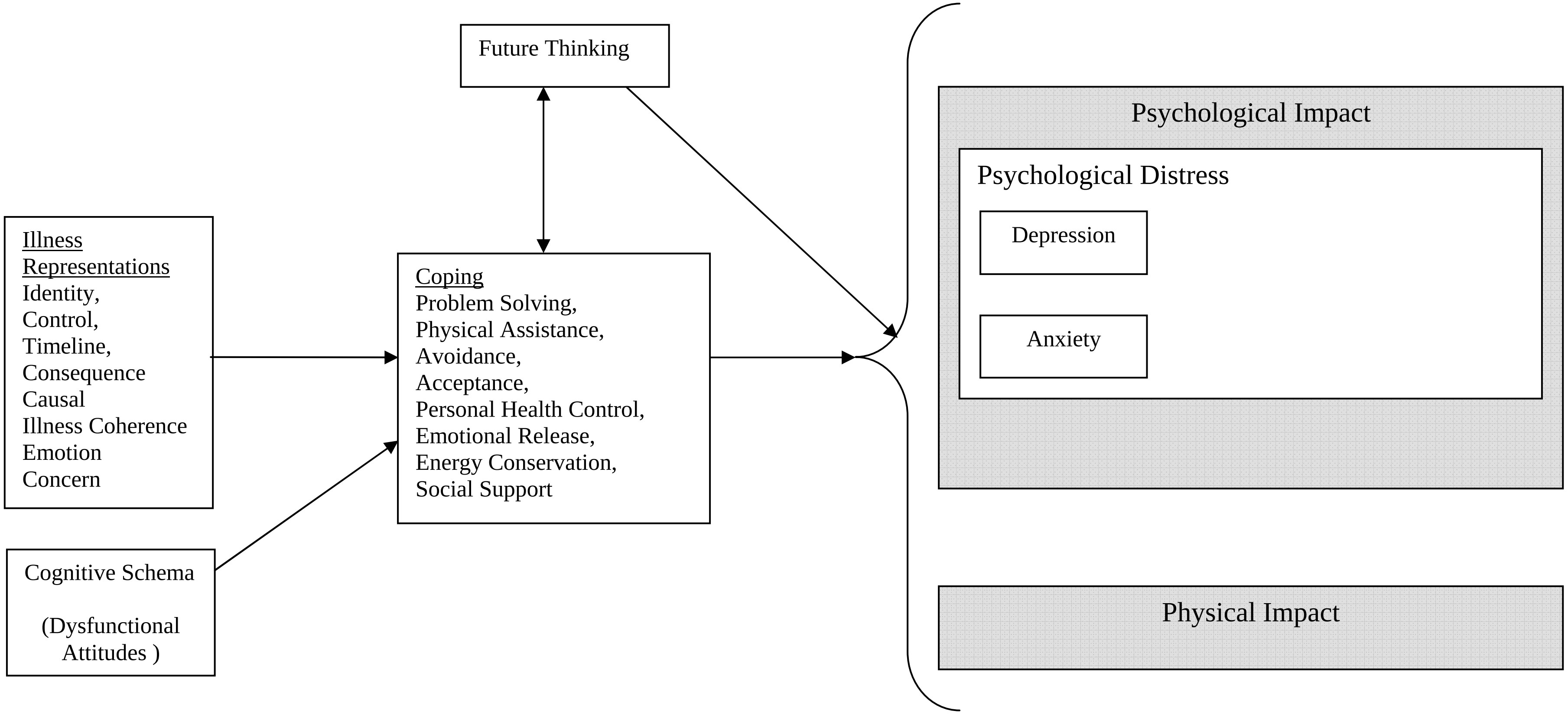
The following chapter details the rational and hypotheses for Study 1. The methodology employed is also discussed, by expanding on the information given about the methods in Chapter 5. This is followed by details of the statistical analyses carried out and the results that were ascertained. The chapter concludes with a brief discussion of the main findings and methodological limitations of Study 1 and the implications of these on the design of Study 2.

6.1 Rationale

Previous research applying psychological models to those with chronic illness have identified a number of key illness cognitions, which influence how individuals adjust. One of the most widely applied self-regulatory models is the Self-Regulation Model (SRM). Examination of the previous MS research revealed that no published studies had successfully applied the full SRM to a sample of MS patients. Those studies investigating the role of illness representations (see Chapter 3, section 3.2.1.2 for a description of these studies) did so without assessing the role of coping. In addition, those investigating the influence of coping on adjustment to MS (see Chapter 3, section 3.2.2 for a description of these studies) did not take into consideration the role of illness representations (see Chapter 3, section 3.2.2.4 for a full discussion on the limitations of this research). The main aim of Study 1 was therefore to apply the SRM framework to investigate the relationship between illness representations, coping and adjustment to MS prospectively. Study 1 therefore represented the first attempt to fully apply the SRM to a sample of MS patients over time.

In addition to applying the SRM, researchers have also applied cognitive models of psychopathology to understand adjustment to MS (see Chapter 2, section 2.2 for a full description of these models). This findings and limitations of this research highlighted the need for further investigation into the role of cognitive schema and future thinking. The current study therefore took into account the role of cognitive schema and future thoughts in predicting adjustment to MS. Study 1 represents the first attempt to investigate the relationship between these factors and examine which psychological factors (illness representations, future thinking, cognitive schema, coping strategies) lead to successful adjustment in MS and which lead to psychological distress. A schematic representation of the relationships which will be investigated in Study 1 is shown in Figure 6-1.

Figure 6-1 A schematic representation of the relationships investigated in Study 1.



6.2 Hypotheses

Based on the findings of previous research, the following hypotheses were developed for Study 1.

6.2.1 Hypothesis 1 (i), (ii) & (iii) - Illness representation correlations and t-tests

(i) It was hypothesised that correlational analysis would indicate that time 1 illness representations are inter-related, with more negative beliefs being related to each other.

(ii) It was hypothesised that illness representations components would significantly change over a short time.

(iii) It was hypothesised that correlation analysis would indicate that illness representations are related to dysfunctional attitudes and future thinking, with more negative illness representations being related to greater dysfunctional attitudes, negative future thinking and less positive future thinking.

6.2.2 Hypothesis 2 (i), (ii) & (iii) - Self-Regulation in MS

(i) It was hypothesised that correlation analysis would indicate that illness representations and coping are related, consistent with the relationships, outlined in the SRM.

(ii) It was hypothesised that correlation analysis would indicate that coping strategies are related to adjustment at time 1 and time 2, consistent with the relationships, outlined in the SRM.

(iii) It was hypothesised that correlation analysis would indicate that illness representations and adjustment to MS time 1 and 2 are related with more negative beliefs being related to poorer adjustment.

6.2.3 Hypothesis 3 (i), (ii) & (iii) - Dysfunctional attitudes and future thinking correlations

(i) It was hypothesised that correlation analysis would indicate that dysfunctional attitudes and future thinking are related, with greater dysfunctional attitudes being related to greater negative and less positive future thinking.

(ii) It was hypothesised that correlation analysis would indicate that dysfunctional attitudes, coping and adjustment are related, with greater dysfunctional attitudes being related to more maladaptive coping and poorer adjustment at time 1 and 2.

(iii) It was hypothesised that correlation analysis would indicate that future thinking, coping and adjustment are related, with greater negative and less positive future thinking being related to more maladaptive coping and poorer adjustment at time 1 and 2.

6.2.4 Hypothesis 4 (i) & (ii) - Concurrent and prospective investigation of illness representations

(i) It was hypothesised that illness representations and coping would be predictive of adjustment at time 1 and 2, consistent with the relationships, outlined in the SRM.

(ii) It was hypothesised that coping would mediate the relationship between illness representations and adjustment to MS, at time 1 and 2.

6.2.5 Hypothesis 5 (i) & (ii) - Concurrent and prospective investigation of dysfunctional attitudes

(i) It was hypothesised that dysfunctional attitudes and coping would be predictive of adjustment at time 1 and 2, with greater dysfunctional attitudes and maladaptive coping leading to poorer adjustment.

(ii) It was hypothesised that coping would mediate the relationship between dysfunctional attitudes and adjustment to MS, at time 1 and 2.

6.2.6 Hypothesis 6 (i) & (ii) - Concurrent and prospective investigation of future thinking.

(i) It was hypothesised that future thinking and coping would be predictive of adjustment at time 1 and 2.

(ii) It was hypothesised coping would mediate the relationship between future thinking and adjustment to MS, at time 1 and time 2.

6.3 Method

6.3.1 Design

This is prospective study, in which Multiple Sclerosis (MS) patients (N = 103) completed a range of psychological measures at two time points. MS patients were recruited from the Fife Physical Rehabilitation Service (FPRS) and Forth Valley Area Rehabilitation Team (FVART) (details of these services are given in Chapter 5, section 5.2.1). Those who volunteered completed a number of recognised psychological measures. They were then asked if they would be willing to take part in a short telephone interview, answering questions about how they were adjusting to MS. Those who agreed to take part in the second interview were telephoned two months later. Full details of the procedure are given in Chapter 5 section 5.4.

Although two months may be considered a relatively short time frame, it has been shown in other studies to be sufficient to detect a change in well-being (O'Connor & O'Connor, 2003). Furthermore, the aim of Study 1 was to test a range of psychological measures in adjustment to MS and based on these findings, design a second longitudinal study with a longer follow up time. By assessing participants at two time points it was hoped that contemporaneous contamination would be avoided. It was felt that this would increase the likelihood of seeing change across a time-span with minimum attrition. Unfortunately however, due to the time constraints of the PhD only a two month follow-up design for Study 1 could be employed.

6.3.2 Participants

6.3.2.2 Sample Size

A G-Power analysis was carried out to determine the sample size, which would be required at follow-up for the results to be statistically meaningful, when using a Multiple

Regression. In addition to conducting the formal G-Power analysis, the sample size was also based on the follow-up rate of a previous research with a similar population. Ray et al's (1997) study of Chronic Fatigue Syndrome patients' had a 5% attrition rate during the 12 month follow-up. To be conservative a 10% attrition rate at follow-up was estimated. A medium to large effect size of .18 was adopted, consistent with Cohen (1992). As a result setting alpha at 0.05, power 0.8 with 8 predictors (the maximum number of predictors in regression), the power calculation yielded a sample of 92. However, assuming a 10 % attrition rate, a sample size of 102 patients was required to yield a sample of 96 at follow-up.

In total 103 MS patients took part in the study. To recruit participants, information about the study was sent to 150 MS patients treated by the FVART and 200 MS patients seen by FPRS. Thirty seven individuals from the FVART and 67 from the FPRS met these criteria and either telephoned or emailed agreeing to take part, yielding 25% and 34% response rates, respectively. During the course of this study, one participant dropped out. The remaining 103 took part in an interview at time 1 either in their home or at the University of Stirling.

6.3.2.3 Demographic and illness characteristics

The final sample comprised of 36 (35%) males and 67 (65%) females. The age of participants ranged from 26 to 66 years old, with a mean age of 47.91 years (SD=9.9). The onset of participants' MS symptoms varied between 6 months and 50 years and the mean length of time since onset was 15.58 (SD=10.17) years. The time since participants' had received their diagnosis varied between 6 months and 38 years and the mean time since they had received their diagnosis was 10.07 (SD= 8.32) years. Thirteen of the participants had had the illness for over thirty years. The results showed that 75 (72.8%) of the participants were married, 9 (8.7%) were single, 8 (7.8%) were divorced, 6 (5.8%) were cohabiting, 3 (2.9) were separated and 2 (1.9%) were widowed. Due to data protection information was only available for those who volunteered and gave consent to take part in the research. Consequently, the differences between those who volunteered to be involved in the research with those who declined could be assessed.

Two months later participants were asked to take part in follow-up telephone interview. In total, 90 participants agreed to take part at follow-up yielding an 87% response rate. Sixty of these were from the FPRS and 30 were from the FVART yielding 90% and 81% response rates respectively. Those who took part at time 2 did not differ significantly from those who declined to take part in terms of age, gender, marital status, time since diagnosis, MS type, or on any of the time 1 variables with the exception of the timeline component. Independent samples t-tests revealed that those who took part at time 2 and those who declined were differentiated at a statistically significant level by both the timeline component ($p<.05$) and the time since the onset of symptoms ($p<.01$). An examination of the means revealed that those who took part at time 2 believed that their condition would last longer ($X = 9.36$, $SD = 1.23$) than those who declined to take part ($X = 8.54$, $SD =2.79$). The tests also revealed that those who took part had also suffered from the condition for a shorter period of time ($X = 14.56$, $SD = 9.65$) than those who declined ($X = 23.17$, $SD = 15.08$).

6.3.3 Measures

6.3.3.1 Documentation and cognitive assessment.

The documentation used in this study included an information sheet, invitation letter, consent form and questionnaire collecting patients' demographic and illness details. These measures are discussed in more detail in Chapter 5, (see section 5.3.1). Prior to the initial interview the *Mini-Mental State Examination (MMSE: Folstein et al., 1975)* was used to evaluate cognitive function (See Appendix 2, a full description of the MMSE is given in Chapter 5, see section 5.3.1.).

6.3.3.2 Predictor measures

The Future Thinking Task (FTT: MacLeod et al., 1997) was used to measure patients' thoughts about the future. Before administration of the FTT, all participants completed the standard verbal fluency task (Lezak, 1976) – to take into consideration participants general cognitive fluency. A correlation analysis revealed that participants verbal fluency was not statistical related to any of the outcome variables. A full description of this task is given in Chapter 5 (see section 5.3.2.1).

Illness Perceptions Questionnaire –Brief (IPQ-Brief: Broadbent et al, 2006) was used to measure the participants' illness perceptions (see Appendix 3). It is self-report measure containing nine statements which each correspond to one of the following components; identity, consequences, control/cure cause, chronic/cyclical timeline or illness coherence. A full description of this scale is given in Chapter 5 (see section 5.3.2.2).

The Dysfunctional Attitudes Scale (DAS: Weissman & Beck, 1978) is a 100-item self-report measure designed to assess the extent to which an individual endorses general attitudes and underlying assumptions hypothesized by cognitive theory to be associated with depression (see Appendix 5). A full description of the scale is given in Chapter 5 (see section 5.3.2.3). The DAS had good internal reliability in this study with a Cronbach alpha of .90.

The Coping with Multiple Sclerosis (CMSS: Pakenham, 2001) was used to measure how participants' cope with their condition (see Appendix 7). The CMSS is a self-report measure of coping specific to MS requiring individuals to identify their main MS-related problem and indicate on a 5-point Likert scale how often they have used each of the

43 coping strategies. A full description of the scale is given in Chapter 5 (see section 5.3.2.5). The internal reliability scores (Cronbach's alpha) for the subscales of the CMSS are shown in table 6-1. The Cronbach's α for the five-item problem solving and the five-item physical assistance subscales were both α = .60. The Cronbach alpha's for the four-item avoidance subscale (α = .53), the four-item personal health control subscale (α = .55), and the six item acceptance subscale α = .59). For the six-item emotional release subscale, the four-item energy conservation subscale and the two-item social support subscale the alphas were α = .73 and α = .72, and α = .67 respectively.

Table 6-1 Cronbach alphas for the CMSS.

Component	α
Problem Solving	.60
Physical Assistance	.60
Emotional Release	.73
Avoidance	.53
Personal Health Control	.55
Acceptance	.59
Energy Conservation	.72
Social Support	.67

6.3.3.3 Outcome measures

The Multiple Sclerosis Impact Scale (MSIS-29: Hobart et al, 2001) was used to measure the physical and psychological impact of MS (see Appendix 9). In the present study the Cronbach's α for this scale was .92 at time 1 and at time 2 it was .95. The MSIS-29 is a disease specific, self-report measure which contains 29 items (20 items for physical impact and 9 for psychological impact). A full description of the MSIS is given in Chapter 5 (see section 5.3.3.2). The physical impact scale had good internal reliability at time 1 (α = .91) and time 2 (α = .94) so did the psychological impact scale at time 1 (α = .86) and time 2 (α = .89).

Hospital Anxiety and Depression Scale (HADS: Zigmond and Snaith, 1983) was used to measure symptoms of depression and anxiety (see Appendix 8). The HADS scale is a self-rating questionnaire which contains fourteen items (seven for depression and seven for anxiety). The two subscales are rated depending on the extent to which they have been experienced over the past week. A full description of the HADS is given in Chapter 5 (see section 5.3.3.1). The anxiety subscale had good internal reliability at time 1 ($\underline{\alpha}$ = .81) and time 2 ($\underline{\alpha}$ = .85.) so did the depression subscale at time 1 ($\underline{\alpha}$ = .74) and time 2 ($\underline{\alpha}$ = .71).

6.4 Results

This section discusses the results of Study 1. Each of the research methods and the reasons for their use are outlined as appropriate throughout this chapter. However, due to the volume of the analysis, a brief summary of how the analyses are grouped and presented follows.

6.4.1 Analytical strategy

Due to the nature of this research, various methods were employed to analyse the data. Pearson's Product Moment Correctional analyses were carried out to investigate the relationship between the various components measured in this study. These correlations formed the basis for the entry of components into the hierarchical regression analysis, which were undertaken to investigate relationships outlined by the proposed model in Figure 6-1. To reduce the likelihood of making Type 1 errors when carrying out the regression analysis, p<.01* was taken as the critical level of significance and only those predictor variables, which correlated with the dependent variable at p<.01 were entered into the regressions.

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* A p <.01 level of significance was taken as the critical level of significance to control for multiple comparisons.

The regression procedure employed was the Hierarchical (enter) method. It was felt that this would be the most appropriate method for hypothesis testing and testing the proposed model in Figure 6-1. Furthermore, by entering all the independent variables simultaneously the unique contribution of each predictor was examined, while the relationships between the other independent variables were controlled for. A p<.01 was also taken as the critical level of significance when making multiple comparisons across the data, again to reduce the likelihood of Type 1 errors. However, those variables found to be significant at the p<.05 level were noted as points of interest.

In order to test for the possible mediating effects of coping on the relationship between the other predictor variables and the outcome variables, formal mediational analysis was carried out on variables showing possible mediation effects. These were confirmed using the Sobel test.

6.4.2 Illness characteristics

The illness characteristics of the sample are detailed in table 6-2. The study included individuals with all four types of MS (see Chapter 1, section 1.5 for details of the different types). Information about the type of MS patients suffered from was available for 94 of the participants. The majority suffered from the relapsing-remitting form, in total 41 (39.8%) had this type of MS. Twenty (19.4%) had primary progressive, 28 (27.2%) had secondary progressive and 5 (4.8%) had the benign form. Information about whether patients had taken steroids was available for 79 of the participants. Sixty one (59.2%) participants had taken some form of steroids since they were diagnosed with MS. Twenty two (21.4%) participants had had steroids intravenously injected (IV) only, 21 (20.4%) had only taken them orally and 18 (17.5%) had taken steroids both intravenously and orally. Fifty three of participants had no family history of MS. No information on family history was available for 32 of the participants.

Table 6-2 Illness characteristics of sample.

Variable		Number (Percentage)
Current state of MS (%)	Benign	5 (4.8%)
	Relapsing Remitting	41 (39.8%)
	Secondary - progressive	28 (27.2%)
	Primary - progressive	20 (19.4%)
Steroid use	None	18 (17.5%)
	Intravenously Injected (IV)	22 (21.4%)
	Orally Taken	21 (20.4%)
	Both IV and Oral	18 (17.5%)
Relative with MS	None	53 (51.5%)
	Mother	4 (3.9%)
	Father	3 (2.9%)
	Sister	4 (3.9%)
	Daughter	1 (1%)
	Cousin	9 (8.7%)
	Second Cousin	1 (1%)
		Number (Standard Deviation)
Mean time since	Onset of symptoms	15.55 (SD=10.71) years
	Diagnosis	10.07 (SD=8.32) years

IV = Steroids were intravenously injected; Oral = Steroids were taken orally

6.4.3 The nature of illness representations, dysfunctional attitudes, future thinking, coping and adjustment.

The mean scores and standard deviations for each of the illness representations components, dysfunctional attitudes, coping strategies, future thinking components and adjustment variables were calculated to provide a clearer understanding of these variables. Categorical analyses were also carried out to investigate participants’ beliefs about what caused their MS and what their main MS-related problem had been in the last month.

6.4.3.1 Illness representations, dysfunctional attitudes and future thinking.

Mean scores were calculated for each of the IPQ-Brief components, dysfunctional attitudes and future thinking components. These are shown in table 6-5. As this table shows the mean score for the timeline component at time 1 and time 2 (T1: M= 9.47, SD=1.54, T2; M=9.12, SD=1.87) was greater that the other illness beliefs. It also shows that the mean score for the total positive future thoughts (M= 4.5, SD=1.86) was higher than the total number of negative future thoughts (M=2.37, SD=1.43).

The causal component of the IPQ-Brief was analysed categorically. The IPQ-Brief requires participants to identify three main factors they believe caused their illness. The primary cause identified was grouped into the categories given in table 6-3. These categories are based on those identified by the IPQ-R (Moss-Morris et al., 2002). However, the IPQ-R only acted as a guide, if addition factors were identified these were given their own category. As can be seen from table 6-3 there are a number of differences between the primary factors identified at time 1 and those identified 2 months later. At time 1 15.5% of participants could not identify any factor as causing their MS, by time 2 this increased to 26.2%. At time 1 the most common factor identified was stress (25.2%), followed by hereditary (13.6%), germ/virus (13.5%) and then accident/injury (9.7%). At time 2 however, the most common factor was germ/virus (16.5%) followed by stress (10.7%).

Table 6-3 The number and percentage of MS patients identifying different causal factors at time 1 and time 2.

Cause	Number (Percentage) at Time 1	Number (Percentage) at Time 2
Unknown	16 (15.5%)	27 (26.2%)
Stress	26 (25.2%)	11 (10.7%)
Hereditary	14 (13.6%)	8 (7.8%)
Germ/Virus	14 (13.6%)	17 (16.5%)
Diet	2 (1.9%)	2 (1.9%)
Chance	6 (5.8%)	7 (6.8%)
Poor Medical Care	1 (1.0%)	1 (1.0%)
Pollution	4 (3.9%)	2 (1.9%)
Family Problems	1 (1.0%)	3 (2.9%)
Overwork	1 (1.0%)	0
Accident/Injury	10 (9.7%)	5 (4.9%)
Personality	1 (1.0%)	0
Altered Immunity	1 (1.0%)	0
Geographic Location	2 (1.9%)	1 (1.0%)
Childbirth	2 (1.9%)	2 (1.9%)
Age	1 (1.0%)	1 (1.0%)
Sunlight Exposure	1 (1.0%)	0

6.4.3.2 Coping strategies

The mean scores were calculated for each of the coping strategy categories. The mean scores for problem solving (M= 2.78, SD= 0.7), acceptance (M=2.77, SD=0.76) and energy conservation (M=2.66, SD= 0.88) were higher than the other coping strategies.

Prior to completing the coping measure participants were asked to identify their main MS-related problem, in other words, what was it about their MS that had bothered them the most over the past month. Closer examination of their responses revealed that they could be separated into twelve main MS-related problems shown in table 6-4. The majority of participants (35%) identified mobility issues as their main difficulty. Both fatigue and bladder/bowel dysfunctions were identified by 15.5% of participants.

Table 6-4 Main MS-related problem

Main MS-related problem	Number (Percentage)
Mobility	37 (35.9%)
Fatigue	16 (15.5%)
Loss of sensation/feeling	5 (4.9%)
Bladder/Bowel Problems	16 (15.5%)
Pain	3 (2.9%)
Financial Difficulties	5 (4.9%)
Tremor/Spasm	2 (1.9%)
Cognitive difficulties	3(2.9%)
Eyesight problems	4 (3.9%)
Loss of independence	3 (2.9%)
Balance	3 (2.9%)
Emotional difficulties	6 (5.8%)

6.4.3.3 Adjustment variables

The mean depression scores were 6.37 (SD=3.65) at time 1 and 6.94 (SD= 3.57) at time 2. The mean anxiety scores were slightly higher at 7.86 (SD=4.45) at time 1 and 7.93 (SD= 4.69) at time 2. This suggests that the majority of patients experienced normal levels of depression symptoms and their levels of anxiety were borderline between normal and mild.

To investigate the levels of depression and anxiety further, the number of participants at time 1 which fell into the different categories (normal, mild, moderate and severe) as suggested by the HADS were examined. The results showed that 66 (63.5%) patients experienced a ‘normal’ level of depressive symptoms, whereas only 51 (49%) had a level of anxiety within the ‘normal’ 0-7 range. A greater number of patients were found to fall in the ‘mild’ range of anxiety compared to those falling into the ‘mild’ range for depression, 27 (26%) and 21 (20.2%) respectively. The same number of patients experienced ‘moderate’ levels of depression as those experiencing ‘moderate’ levels of anxiety. However, while only 1 patient experienced severe depression, 10 (9.6%) patients suffered from severe anxiety.

6.4.4 Correlations between variables

In order to investigate hypotheses 1, 2 and 3 regarding the relationships between the various subscales of the measures being used, initial exploratory correlation analyses were conducted between the IPQ-Brief subscales, DYS, FTT components, CMSS, MSIS-29 and the HADS subscales. It must be remembered when interpretating the correlations that high scores in the adjustment variables indicate poorer adjustment levels.

6.4.5 Hypothesis 1 - Illness representations correlations and t-tests.

It was hypothesised (1i) that time 1 illness representations would be correlated with each other. As shown in table 6-5, the findings supported this hypothesis. A strong identity at time 1 was positively related to consequences ($r = .62$, $p<.001$), emotion ($r = .39$, $p<.001$) and concern ($r = .49$, $p<.001$) at time 1. A belief in the serious consequences was positively related to the emotion ($r = .57$, $p<.001$) and concern ($r = .53$, $p<.001$). The emotion component was positively related to concern ($r = .69$, $p<.001$).Furthermore, more positive beliefs were related to one another. Illness coherence was found to be positively related to personal control ($r = .26$, $p<.01$).

Table 6-5 Correlations among different dimensions of time 1 (N= 103) and time 2 (N=90) illness representations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Identity		.089	.623***	-.094	.385***	.491***	-.056	-.018	.240*	.175*	.274**	.132	.337***	.170	.045	-.088
2. Time			.084	.017	.152	.050	-.156	-.003	-.037	.026	-.095	-.007	.044	-.071	-.098	-.012
3. Consequence				-.211*	.566**	.532***	-.170	-.066	.284**	.086	.619***	.151	.414***	.373***	-.038	-.155
4. Illness coherence					-.157	-.221*	.264**	.049	.186*	-.014	-.107	.557***	-.066	-.107	.204*	.048
5. Emotion						.685***	-.106	.033	.081**	.073	.391***	-.092	.687***	.504***	-.031	.081
6. Concern							-.244	-.145	.149	.147	.407***	-.107	.513***	.634***	-.095	-.170
7. Personal control								.105	-.127	.035	-.007	.219*	.123	-.160	.235*	.024
8. Treatment Control									-.137	-.151	-.208*	.068	-.008	-.159	.287**	.569***
9. Time 2 Identity										-.049	.456***	.092	.177*	.296**	-.164	-.181*
10. Time2 Time											-.03	.009	-.059	.072	-.028	-.157
11. Time 2 Consequence												-.003	.266**	.317***	-.210*	-.355***
12. Time 2 illness coherence													.063	-.135	.110	.008
13. Time 2 Emotion														.533***	.063	.019.
14. Time 2 Concern															..004	-. 059
15. Time 2 Personal control																.366***
16. Time 2 Treatment Control																
Mean	6.69	9.47	6.85	7.15	6.1	5.91	3.84	4.86	6.42	9.12	6.77	7.89	5.71	5.78	4.92	5.08
SD	2.21	1.54	2.28	2.55	3.04	3.06	2.67	2.85	1.92	1.87	2.29	2.13	2.82	2.95	2.40	3.11

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

It was hypothesised (1ii) that illness representations would significantly change over time. To test this hypothesis, a series of t-tests were carried out to examine the differences between each of the illness representations at time 1 with those at time 2. As shown in table 6-6, some of the illness representations components at time 1 differed statistically significantly from those at time 2. Most notably, personal control and illness coherence at time 1 and 2 differed significantly at a p<.001 level. These findings therefore supported hypothesis 1 (ii), suggesting that these illness representation components changed over the 2 month period.

Table 6-6 Paired samples t-test to investigate the differences between illness representations at time 1 and those at time 2.

	Time 1	Time 2	T (df = 89)
Identity	6.84 (2.05)	6.42 (1.91)	1.64
Timeline	9.6 (1.23)	9.12 (1.87)	2.05*
Consequences	6.91(2.16)	6.77 (2.29)	7.04
Emotion	6.28 (2.87	5.71 (2.82)	2.38*
Concern	6.01 (0.31)	5.78 (2.95)	.88
Personal Control	3.73 (2.58)	4.92 (2.40)	-3.65***
Treatment Control	4.89 (2.86)	5.08 (3.12)	-.642
Illness Coherence	7.07 (.264)	7.89 (2.13)	-3.536***

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

It was hypothesised (1iii) that illness representations would be related to dysfunctional attitudes and future thinking. The correlations shown in table 6-7 provide some support for hypothesis 1(iii). The identity component was negatively related to positive future thoughts over the next year (r = -.23, p<.01). The consequences component was negatively related to positive future thoughts over the next week (r = -.24, p<.01). Emotion was positively related to dysfunctional attitudes (r =.25, p<.01). No relationships were identified between illness representations and negative future thinking.

Table 6-7 Correlations of time 1 illness representations with dysfunctional attitudes and future thinking (N=103).

	Identity	Time	Consequence	Illness Coherence	Emotion	Concern	Personal Control	Treatment Control
Dysfunctional Attitudes	.140	-.271*	.125	-.065	.256**	.194*	.135	.135
Positive Week	-.115	-.056	-.243**	.102	-.148	-.184*	.114	.092
Positive Year	-.233**	.028	-.156	-.002	-.093	-.150	-.060	.074
Positive 5 1-10 yr	-.124	-.040	-.129	-.208*	-.016	-.150	.116	.206*
Positive Total	-.185*	-.029	-.212*	.121	-.105	-.193	.070	.146
Negative week	-.013	.020	-.007	.050	.112	.153	-.106	-.033
Negative Year	.068	.019	.016	.149	.096	.086	-.039	-.037
Negative 5 -10 year	.030	.021	.073	.103	.118	.016	.079	.046
Negative Total	.036	.025	.035	.125	.134	.102	-.023	-.009

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

6.4.6 Hypothesis 2 – Self-Regulation in MS.

Hypothesis 2 (i) postulated that illness representations, and coping would be correlated, consistent with the relationships outlined by the SRM (see table 6-8). A belief in serious consequences was positively associated with asking for physical assistance (r =.28, p<.01), and negatively related to avoidance techniques (r = -.23, P<.01) and acceptance (r = -.34, p<.001). The emotion component was negatively associated with problem-solving coping (r = -.23, p<.01) and acceptance (r = -.57, p<.001). Concern was also inversely related to acceptance (r =-.50, p<.001).

It was also hypothesised (2ii) that coping strategies would be correlated with adjustment at time 1 and time 2, consistent with the relationships outlined in the SRM. As summarised in table 6-9, employing a problem solving strategy was negatively related psychological impact (r = -.30, p<.01) at time 1. At time 1 and time 2 physical assistance was positively related to overall MS impact (T1 r =.34, p<.001; T2 r =.33, p<.001) and physical impact (T1 r =.47, p<0.01; T2 r =.44, p<.001). Emotional release was also positively correlated with overall MS impact (T1 r =.28, p<.001; T2 r =.27, p<.01) and physical impact (T1 r =.33, p<.01; T2 r =.31, p<.01). Energy conservation was positively related to physical impact of MS at time 1 (r =.24, p<.01) and acceptance was inversely related to all the adjustment variables at time 1 and time 2.

It was also hypothesised (2 iii) that illness representations and adjustment to MS at time 1 and time 2 would be related. These are also shown in table 6-8. Timeline was negatively related to anxiety (r =-.262, p<.01) at time 1. Concern, emotion and consequences were all positively related at a p<.001 level to each adjustment variable at both time points. The identity components positively related to the adjustment variable at time 1 and 2 with the exception of time 1 anxiety.

Table 6-8 Correlations among illness representations, coping and adjustment at time 1 (N=103) and time 2 (N=90).

	Identity	Time	Consequence	Illness Coherence	Emotion	Concern	Personal Control	Treatment Control
Problem Solving	-.049	-.025	-.105	.143	-.234**	-.182*	.175*	.147
Physical Assistance	.190*	-.054	.281**	.010	.012	.156	-.015	-.112
Emotional Release	.187*	-.052	.013	-.012	.120	.160	.097	-.124
Avoidance	-.150	-.101	-.234**	.038	-.111	-.112	.116	.065
Personal Health Control	-.075	-.013	-.034	-.037	-.056	.035	.115	.227*
Acceptance	-.218*	.093	-.339***	.009	-.567***	-.495***	.033	.087
Energy Conservation	-.023	.004	.032	-.048	-.004	.120	-.063	-.085
Social Support	.159	-.020	.040	.027	.031	.194*	-.011	.018
Overall MS Impact Time 1	.497***	.038	.653***	-.144	.65***	.615***	-.103	-.188
Psychological Impact Time 1	.310***	.037	.413***	-.031	.709***	.547***	-.016	-.05
Physical Impact Time 1	.495***	.031	.647***	-.175*	.494***	.526***	-.128	-.218
Anxiety Time 1	.103	-.262**	.222*	.060	483***	.379***	.017	-.045
Depression Time 1	.311***	.022	.371***	-.065	.579***	.461***	-.076	-.061
Overall MS Impact Time 2	.389***	-.029	.553***	-.083	.549***	.525***	-.010	-.242*
Psychological Impact Time 2	.322***	-.017	.528***	-.106	.736***	.601***	.040	-.127
Physical Impact Time 2	.366***	-.031	.487***	-.059	.377***	.412***	-.034	-.265
Depression Time 2	.203*	.015	.467***	-.162	.575***	.408***	.040	-.231*
Anxiety Time 2	.242*	-.020	.398***	-.130	.604***	.506***	-.034	-.088

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

Table 6-9 Correlations among coping and adjustment at time 1 (N=103) and time 2 (N=90).

	Problem Solving	Physical Assistance	Emotional Release	Avoidance	Personal Health Control	Accept	Energy Conservation	Social Support
Overall MS Impact Time 1	-.091	.341***	.283***	-.139	.087	-.422***	.195*	.158
Psychological Impact Time 1	-.295**	-.041	.086	-.045	-.084	-.592***	.040	.028
Physical Impact Time 1	.035	.472**	.329**	-.160	.160	-.247**	.237**	.194*
Anxiety Time 1	-.167*	-.029	.053	.104	-.080	-.423**	-.072	.116
Depression Time1	-.313*	-.005	.008	-.115	-.124	-.499***	-.043	-.082
Overall MS Impact Time 2	-.027	.333***	.266**	-.160	.027	-.333***	.185*	.053
Psychological Impact Time 2	-.126	.033	.109	-.070	-.068	-.487***	.147*	.009
Physical Impact Time 2	.027	.442***	.306**	-.182*	.071	-.209**	.177*	.062
Anxiety Time 2	-.123	-.009	.079	-.037	-.035	-.365***	.092	.001
Depression Time 2	-.172	.027	.055	-.147	-.099	-.309**	.117	-.059

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

6.4.7 Hypothesis 3 - Dysfunctional attitudes and future thinking correlations.

It was hypothesised (3i) that dysfunctional attitudes and future thinking would be correlated with greater dysfunctional attitudes being related to greater negative and less positive future thinking. As shown in table 6-10, dysfunctional attitudes were inversely related to positive future thoughts over the next week (r = -.244, p<.01), next year (r = -.27, p<.01), next 5-10 years (r = -.26, p<.01) and overall positive future thoughts (r = -.3, p<.01). These findings provide some support for hypothesis 3 (i), although no relationships were identified between dysfunctional attitudes and negative future thinking. All of the future thinking variables positively related to each other at a p<.01 level, with the exception of negative future thoughts for the next week.

It was also hypothesised (3ii) that dysfunctional attitudes, coping and adjustment would be correlated. As shown in table 6-11 dysfunctional attitudes were negatively related to three of the coping strategies: problems solving (r = -.23, p<.01), acceptance (r= -.36, p<0.001) and energy conservation (r = -.24, p<.01). Both problem solving and acceptance have been found to be adaptive providing some support for hypothesis 3 (ii). Furthermore, dysfunctional attitudes were positively related to anxiety (T1 r =.40, p<.001; T2 r =.27, p<.01) and depression (T1 r =.48, p<.001).

Hypothesis 3 (iii) postulated that future thinking, coping and adjustment would be correlated, with greater negative and less positive future thinking being related to more maladaptive coping and poorer adjustment at time 1 and 2. Problem solving strategies were positively related to total positive future thoughts (r =.31, p<.001), positive thoughts for the next week (r =.28, p<.01) and positive thoughts about the next year (r =.33, p<.001). Positive future thoughts about the next week was inversely related to anxiety (r = -.27, p<.01) and depression (r = -.21, p<.01) at time 1 only. Positive thoughts about the next 5 to 10 years were also negatively related to depression (r = -.25, p<.01) at time 1 and overall positive future thinking was negatively related to depression (r = -.26, p<.01) but at time 1 only. There was also evidence that some of the negative future thinking components positively predicted problem-solving, energy conservation, avoidance and anxiety at time 1 and 2 at a p<.05 level. These correlations therefore provide support for hypothesis 3 (iii) and can be seen in table 6-11.

Table 6-10 Correlations among dysfunctional attitudes and future thinking (N=103).

	Dysfunctional Attitudes	Positive Week	Positive Year	Positive 5-10 Year	Positive Total	Negative Week	Negative Year	Negative 5-10 Year	Negative Total
Dysfunctional Attitudes		-.244**	-.272**	-.260**	-.307**	.074	-.055	-.066	-.022
Positive Week			.618***	.555***	.873***	.195*	.238**	.320***	.310***
Positive Year				.505***	.837***	.135	.274**	.300***	.294***
Positive 5 -10 Year					.810***	.148	.280**	.305***	.304***
Positive Total						.191*	.312***	.367***	.360***
Negative Week							.510***	.423***	.780***
Negative Year								.539***	.845***
Negative 5 -10 Year									.813***
Mean	108.76	5.19	4.95	3.39	4.51	2.29	2.5	2.33	2.37
SD	31.62	2.38	2.13	2.12	1.86	1.66	1.81	1.83	1.44

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

Table 6-11 Correlations among future thinking, dysfunctional attitudes, coping and adjustment at time 1 (N=103).and time 2 (N=90).

	Dysfunctional Attitudes	Positive Week	Positive Year	Positive 5-10 Year	Positive Total	Negative Week	Negative Year	Negative 5-10 Year	Negative Total
Problem Solving	-.233**	.277**	.326***	.169*	.306***	-.024	.163	.232*	.157
Physical Assistance	-.060	-.019	-.076	-.015	-.043	-.176*	-.081	-.060	-.128
Emotional Release	-.166*	.092	-.001	.036	.052	.015	.143	.040	.083
Avoidance	.082	.073	.206*	.103	.149	.092	.219*	.143	.188*
Personal Health Control	-.155	.053	.144	.093	.113	-.035	.052	.127	.062
Acceptance	-.360***	.216*	.161	.077	.182*	-.229*	-.079	.009	-.117
Energy Conservation	-.237**	.052	.074	.010	.054	.043	.213*	.177*	.181*
Social Support	-.159	-.003	-.057	.085	.010	-.008	.139	.123	.107
Overall MS Impact Time 1	.120	-.180*	-.073	-.062	-.128	.015	.076	.072	.068
Psychological Impact Time 1	.225*	-.144	-.106	-.122	-.148	.142	.066	.061	.109
Physical Impact Time 1	.04	-.162	-.040	-.017	-.091	-.056	.066	.063	.033
Anxiety Time 1	.401***	-.266**	-.110	-.128	-.204*	.102	.196*	.061	.147
Depression Time 1	.478***	-.205**	-.159	-.248**	-.262**	.079	.011	.032	.049
Overall MS Impact Time 2	103	-.085	-.057	-.078	-.088	.019	-.073	.031	-.010
Psychological Impact Time 2	.213*	-.111	-.092	-.051	-.102	.189*	.057	.104	.140
Physical Impact Time 2	.033	-.059	-.031	-.081	-.068	-.068	-.127	-.010	-.084
Depression Time 2	.210*	-.136	-.171	-.135	-.075	.076	-.025	.079	.052
Anxiety Time 2	.266**	-.089	-.070	-.050	-.083	.228*	.137	.119	.195*

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

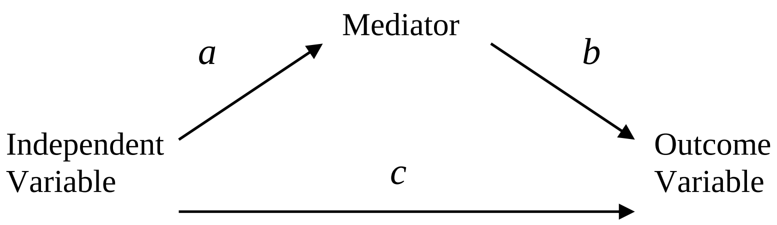
6.4.8 Regression Analyses

With reference to hypothesis 4, 5 and 6 the following regression procedures were applied to test the utility of illness representations, dysfunctional attitudes, future thinking and coping in the prediction of adjustment to MS. Multiple regression analysis is a statistical procedure that assesses the determination of a criterion variable from several predictor variables. In other words, it involves the simultaneous use of two or more independent variables in ‘predicting’ a dependent variable. In addition to multiple regression analyses, formal mediation analyses were also carried out on those variables, which met Barons and Kenny’s (1986) conditions for mediation. A brief description of mediator variables will now be given based on Baron and Kenny’s (1986) research. In the cross-sectional analysis the adjustment variables were not actually being ‘predicted’, however, this terminology is employed.

6.4.9 Mediators

The mediator function of the third variable reflects the generative mechanism through which the independent variable is able to influence the variable of interest. In other words, the third variable mediates the effect of the predictor variable, on the outcome/adjustment variable. A variable is said to function as a mediator based on the extent that it explains the relationship between the predictor and the outcome variable. According to Baron and Kenny (1986), there are two paths which feed into the outcome variable; 1) the direct impact of the independent variable and 2) the impact via the mediator. The independent variable may also impact on the mediator.

Figure 6-2 Mediational model



Source: Barony and Kenny (1986)

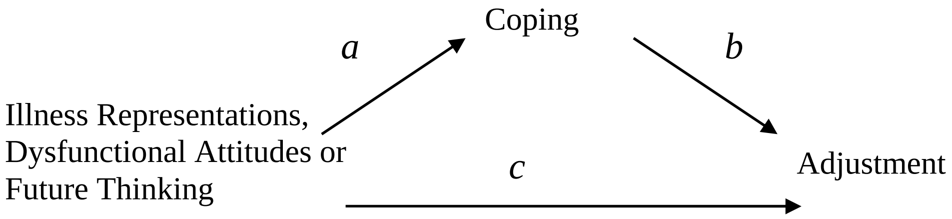
A variable is considered to act as a mediator when: (i) variations in levels of the independent variable significantly account for variations in the presumed mediator (path a); (ii) variations in the mediator significantly account for variations in the dependent variable (path b) and; (iii) when paths a and b are controlled for a previously significant relation between the independent and dependent variables is no longer significant. This is most strongly evident when path c equals 0, however it is enough that the mediators significantly decrease path c.

According to the Self-Regulation Model (Leventhal et al., 1980), coping strategies mediate the effect of illness representations on outcomes. In the proposed model in Figure 6-1 this has been extended to include dysfunctional attitudes and future thinking. This extended self-regulation model suggests that coping also mediates the relationship between (i) dysfunctional attitudes and outcome and; (ii) future thinking and outcome.

Within the context of the hypothesised extended SRM, where illness representations, dysfunctional attitudes and future thinking predict coping, which in turn predicts adjustment to MS, the following conditions are required to be met for mediation. This is consonant with the recommendations for mediation identified by Baron and Kenny (1986). It is necessary that (i) variations in the levels of illness representations, dysfunctional attitudes or future thinking components are related to the proposed mediation of coping (path a), (ii) for coping to be related to variations in the dependent variable (path

b) and finally, (iii) for the inclusion of the mediators to significantly reduce the previously significant relationship between illness representations, dysfunctional attitudes or future thinking and outcome (path c). These relationships are outlined in Figure 6-3.

Figure 6-3 Mediation as it applies to the hypothesised by the proposed model (see Figure 6-1).



Recent research employing this approach to test for mediation has been carried out by researchers testing models of health behaviour (Armitage et al., 2002). The present research will employ formal mediation analysis to investigate further any possible mediation effects suggested by the results of the regressions. This will involve carrying out additional regressions between (i) the independent variable (illness representations, dysfunctional attitudes or future thinking) and coping and (ii) the independent variables, coping and the adjustment variable. The unstandardized coefficients and standard errors from these regressions will then be used to carry out the Sobel test, enabling mediation to be confirmed.

6.4.10 Predicting outcome

Before testing the study’s hypotheses, correlations between the key demographic factors (age, gender, marital status,) and all the outcome and adjustment variables were calculated to determine whether these factors should be controlled for in future analyses. Gender, age and marital status showed no significant associations with any of the adjustment variables and were consequently not included as covariates.

To test hypotheses 4, 5 and 6 a series of hierarchical regression analyses were conducted to determine whether illness representations, future thinking, dysfunctional attitudes and coping predict concurrent and prospective adjustment. In all the analyses, the adjustment variables acted as dependent variables. All the adjustment variables met the basic assumptions of normality. Measures of illness representations, future thinking, dysfunctional attitudes and coping acted as predictor variables. Firstly, this results section investigates the role of illness representations and coping on adjustment to MS at time 1 and time 2. It then examines the role of dysfunctional attitudes and then finally, the role of future thinking.

6.4.11 Hypothesis 4 - Concurrent and prospective investigation of illness representations, coping and adjustment.

Hypothesis 4 (i) postulated that illness representations and coping would be predictive of adjustment at time 1 and 2, in line with the relationships outlined in the SRM. A series of regression analyses were, therefore, carried out to investigate whether illness representations and coping predict adjustment at time 1 at time 2. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn hypothesised to be predicted by illness representations. To reduce the likelihood of making a Type 1 error, only those illness representations and coping strategies which correlated with the outcome variables at a $p<.01$ level of significance were entered into the regression analysis. It was also hypothesised (4ii) that coping mediates the relationship between illness representations and adjustment to MS at time 1 and 2.

6.4.11.1 Hierarchical regression analysis to determine whether illness representations and coping predict time 1 adjustment.

First of all, a series of regression analyses were carried out to investigate whether illness representations and coping predict adjustment at time 1. These are shown in table 6-12. The illness representations which correlated with the outcome variable at $p<.01$ significance level were entered into step one and the coping strategies variables, which correlated with the outcome variable were entered in step two. As shown in table 6-12, all the steps in each of the regressions (except anxiety step two) were significant. Overall MS impact at time 1 was predicted by the consequences ($\beta = .321$, $p < .001$) and emotion ($\beta = .313$, $p < .01$) components in step one and these remained significant in step two. When coping strategies were added to the model, the consequences beta reduced and coping strategies physical assistance ($\beta = .202$, $p < .01$) and emotional release ($\beta = .172$, $p < .01$) were significant. This suggests that the relationship between consequences and overall MS impact may be mediated by physical assistance or emotional release. However, Sobel testing did not confirm that the inclusion of physical assistance ($z = 1.76$, $p = .09$) or emotional release ($z = 1.47$, $p = .88$) reduced the beta significantly.

Psychological impact at time 1 was positively predicted by the emotion dimension ($\beta = .642$, $p < .001$) in step one. In step two acceptance negatively predicted psychological impact ($\beta = -.247$, $p < .01$) and the beta for emotional representations reduced to .527 ($p<.001$). This suggests that acceptance mediates the relationship between emotion and concurrent psychological impact in MS. However, Sobel testing did not confirm that the inclusion of acceptance reduced the beta significantly ($z = -.412$, $p = .68$).

Greater physical impact at time 1 was positively predicted by the consequences component ($\beta = .440$, $p < .001$) in step one and the beta reduced to .375 ($p<.001$) when coping strategies were added into the model. Both physical assistance ($\beta = .281$, $p < .001$)

and emotional release (β = .183, p < .05) positively predicted time 1 physical impact in step two. This suggests that these coping strategies mediate the relationship between consequences and concurrent physical impact. Sobel testing did confirm mediation by physical assistance (z = 2.43, p <.01) but not by emotional release (z = .15, p =.88).

Anxiety at time 1 was positively predicted by emotion (β = .497, p < .001) and negatively predicted by the timeline component (β = -.348, p < .001) in step one and these remained significant in step two.

Depression at time 1 was positively predicted by the concern dimension (β = .527, p < .001) in step one and the beta reduced to .426 (p<.001) when acceptance was added to the model (β = -.237, p < .05). This suggests that acceptance mediates the relationship between concern and concurrent depression. This was confirmed by Sobel testing (z = 3.10, p <.01).

Table 6-12 Hierarchical regression analysis to determine whether illness representations, and coping predict adjustment at time 1.

		Step/Predictors	R^2	Beta (Step 1)	Beta (Step 2)
Overall MS Impact Time 1			.		
	1	Identity	574***	.083	.048
		Consequence		.321***	.288**
		Emotion		.313**	.320***
		Concern		.191	.114
	2	Physical Assistance	.651***		.202**
		Emotional Release			.172**
		Acceptance			-.097
Psychological Impact Time 1					
	1	Identity	.516***	.026	.049
		Consequence		-.03	-.036
		Emotion		.642***	.527***
		Concern		.113	.055
	2	Acceptance	.565**		-.247**
		Problem Solving			-.045

		Step/Predictors	R^2	Beta (Step 1)	Beta (Step 2)
Physical Impact Time 1					
	1	Identity	.516***	.096	.066
		Consequence		.440***	.375***
		Emotion		.076	.161
		Concern		.192	.089
	2	Acceptance	.565***		-.017
		Physical Assistance			.281***
		Emotional Release			.183*
		Energy Conservation			.111
Anxiety Time 1					
	1	Emotion	.356***	.497***	.434***
		Concern		.058	.034
		Timeline		-.348***	-.325***
	2	Acceptance	.368		-.134
Depression Time 1					
	1	Identity	.366***	.085	.105
		Consequence		-.017	-.023
		Emotion		.068	.014
		Concern		.527***	.426***
	2	Acceptance	.403*		-.237*

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

6.4.11.2 Hierarchical regression analysis to determine whether illness representations and coping predict time 2 adjustment.

A series of regression analyses were also carried out to investigate whether illness representations predict coping and adjustment to MS 2 months later. Firstly, separate regressions were carried out to investigate separately the relationships between: 1) illness representations and adjustment and 2) coping and adjustment. These were followed by a series of hierarchical regression analysis to examine whether illness representations predict coping, which in turn predict adjustment to MS, 2 months later.

6.4.11.3 Separate regressions (consonant with Moss-Morris et al, 1996).

Consistent with Moss-Morris et al (1996), separate regressions were initially performed in order to investigate, in greater detail, the following relationships: (1) the relationship between illness representations and adjustment variables at time 2 and (2) between coping responses and adjustment variables at time 2.

6.4.11.4 Illness representations in relation to time 2 adjustment.

As shown in table 6-13, illness representations positively predicted overall MS impact ($R^2 = .451$, $p<.001$), psychological impact ($R^2 = .587$, $p< .001$), physical impact ($R^2 = .286$, $p<.001$), anxiety ($R^2 = .394$, $p<.01$) and depression ($R^2 = .367$, $p<.01$) two months later. The emotion component positively predicted overall MS impact ($\underline{\beta} = .307$, $p <.01$), psychological impact ($\underline{\beta} = .544$, $p < .001$) depression ($\underline{\beta} = .447$, $p < .001$) and anxiety ($\underline{\beta} = .450$, $p <.001$) at two months.

Table 6-13 Hierarchal regression analysis between illness representations and time 2 adjustment.

	Predictors	R^2	Final Beta
Overall MS Impact Time 2			
	Emotion	.451***	.307**
	Concern		.125
	Identity		.114
	Consequence		.241*
	Treatment Control		-.163
Psychological Impact Time 2			
	Emotion	.587***	.544***
	Concern		.177
	Identity		.027
	Consequence		.136
Physical Impact Time 2			
	Emotion	286***	.085
	Concern		.160
	Identity		-.112
	Consequence		.303*
Depression Time 2			
	Emotion	.367**	.447***
	Concern		.016
	Consequence		.221*
Anxiety Time 2			
	Concern	.394**	190
	Consequence		.064
	Emotion		.450***

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

6.4.11.5 Coping in relation to time 2 adjustment.

A series of regression analyses were also carried out to investigate whether coping predicts adjustment two months later. As shown in table 6-14, coping strategies positively predicted overall MS impact (R^2 = .272, p<.001), psychological impact (R^2 = .237, p< .001), physical impact (R^2 = .292, p<.001), depression (R^2 = .096, p<.05) and anxiety (R^2 = .133, p<.001), two months later. Acceptance negatively predicted overall MS impact (β = -.351, p < .001), psychological impact (β = -.487, p< .001), physical impact (β = -.228, p <.05), depression (β = -.302, p <.001) and anxiety (β = -.366, p <.001), at two months. Overall MS impact at two months was also positively predicted by physical assistance (β = .283, p <.01) and emotional release (β = .229, p <.05). Physical impact two months later was also positively predicted by emotional release (β = .234, p < .05) and physical assistance (β = .391, p < .001).

Table 6-14 Hierarchal regression analysis to determine whether coping predicts time 2 adjustment.

	Predictors	R2	Final Beta
Overall MS Impact Time 2	Physical Assistance	.272***	.283**
	Emotional Release		.227*
	Acceptance		-.351***
Psychological Impact Time 2			
	Acceptance	.237***	-.487***
Physical Impact Time 2			
	Physical Assistance	.292***	.391***
	Emotional Release		.234*
	Acceptance		-.228*
Depression Time 2			
	Acceptance	.096*	-.309**
Anxiety Time 2			
	Acceptance	.133***	-.365***

*p<0.05; **p<0.01, ***p<.001

6.4.11.6 Hierarchical regression analysis to determine whether illness representations and coping predict adjustment at time 2, controlling for time 1.

A series of regression analyses were carried out to investigate the relationship between illness representations, coping and adjustment at time 2. The steps reflect a model in which adjustment is assumed to be predicted by coping, which in turn is assumed to be predicted by illness representations. For this analysis, only those illness representation components and the coping strategies, which correlated with the adjustment variable at a $p<.01$ level of significance were included in the analysis. The scores for the outcome variables measured at time 1 were entered first (step one). The illness representations, which correlated with the outcome variable at $p<.01$ significance level were then entered into step two and the coping strategies, which correlated with the outcome variable were entered in step three. As shown in table 6-15, all the steps controlling for time 1 were significant in each of the regressions. Step two was also significant for psychological impact, anxiety and depression. The only illness representation components, which were found to predict any of the time 2 adjustment variables were the consequences and emotion components. A belief that MS has serious consequences was found to be positively related to psychological impact ($\underline{\beta} = .167$, $p < .05$), depression ($\underline{\beta} = .243$, $p < .01$) and anxiety ($\underline{\beta} = .133$, $p < .05$). Psychological impact at two months was also positively predicted by the emotion dimension ($\underline{\beta} = .230$, $p < .05$).

Table 6-15 Hierarchical regression analysis testing the relationship between illness representations, coping and outcomes at time 2, controlling for time 1.

		Step/Predictors	Total **R**^{2}	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 2						
	1	Overall MS Impact Time 1	.607***	.779***	.670***	.638***
	2	Identity	.616		.026	.030
		Consequence			.085	.076
		Emotion			.038	.083
		Concern			.032	.031
	3	Physical Assistance	.620			.056
		Emotional Release				.007
		Acceptance				.039
Psychological Impact Time 2						
	1	Psychological Impact Time 1	.608***	.780***	.497***	.524***
	2	Identity	.689***		.008	.007
		Consequence			.162	.167*
		Emotion			.212	.230*
		Concern			095	.108
	3	Acceptance	.693			.082
Physical Impact Time 2						
	1	Physical Impact Time 1	.495***	.704***	.628***	.527***
	2	Identity	.502		.042	.047
		Consequence			.049	.041
		Emotion			.027	.081
		Concern			.026	.003
	3	Physical Assistance	470			.145
		Emotional Release				.041
		Acceptance				-.005
Anxiety Time 2						
	1	Anxiety Time 1	.458***	.677***	.486***	.491***
	2	Consequence	.530**		.130	.133*
		Concern			.089	.102
		Emotion			.172	.199
	3	Acceptance	.533			.067
Depression Time 2						
	1	Depression Time 1	.441***	.664***	.506***	.531***
	2	Consequence	.522**		.237*	.243**
		Emotion			.170	.225
		Concern			-.056	-.026
	3	Acceptance	.537			.158

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

6.4.11.7 Hierarchical regression analysis to determine whether illness representations and coping predict outcomes at time 2, when time 1 is not controlled for.

Due to the small number of significant results found by the regressions controlling for time 1, a second series of regression analyses were carried out. As shown in table 6-16, these regression analyses included the same outcome variables. However, the outcome measure taken at time 1 for each outcome variable was not controlled for. The correlated illness representation variables were entered at step one and the correlated coping strategies were entered at step two. As shown in table 6-16, all the steps for illness representations were significant in each of the regressions.

Overall MS impact at two months, was positively predicted by the consequences (β = .272, p < .05) and emotion (β = .263, p < .05) components in step one and these remained significant when coping strategies were added to the model. In step two, physical assistance coping was also significant (β = .177, p < .05) and the beta for consequences reduced to .227 suggesting that asking for physical assistance mediates the relationship between the consequences component and MS impact at two months. However, Sobel testing did not confirm that the inclusion of physical assistance reduced the beta for consequences significantly (z = 1.62, p =.105).

Psychological impact was positively predicted by emotion in step one (β = .546, p < .001) and step two (β = .533, p < .001). Physical impact at two months was positively predicted by consequences (β = .301, p < .05) in step one. In step two, the beta dropped to .216 and became non-significant suggesting possible mediation by physical assistance (β = .299, p < .01). This was confirmed by Sobel testing (z = 2.24, p <.05).

Anxiety two months later was positively predicted by the emotion component (β = .448, p < .001) in step one, and in step two when coping was added to the model emotion remained significant (β = .464, p < .001) and consequences became significant (β = .072, p <.05). Depression was positively predicted by the components consequences (β = .221, p < .05) and emotion (β = .447, p < .001). These also remained significant when coping strategies were added in step two.

Table 6-16 Hierarchical regression analysis to determine whether illness representations and coping predict outcomes at time 2 when time 1 is not controlled for.

		Step/Predictors	Total R2	Beta (Step 1)	Beta (Step 2)
Overall MS Impact Time 2					
	1	Identity	.427***	.093	.056
		Consequence		.272*	.227*
		Concern		.183	.123
		Emotion		.263*	.321*
	2	Physical Assistance	.486*		.177*
		Emotional Release			.153
		Acceptance			.005
Psychological Impact Time 2					
	1	Identity	.588***	.027	.027
		Consequence		.134	.133
		Concern		.177	.171
		Emotion		.546***	.533***
	2	Acceptance	.588		-.028
Physical Impact Time 2					
	1	Identity	.286***	.112	.073
		Consequence		.301*	.216
		Emotion		.085	.189
		Concern		.160	.067
	2	Acceptance	.363***		.020
		Physical Assistance			.299**
		Emotional Release			.179
Anxiety Time 2					
	1	Consequence	.395***	.070	.072*
		Concern		.189	.197
		Emotion		.448***	.464***
	2	Acceptance	.396		.037
Depression Time 2					
	1	Consequence	.367***	.221*	.224*
		Concern		.016	.032
		Emotion		.447***	.479***
	2	Acceptance	.371***		.075

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

6.4.12 Hypothesis 5 - Concurrent and prospective investigation of dysfunctional attitudes, coping and adjustment.

Hypothesis 5 (i) postulated that dysfunctional attitudes and coping would be predictive of adjustment at time 1 and 2, with greater dysfunctional attitudes and maladaptive coping leading to poorer adjustment to MS. It was also hypothesised (5ii) that coping would mediate the relationship between dysfunctional attitudes and adjustment to MS at time 1 and 2.

6.4.12.1 Hierarchical regression analysis to determine whether dysfunctional attitudes and coping predict adjustment to MS at time 1.

Firstly, a series of regression analyses were carried out to determine whether dysfunctional attitudes and coping predicted adjustment to MS time 1. Only those coping strategies, which correlated with the outcome variable at a $p<.01$ level were included in the analysis. As shown in table 6-11, the dysfunctional attitudes only correlated with time 1 anxiety and depression.

As shown in table 6-17, dysfunctional attitudes were positively related to anxiety in step one ($\beta = .400$, $p < .001$). In step two the beta dropped to .283 and acceptance was found to be significantly related to anxiety ($\beta = -.325$, $p < .001$). This suggests that acceptance may mediate the relationship between dysfunctional attitudes and concurrent anxiety. Sobel testing confirmed mediation by acceptance ($z = 2.47$, $p <.01$). Dysfunctional attitudes were also found to be positively related to concurrent depression ($\beta = .479$, $p < .001$) in step one. In step two, the beta dropped to .344 and acceptance was found to be negatively related ($\beta = -.375$, $p < .001$). This suggests that acceptance may mediate the relationship between dysfunctional attitudes and concurrent depression. Sobel testing confirmed mediation by acceptance ($z = 2.72$, $p <.01$).

Table 6-17 Hierarchical regression analysis to determine whether dysfunctional attitudes and coping predict adjustment at time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)
Anxiety Time 1					
	1	Dysfunctional Attitudes	.162**	.400***	.283**
	2	Acceptance	.252***		-.325***
Depression Time 1					
	1	Dysfunctional Attitudes	.229***	.479***	.344***
	2	Acceptance	.352***		-.375***

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

6.4.12.2 Dysfunctional attitudes in relation to anxiety at time 2.

In order to examine the relationship between dysfunctional attitudes and time 2 adjustment to MS in greater detail, separate regressions were carried out. However, dysfunctional attitudes only correlated at a p<.01 level with anxiety at time 2. The only regression that was therefore carried out investigated the relationship between dysfunctional attitudes and anxiety at two months. This is shown in table 6-18 below. Dysfunctional attitudes were found to predict anxiety at time 2 ($\beta = .266$, $p < .05$).

Table 6-18 Hierarchal regression analysis between dysfunctional attitudes and time 2 adjustment.

	Predictors	R2	Final Beta
Anxiety Time 2			
	Dysfunctional Attitudes	.071*	.266*

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

6.4.12.3 Hierarchical regression analysis to determine whether dysfunctional analysis and coping predict adjustment at time 2.

Since dysfunctional attitudes were found to correlate significantly with anxiety at time 2. A regression analysis was carried out to examine this relationship and is shown in table 6-19. Anxiety at time 1 was controlled for in step one, dysfunctional attitudes was entered at step two and coping in step three. However, dysfunctional attitudes were not found to be significantly related to anxiety at time two.

Table 6-19 Hierarchical regression analysis testing the relationship between dysfunctional attitudes, coping and outcomes at time 2, controlling for time 1.

		Step/Predictors	Total R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2						
	1	Anxiety Time 1	.677***	.685***	.650***	.458***
	2	Dysfunctional Attitudes		-.015	-.038	.458
	3	Acceptance			-.098	.465

*p<0.05; **p<0.01, *** p<0.001

6.4.12.4 Hierarchical regression analysis to determine whether dysfunctional attitudes and coping predict outcomes at time 2 when, time 1 is not controlled for.

In the light of the few significant findings from the regressions, another hierarchical regression analysis was carried to investigate the relationship between dysfunctional attitudes and anxiety at two months, not controlling for time 1. This is shown in table 6-20. Dysfunctional attitudes were entered at step one and acceptance was entered at step two. Anxiety was positively predicted by dysfunctional attitudes in step one (β =.265, $p < .05$)

and the beta reduced to .152 and became insignificant when acceptance, which was negatively related to anxiety ($\underline{\beta}$ = -.309, p < .01) was added to the model. This suggests that acceptance may mediate the relationship between dysfunctional attitudes and anxiety at two months. This was confirmed by Sobel testing (z = 2.23, p <.05).

Table 6-20 Hierarchical regression analysis to determine whether dysfunctional attitudes and coping predict outcomes at time 2, when time 1 is not controlled for.

		Step/Predictors	Total R2	Beta (Step 1)	Beta (Step 2)
Anxiety Time 2					
	1	Dysfunctional Attitudes	.070*	.265*	.152
	2	Acceptance	.153**		-.309**

*p<0.05; **p<0.01, ***p<0.001

6.4.13 Hypothesis 6 - Concurrent and prospective investigation of future thinking.

Hypothesis 6 (i) postulated that future thinking and coping would be predictive of adjustment at time 1 and 2, with greater negative and less positive future thinking predicting poorer adjustment. A series of regression analysis were, therefore, carried out to investigate whether future thinking and coping predict adjustment at time 1 and time 2. It was also hypothesised (6ii) that coping mediates the relationship between future thinking and adjustment to MS at time 1 and 2.

6.4.13.1 Hierarchical regression analysis to determine whether future thinking and coping predict adjustment at time 1.

A series of regression analyses were carried out to investigate whether future thoughts and coping predicted adjustment at time 1. These are shown in table 6-21. The future thinking components, which correlated with the outcome variable at p<.01 significance level were entered into step one and the coping strategies, which correlated with the outcome variable were entered in the step two. As shown in table 6-8 the future thinking components only correlated with time 1 anxiety and depression. Concurrent anxiety was also found to be negatively predicted by positive future thoughts over the next week (β = -.265, p < .001) in step one. In step two, the acceptance component was found to negatively predict (β = -.391, p < .001) anxiety and the beta for the positive future thoughts component reduced to -.181 and became non-significant. This suggests that acceptance may mediate the relationship between positive future thinking for the next week and concurrent anxiety. However, Sobel testing did not confirm that the inclusion of acceptance reduced the beta significantly (z = -1.92, p =.056). None of the future thinking components were significantly related to concurrent depression.

Table 6-21 Hierarchical regression analysis to determine whether future thinking and coping predict adjustment at time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)
Anxiety Time 1					
	1	Positive Week	.070**	-.265**	-.181
	2	Acceptance	.216***		-.391***
Depression Time 1					
	1	Positive Total	.081*	.209	.113
		Positive 5-10 Year		-.281	-.211
		Positive Week		-.172	-.233
	2	Acceptance	.310***	-.491***	

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

As shown in table 6-11 none of the future thinking components correlated at $p<0.01$ level with any of the adjustment variables at time 2. Therefore no regressions were carried out to investigate these relationships further.

6.5 Study 1 Discussion

This section discusses the main findings of Study 1. Based on the SRM framework, an extended SRM was proposed in Figure 6-1, which included cognitive schema and future thinking. Study 1 was designed to test the relationships proposed in this model and based on the results a second longitudinal study was designed. Therefore, in addition to the main findings of this study, the methodological limitations are also discussed and the implications of these on the design of further research are outlined. Finally, the clinical implications of this study are reviewed.

6.5.1 Summary of emergent relationships

In Chapter 4 (section 4.3) a series of research questions were proposed based on the findings and limitations of previous research. Study 1 was designed to address some of these research questions and consequently, determine the utility of the extended SRM model (see Figure 6-1) in predicting adjustment to MS. Using the results from Study 1, this section addresses each of the proposed research questions.

6.5.1.1 Question 1 - What is the relationship between the illness representation components in MS?

According to the SRM (Leventhal et al., 1980), illness representations play a key role in predicting adjustment to illness (See Chapter 2, section 2.6 for a description of the model). Previous research investigating illness perceptions in MS (Vaughan et al, 2003) has identified a number of relationships between the illness representation components (see Chapter 3, section 3.2.1.2). The findings of the current study were consistent with this early research and provided support for the hypothesis (1i) that the illness representation components would be inter-related. The findings of the current study revealed that negative beliefs were correlated with each other, as were the more positive illness beliefs. They suggest that a strong illness identity, a strong emotional impact, being concerned about the condition and feelings of low control increased the individual’s sense that their MS had a wide range of consequences. Furthermore, believing they had a good understanding of MS increased their feelings of control over it. Consistent with Vaughan et al’s (2003) results, the consequences component had the largest number of statistically significant relationships. In addition, the results provided support for the association between a strong illness identity and serious consequences as reported in previous studies (Hampson et al., 1990; Heijmans, 1998; Moss-Morris et al., 1996; Schiaffino et al., 1998; Vaughan et al., 2003; Weinman et al., 1996). According to Vaughan et al (2003), this relationship reflects the wide ranging and debilitating nature of the symptoms of the condition and the unpredictability of the symptom exacerbations.

Overall these findings suggest that some of the illness representation components do not exist independently of each other as single cognitions but could be conceptualised as groups of beliefs or schemata as proposed by Heijmans (1998). Furthermore, it provides support for Hagger and Orbell’s (2003) proposition that some illness representations are not orthogonal but are inter-dependent.

Previous research investigating illness representations in MS has been cross-sectional in nature (see Chapter 3, section 3.2.1.4) consequently it has not assessed whether MS patients perceptions of their illness change over time. The results supported the hypothesis that illness beliefs would change over time. The current study found that patients understanding of their illness and feelings of personal control increased over the 2 month period. As discussed in Chapter 2 (see section 2.6.3) an individual’s perceptions of their condition may change and develop over time as a result of the experience of living with the condition, social messages and increased contact with the medical profession. The findings suggest that these factors may have helped patients to gain a greater understanding of MS and feel more in control.

Previous research investigating the role of illness beliefs, cognitive schema and future thinking in MS, has investigated each of these cognitions separately. To date, no published research has examined the relationship between these illness cognitions in MS. The results of Study 1, supported the hypothesis (1iv) that illness representations would be correlated to dysfunctional attitudes and future thinking. Illness identity and serious consequences were associated with fewer positive future thoughts. This suggests that MS patients who strongly identified with their condition or believed it had serious consequences, struggled to think positively about their future. No significant relationships were identified between illness beliefs and negative future thinking. However, the emotion component was related to greater dysfunctional attitudes. This suggests that those who held more maladaptive beliefs also felt they were more emotionally affected by their condition. The findings of Study 1, therefore suggested that illness representations are not only inter-dependent of each other but are also inter-dependent with other illness cognitions such as positive future thinking and dysfunctional attitudes.

Overall, the findings of the Study 1 provided support for hypotheses 1(i), (ii) and (iii). In addition, to examining the relationships between the illness representations components and their relationship with the other illness cognitions, this study also investigated their relationship with coping and adjustment at time 1 and 2. This is the focus of the following section.

6.6.1.2 Question 2 - What is the relationship between illness representations, coping and adjustment at time 1 and time 2?

The SRM (Leventhal et al., 1980) proposes that an individual’s illness representations are related to how they cope, which in turn is associated with how well they adjust (See Chapter 2, section 2.6). To date, no published research has fully employed the SRM to understand adjustment to MS, prospectively. One of the main aims of study was therefore to investigate the relationships between the components of the SRM in MS. The results supported the hypotheses (2i, 2ii) that illness representations and coping, in addition to coping and adjustment would be correlated, consistent with the relationships outlined in the SRM.

No previous MS research has investigated the relationship between illness beliefs and coping however, research with other conditions provides some evidence for this relationship. Hagger and Orbell (2003) in their meta-analysis found that control beliefs were related to more active coping. This suggests that those individuals who believed they had some control over their condition felt more confident in employing active forms of coping. Similarly, the current study found that those who believed they had more personal control employed more problem-solving coping. Furthermore, those who believe their MS had a strong emotional impact or those who were concerned about their condition, employed lower levels of problem-solving coping. It could be that the emotional impact of the condition and the concern left patients feeling less capable of employing more active forms of the coping.

Previous research with chronic illness has found that problem-focused coping is related to greater well-being (Folkman & Lazarus, 1986; Pakenham, 1999). This was supported by the results of the current study, which found that problem-solving coping was associated with better psychological adjustment at time 1.This suggests that patients who felt more in control of their condition engaged in more active attempts to solve their MS-related problem and those employing more problem-solving coping experienced greater psychological well-being.

Another coping strategy found by the current study to be beneficial for adjustment was acceptance. This coping strategy was associated to better adjustment in all the areas measured, concurrently and 2 months later. Acceptance is a form of emotion-focused coping. Previous research has found that emotion-focused coping is consistently related to greater psychological and emotional distress (Arnett et al., 2002). However, instead of considering a range of strategies within the broad category of emotion-focused research, Pakenham (1999) argues that the more constructive forms of emotion-focused coping including acceptance (Carver et al., 1989) may be more useful in helping individuals adjust to MS. The current study provides support for this proposition, suggesting that acceptance is beneficial for successful adjustment. The results of Study 1 are therefore consistent with the SRM, as those with more negative illness beliefs reported lower levels of acceptance. The results suggested that MS patients were less likely to accept their condition if they believed that it had serious consequences, that it strongly emotionally affected them, if they had a strong illness identity or if they were concerned about the condition. In addition to being associated with lower levels of adaptive coping such as acceptance or problem-solving, negative beliefs were also associated with greater maladaptive coping. Those who believed their condition had serious consequences or a strong illness identity were also more likely to ask for physical assistance. This type of coping was correlated with greater physical and overall dysfunction. The findings suggest that those who were more physically disabled were more likely to ask for physical assistance.

Previous findings by Hagger and Orbell (2003) revealed that a strong illness identity was associated with expressing emotion. This relationship between identity and emotional release was also found in the current study. Previous research by Pakenham (2001) suggested emotional release was beneficial and was related with better adjustment. The results of Study 1 were inconsistent with this as emotional release was associated with greater physical dysfunction. According to Hagger and Orbell (2003), however this strategy is maladaptive as it reduces the patient's motivation to seek help or acknowledge their condition.

Taken together the correlations of Study I suggest that negative illness beliefs were associated with greater maladaptive coping and less adaptive coping, which in turn were associated with greater physical and psychological dysfunction. These findings are therefore consistent with the relationships outlined in the SRM.

Although the SRM proposes that coping mediates the relationship between illness representations and adjustment, previous MS research (see Chapter 3 section 3.2.1.2) suggests that illness representations are also directly associated with how well MS patients adjust. Their findings suggested that those who held a more negative view of their illness also experienced greater levels of psychological distress. Consistent with this, the current study suggests that those with a more negative perceptions of their illness (i.e. those with a strong illness identity, those who felt they were emotionally affected by the condition, those who felt concerned about it and those who felt it had serious consequences) experienced greater anxiety, depression and poorer physical and psychological adjustment, concurrently and two months later. The results therefore supported the hypothesis (2iii) that illness representations and adjustment to MS time 1 and 2 would be correlated.

Overall the findings of the correlations provide support for hypotheses 2 (i), 2(ii) and 2(iii). They show that illness beliefs, coping and adjustment at time 1 and 2 are all statistically correlated, in line with the SRM. Furthermore, they are consistent with the findings of previous research, which suggests that illness beliefs are directly related to adjustment. To investigate these relationships further, Study 1 also carried out a series of regression and mediation analysis to determine whether illness representations and coping predict adjustment to MS, prospectively. These findings are discussed in the following section.

6.5.1.3 Question 3 – Do illness representations and coping predict adjustment to MS?

According to the SRM (Leventhal et al 1980) an individual's illness representations can predict how they cope, which in turn, will predict how well they adjust to their illness. To date, no published research has fully applied the SRM, to predict adjustment to MS over time. The results supported the hypothesis (4i) that illness representations and coping would be predictive of adjustment at time 1 and time 2, consistent with the relationships outlined in the SRM. The study found that negative illness representation components (consequences, emotion, concern, timeline) predicted poorer psychological and physical adjustment and greater psychological distress at time 1. These findings are consistent with previous research by Vaughan et al (2003) and Jopson and Moss-Morris (2003) which also found an association between more negative illness beliefs and poorer outcome. However, this earlier research was cross-sectional in nature and therefore did not provide any evidence for the role of their illness beliefs in predicting adjustment to MS over time. The current study however, revealed that the emotion and consequences components predicted poorer adjustment to MS 2 months later, even when time 1 adjustment was controlled for. The results suggest that the consequences component predicted an increase in patients' psychological dysfunction, depression and anxiety over the two month period. In addition, the emotion dimension predicted the increase in their psychological dysfunction. This highlights the importance of patients illness beliefs in predicting adjustment to MS over time, in particular a belief in the serious consequences of the condition.

MS is a life long condition and since many of the participants had suffered from the illness for many years, it is likely that changes in adjustment would occur over a longer time frame than two months. Further analyses were, therefore, carried out not controlling for time 1 adjustment. The result of these analyses revealed that serious consequences and emotion predicted poorer adjustment on almost all the outcome measures at time 2. They suggested that individuals who believe their condition has serious consequences or has a strong emotional impact on them, are more likely to experience poorer adjustment two months later. The importance of the consequences dimension in influencing adjustment was also identified by previous cross-sectional research by Heijmans (1998) and Vaughan et al (2003). In the latter of these two studies, Vaughan et al (2003) found that this component explained variance in all areas of outcome. The current research therefore adds to this finding by providing evidence for this component predicting adjustment over time. Taken together the findings highlight the importance of MS patient’s perceptions, regarding the impact of their condition on their daily lives, in contributing to their psychological distress.

Overall these findings highlight the importance of illness beliefs in predicting adjustment to MS. However, the current study also found that coping plays an important role in predicting adjustment. One of the main limitations of previous MS research investigating the role of illness beliefs was that it did not assess the role of coping (see Chapter 3, section 3.2.1.4). The results from both the cross-sectional and longitudinal analyses in the current study revealed that coping mediated some of the relationships between illness beliefs and adjustment. This finding is consistent with the relationships outlined in the SRM and provides support for hypothesis 4ii. Physical assistance and acceptance coping were both found to play a mediating role. The results suggested that those individuals who believed their MS had serious consequences were more likely to cope by asking for physical assistance and as a result experienced greater physical dysfunction concurrently and two months later. In addition, those concerned about their

MS were less accepting of the illness and as a result experienced greater depression at time 1. Previous MS research has suggested that illness beliefs have a direct impact on adjustment (see Chapter 3, section 3.2.1.2) and although the results of the current study found support for this, they also highlight the importance of taking into consideration the role of coping.

6.5.1.4 Question 4– What is the relationship between dysfunctional attitudes, future thinking, coping and adjustment to MS?

The proposed model in Figure 6-1 was developed based on the SRM framework. However, the original SRM was extended to include dysfunctional attitudes and future thinking. The results provide some support for the hypothesis (3i) that dysfunctional attitudes and future thinking would be correlated. Although the results found no relationship between dysfunctional attitudes and negative future thinking, they did reveal that greater dysfunctional attitudes were correlated to less positive future thinking. This is consistent with the finding that more negative illness beliefs were correlated with lower levels of positive future thinking but were unrelated to negative future thoughts. Considered within the context of Beck’s Cognitive Theory of Depression (see Chapter 2 section 2.9 for details of this theory) the findings suggest that individuals who form maladaptive schemas or cognitive distortions struggle to think positively about the future. The current study also found that these cognitive distortions or dysfunctional attitudes were associated with lower levels of adaptive coping such as problem solving coping and acceptance. The findings therefore provided some support for hypothesis 3 (ii) which proposed that dysfunctional attitudes, coping and adjustment would be correlated.

The results of the Study 1 correlations also provided support the hypothesis (3iii) that future thinking, coping and adjustment would be correlated. Those with more positive thoughts about their future engaged in more problem-solving coping. In addition, positive future thinking was related to lower levels of anxiety and depression. The findings highlight the importance of positive over negative future thoughts in coping and adjustment to illness. This is consistent with earlier research (Hunter & O'Connor, 2003; MacLeod et al., 1993; O'Connor et al., 2004) which found that it was lower levels of positive future thinking not greater negative thinking that predicted suicide ideation.

Overall, the results of the correlations suggest that as expected, dysfunctional attitudes and future thinking are related to how individuals cope and adjust to MS. To investigate these relationships further, a series of regression analysis were carried out, to test whether these illness cognitions can predict how MS patients cope and adjust. The subsequent sections discuss these findings by examining role of dysfunctional attitudes first, followed by the role of future thinking.

6.5.1.5 Question 5 – Do dysfunctional attitudes predict coping and adjustment to MS?

Based on the SRM framework, the model in Figure 6-1 proposes that dysfunctional attitudes and coping predict adjustment to MS. The results from Study 1 supported the hypothesis (5i) that dysfunctional attitudes and coping would predict adjustment at time 1 and 2. Greater dysfunctional attitudes were found to predict greater concurrent anxiety and depression. Furthermore, acceptance mediated these relationships. This suggests that those with dysfunctional attitudes were less likely to accept their condition and as a result experienced greater levels of psychological distress.

This study also examined the relationship between dysfunctional attitudes and adjustment two months later. The results from the regressions controlling for time 1 did not find evidence to suggest that dysfunctional attitudes could predict the change in patients levels of anxiety over two months. As discussed previously many of the patients had suffered from the condition for a long time, two months therefore may not have been a long enough period time in which to notice a change in their adjustment. When time 1 was not controlled for, greater dysfunctional attitudes led to greater anxiety two months later. Beck's Cognitive Theory of Depression (see Chapter 2 section 2.9 for a description of this theory) suggests that maladaptive cognitive schemas lead individuals to experience greater psychological distress. Although the results do not provide support for the role of dysfunctional attitudes in predicting depression, they do suggest that MS patients with greater cognitive distortions experience greater levels of anxiety at two months. The results of Study 1 also revealed that acceptance mediated this relationship at time 1 and 2. The findings suggest that those with dysfunctional attitudes are less likely to accept their condition and as a result experience greater anxiety.

Overall the findings provide support for hypothesis 5 (i), (ii) and the relationship between dysfunctional attitudes, coping and adjustment to MS as proposed in Figure 6-1. However, the findings only provide limited evidence for the role of dysfunctional attitudes in predicting adjustment to MS, prospectively. Previous research carried out by Shnek (1995) found limited support for the role of cognitive schema in predicting adjustment to MS. The findings of Study 1 appear to be consistent with these earlier findings. In addition, to assessing the role of dysfunctional attitudes, Study 1 also examined the role of future thinking in predicting adjustment to MS. These findings are discussed in the following section.

6.5.1.6 Question 6 – Does future thinking and coping predict adjustment to MS?

Previous research identified future thinking as an important predictor of psychological distress. However, to date only one study (Moore et al., 2006) has investigated the role of future thinking in MS (see Chapter 3, section 3.9). The findings of the current study revealed that lower positive future thinking was associated with greater anxiety at time 1. This is consistent with previous research (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004) which found that lower positive future thinking as opposed to greater negative future thinking predicted greater suicide ideation (see Chapter 2, section 2.11.2).

Overall, the results provided limited support for the hypothesis (6i) that future thinking and coping would be predictive of adjustment at time 1 and 2. No support was found for the hypothesis (6ii) that coping would mediate this relationship. However, the only adjustment variables assessed in this study were anxiety, depression and a measure of physical and psychological impact. Previous research has suggested that future thinking is an important predictor of hopelessness and suicide ideation (see Chapter 2, section 2.11.2), neither of which were assessed by this study or previous MS research. This highlights the need to investigate the relationship between future thinking and these outcome variables in MS. Furthermore, the results of the correlations showed that negative future thinking was significantly related to anxiety at time 1 and time 2 but only at a $p<.05$ level. This suggests that there may not have been a large enough sample size highlighting the need to investigate these relationships further with a larger sample of MS patients.

6.5.2 Methodological criticisms and implications for further research

Despite finding some support for the hypotheses in the present investigation, it is important to take into consideration the limitations of the research. Firstly, Study 1 was designed to test a range of psychological measures in adjustment to MS. To avoid contemporaneous contamination, participants were assessed at two time points. By doing so it was hoped that the likelihood of seeing change across a time-span with minimum attrition would be increased. Due to the constraints of the PhD however, only a 2 month follow up period was employed. The results from the longitudinal analysis, suggest that this may not have been a long enough period of time in which to notice a significant change in participants levels of adjustment. This highlights the need for additional research to investigate these relationships over a longer period of time.

This study was also limited by the sample used. As a result of the recruitment procedure, it is possible that a selection bias operated. All participants were screened for emotional difficulties prior to being invited to participate. Consequently, those taking part may have better adjusted to their MS. The results of the current study revealed that only 1 participant suffered from severe depression and 10 from severe anxiety. Consequently, the sample may not be as representative of those suffering from greater psychological distress. A further limitation was the size of the sample. The results of the correlations between future thinking and adjustment suggest that there may not have been a large enough sample size. In total, 103 participants took part at time 1 and although the study had a good follow up rate (87%), only 90 MS patients took part at time 2. The findings highlight the need for further research to investigate the role of future thinking using a larger sample size.

Prior to investigating hypotheses 4, 5 and 6 a series of correlations were carried out to examine whether age, gender marital status should be controlled for. One of the limitations of this study was that impact of other factors such as MS type, time since onset, time since diagnosis, steroid use, treatments and family history on adjustment to MS was not assessed due to incomplete information in the hospital medical notes. Unfortunately this was not discovered until after the participants had completed the research. In Study 3 this information was therefore collected during the interviews and the case notes and was used to identify any missing information.

6.5.3 Clinical implications

The findings of Study 1 have a number of implications for those working with MS patients. The results suggest that through examination of patients’ illness cognitions and coping strategies, health professionals would be able to identify those as risk of psychological distress. The research suggests that patients with a more negative view of their MS will experience greater anxiety and depression. In particular, the Study 1 highlights the importance of the patients’ perceptions about the impact of their condition in determining how well they will adjust over time. A belief that MS has serious consequences was found to predict an increase in anxiety, depression and psychological dysfunction over a two month time period. This suggests that health professionals would be able to identify those vulnerable to psychological distress based on their belief about the impact of the condition on their day to day life. The results also suggest a belief that MS has serious consequences was associated with other illness belief components such as a strong illness identity, low control and greater concern. Interventions could therefore target these beliefs in order to change patients’ perceptions about the consequences of the condition. For example they could aim to reduce patients’ illness identity by helping patients identify those everyday symptoms, which are unrelated to their MS. Furthermore, they could attempt to increase the patient’s sense of control over their illness. The findings suggest that by changing these illness beliefs the patient’s perceptions about the consequences of their MS would also be affected. In addition, interventions could be designed to teach patients how to cope more effectively with the illness. The findings of Study 1 provided evidence for the mediating role of coping. This suggests that by teaching more effective coping those patients with a more negative view of their illness would be less likely to experience psychological distress. A full discussion of the clinical implications of the research findings are given in Chapter 9.

6.5.4 Summary

The findings for Study 1, provide support for the utility of the SRM in predicting adjustment to MS prospectively. The results revealed that the beliefs an individual has about their MS and the coping strategies they employ, can have a direct impact on how well they adjust. The findings also provide support for the mediating role of coping, as proposed by the SRM.

The model in Figure 6-1, extends the SRM framework to include the role of dysfunctional attitudes and future thinking. Consistent with previous research by Shnek et al (1995) (see Chapter 3, section 3.8), the results found limited support for the role of dysfunctional attitudes in predicting adjustment to MS. This study also found limited evidence for the role of future thinking. However, previous research has suggested that future thinking is a key predictor in suicide ideation, which was not assessed in this study. Based on the findings and limitations of Study 1 a second longitudinal study was designed to investigate these relationships further. This will be presented in Chapter 8. In addition to investigating adjustment to MS using quantitative research methods, the current doctorate research carried out a qualitative study to investigate the experience of MS from the patient's perspective. This is study is focus of the following chapter and provides a fuller understanding of the psychological mechanisms underlying successful adjustment to MS.

Chapter 7: A Qualitative Investigation into the Experience of Living with Multiple Sclerosis

7 Overview

This chapter describes the second study, carried out as part of the current doctorate research. Study 1 was designed to investigate the role of illness representations, coping and adjustment to MS over time using a quantitative research design. The aim of Study 2 was to examine the experience of living with MS from the “insider’s” perspective using a qualitative research design. By using mixed quantitative and qualitative research designs, it was hoped that the psychological mechanisms involved in successful adjustment to MS could be explored more fully. This chapter, first of all, discusses the rationale behind Study 2. This is followed by an outline of the methodology employed, expanding on the information given about the methods in Chapter 5. Finally, the findings of Study 2 are presented and these are discussed in relation to earlier research and the findings of Study 1.

7.1 Rationale

Although Study 1 was designed based on the SRM framework for the current study, an inductive approach was adopted for analysing the interviews in Study 2. The aim was to employ an approach which would mean that the analysis was not driven by the researcher’s theoretical interest in the area. The questions developed for the interview schedule centred around the patient’s ideas about their condition, how they coped and how they felt the illness impacted on their overall quality of life. However, the data was coded without trying to fit it into pre-determined categories or a priori assumptions. This enabled the experience of living with MS to be examined from the patient’s point of view. By investigating adjustment from the insider’s perspective it was hoped that the findings, in combination with those from Study 1, would provide a rich and insightful understanding of the psychological mechanisms, which lead to successful adjustment to MS. Since an inductive approach was adopted for the analysis, no specific research questions or hypotheses were developed.

The aim of the present study was, therefore, to investigate patient’s perceptions of their MS, how they coped and the impact of the condition on their overall quality of life using a qualitative research design. This provides a greater insight into these components from the patient’s perspective.

7.2 Method

7.2.1 Design

This is a qualitative study, in which MS patients (N=15) took part in a semi-structured interview investigating their experience of living with MS from the insider’s perspective. The interviews were conducted by the first author (a white female PhD student) throughout October 2005 and lasted between 20 and 60 minutes. The interview questions focused on the individual’s beliefs about their MS, how they coped with the condition and how much they felt it affected their quality of life (see Appendix 11 for a copy of the semi-structured interview schedule).

7.2.2 Participants

7.2.2.1 Recruitment of participants

Fifteen patients with Multiple Sclerosis were recruited from the Forth Valley Area Rehabilitation Team (FVART) (see Chapter 5, section 5.2.1 for full details of this service). One hundred and fifty participants were approached to take part in a Study 1. Of the 37 recruited from the FVART for Study 1, the first fifteen to volunteer were interviewed for the present study (see Chapter 5, section 5.2.2 for full description of exclusion criteria).

7.2.2.2 Demographic and illness characteristics

The final sample comprised of 8 (53.3%) males and 7 (46.7%) females. The age of participants ranged from 27 to 66 years old, with a mean age of 47.4 years (SD=10.19). The onset of participants' MS symptoms varied between 1 year and 40 years and the mean length of time since onset was 14.82 (SD=11.37) years. The time since participants had received their diagnosis varied between 1 year and 33 years and the mean time since they had received their diagnosis was 10.3 (SD= 9.12) years. The results showed that 10 (66.7%) of participants were married, 1 (6.7%) was single, 1 (6.8%) was divorced, 2 (13.3%) were cohabiting and 1 (6.7%) was widowed. Five (33.3%) suffered from the relapsing-remitting type of MS, 4(26.7%) from primary progressive and 6 (40%) from secondary progressive. Table 8-1 provides further background information for each of the participants. All participants taking part were given a pseudonym, to ensure their anonymity.

Table 7-1 Background information for each of the participants in Study 2.

Participant		Marital Status	Gender	Years since onset of MS	Years since Diagnosis of MS	MS Type
Davina	Female	Married	65	40	20	Relapsing Remitting
Jim	Male	Married	48	-	1	Primary Progressive
Raymond	Male	Married	52	1	20	Secondary Progressive
Cara	Female	Married	27	1.5	1.5	Relapsing Remitting
Christine	Female	Widowed	43	6	5	Primary Progressive
Alison	Female	Single	27	9	3	Relapsing Remitting
Gavin	Male	Married	47	18	14	Secondary Progressive
Fraser	Male	Married	54	20	9	Secondary Progressive
Elisha	Male	Married	60	33	33	Secondary Progressive

Participant		Marital Status	Gender	Years since onset of MS	Years since Diagnosis of MS	MS Type
Margaret	Female	Cohabitating	54	3	2	Primary Progressive
Garry	Male	Married	50	15	5	Relapsing Remitting
Mark	Male	Married	45	15	15	Secondary Progressive
Barry	Male	Divorced	49	15	15	Secondary Progressive
Murray	Male	Married	45	10	8	Primary Progressive
Jessica	Female	Cohabitating	45	21	3	Relapsing Remitting

7.2.3 Procedure and interview

The focus of the inquiry in Study 2 was the participants' understanding of what it is like to live with MS. The aim was to recruit a purposive sample in order to generate a homogenous group (individuals who experience similar events, in this study, who live with MS), as opposed to a representative sample. As a result, large numbers of individuals are not necessary. The results, therefore, represent this particular group of MS patients and are not representative of all MS patients in general.

Prior to the interview an interview schedule was prepared. Details of the semi-structured interview schedule are given in Chapter 5, section 5.3.4. It is important to note that an inductive approach was adopted and consequently, the interview schedule was not followed in a strict or rigid way. As a result, the content of each interview followed the participants through their accounts of their MS. Throughout the interviews, a process of reflecting and probing was adopted. The interviewer would often ask for additional details to elicit a more insightful account of how the participant thought about their MS. All the interviews were recorded on an audio recorder and were subsequently transcribed verbatim. Throughout recruitment and data collection there were number of ethical issues, which were taken into consideration (see Chapter 5, section 5.5 for a full discussion of these).

7.3 Results

7.3.1 Analytical strategy

Transcripts were analysed for ‘key’ themes using Thematic Analysis. Each transcript was read repeatedly in order to increase familiarity. Consistent with Braun and Clarke (2006) initial codes were generated by identifying key words, phrases and idiosyncratic figures of speech systematically across the entire data set. These were clustered into groups to identify the emerging themes. This process was repeated for the remaining transcripts. All transcripts were further analysed in order to highlight similarities and differences within the group. The data were then grouped into thematic categories in order to identify key themes. In the present research, if a theme was reported by the majority of the participants (at least 8) it was categorised as a ‘key’ theme. The extracts presented in this following chapter have been chosen because they provide the most powerful or insightful accounts of any given theme.

Thematic analysis is a method of for exploring the participant’s experience of the world and consequently provides a detailed account from an insider’s perspective. This approach identifies, analyses and reports themes within the data. It minimally organizes and describes the data in rich detail (Braun & Clarke, 2006). For the present study an inductive approach was adopted for analysis which meant that the themes identified were strongly linked to the data set (Patton, 1990). The aim was to employ an approach which would mean that the analysis was not driven by the researcher’s theoretical interest in the area. The data were, therefore, coded without trying to fit them into pre-determined categories or a priori assumptions. Consequently, the form of analysis adopted was data driven.

The primary aim of the analysis was to present key themes in the form of an interesting narrative account. Verbatim extracts were used to substantiate the themes being proposed. See Braun and Clarke (2006) for a recent review on thematic analysis.

7.3.2 Key Themes

Three key themes emerged from the data regarding the lack of understanding and the experience of loss associated with Multiple Sclerosis: “Lack of Understanding”; “Loss of Control” and “Loss of Identity”

7.3.2.1 Lack of understanding

All of the participants reported a lack of understanding about MS. This encompassed their own understanding about the cause of the condition, the lack of knowledge by health professionals and the limited understanding about the illness by the general public. Linked to this were feelings of confusion, frustration, anger and even embarrassment.

All 15 of the participants reported a lack of understanding about the cause of their condition. The majority of them identified a number of possible factors, which may have contributed to the onset of the disease, such as a genetic predisposition, environmental factors, geographic location, diet, viral infection and injury. However, they did not know which of these factors were responsible and some of the participants (n=5) concluded that they were just ‘unlucky’. In the following extract, Jim highlights the limited understanding by participants about the cause of the condition and the many conflicting theories, which have been proposed to explain it:

"There's a lot of things that have been laid out as possible causes of MS but there's not really any evidence of a particular factor - if you're Afro Caribbean you're unlikely to get it and if you're a Nordic person you're more likely to get it, if you're Scottish you're more likely to get it, you seem to have a greater than average chance of getting MS. I've been talking about it and there's no specific issue, I mean they talk about infection and things like that. From my own point of view I have come round to the way of thinking that it's just my luck, you know, somebody's got to get it and it's just my luck that it's me. I've never thought about it in the past, obviously concerned that there is some evidence that it's familial, could affect my own kids, they are more likely to develop MS I suppose they are as well." (Jim)

In discussing the variety of factors which have been identified as possible causes, Jim clearly struggles to understand why he has MS. With so many competing theories and no evidence for one specific factor, he has come to the conclusion that it is just his bad "luck". As this extract shows, his lack of understanding gives way to fears about the implications for his children. If the condition is hereditary then they may be at risk of developing the condition later on in life. There is a sense of ongoing confusion and concern about what causes the condition in the above account.

This lack of understanding by participants was also evident in terms of the physical sensations associated with MS. Seven of the participants described the physical symptoms as difficult to understand using words such as 'weird', 'strange' and 'funny':

"I don't know, it's weird because I don't know, it's just like – there's no words to describe having MS, there isn't, because it's just totally bizarre, it really is, the things you feel, it's just like totally out of this world, it's weird, it really is weird, it really is completely and utterly totally out there because I mean you feel all these weird sensations

and you know that nobody else feels them and sometimes you begin to feel yourself is that really that?" (Alison)

There is a profound sense of confusion over the sensations which Alison experiences, as a result of her MS. It is almost as though the physical symptoms are so strange that they are overwhelming to her. The extract highlights the difficulty she is faced with when making sense of her condition and how she even questions herself when she thinks she feels something. This inability to describe the way she feels physically not only makes her question herself but will inevitably make it difficult for others to understand what she is going through.

This lack of understanding by the participants about their condition stems from the limited knowledge about MS by the medical providers. This was clearly highlighted by participants when discussing their encounters with health professionals. Ten of the fifteen participants reported that the medical profession did not understand the condition. In the following extract, Fraser explains how doctors have been unable to explain to him why he has MS:

"they cannot give you a real answer why you took MS, I think that itself is worse, that they can't give you a better answer." (Fraser)

There is a sense of disappointment from Fraser's account that the doctors have been unable to explain to him why he has the condition. It is almost as though not knowing why he has MS is worse than the illness itself.

The limited understanding by the medical profession has also led to a number of other problems. At the heart of this were the difficulties participants experienced in receiving a diagnosis of MS. They reported suffering from their symptoms over a long period of time, making multiple visits to clinics and being misdiagnosed, before receiving a formal diagnosis with MS. In the following extract, Margaret describes the confusion she experienced in receiving a diagnosis:

“the rheumatologist tried to say my symptoms were MS, he said it’s just term…… so he seemed to accept it was MS, Forth Valley (Area Rehabilitation Team) first time said it was MS and then when I saw the current neurologist he went back and said the MRI scans weren’t very clear so I wasn’t very sure if the diagnosis was completely correct.” (Margaret)

This extract highlights the difficulty which Margaret has faced in trying to discover what is wrong with her. With two health professionals providing conflicting conclusions about whether or not she has MS she has been left uncertain about her actual diagnosis.

It could be argued that the difficulties participants faced in receiving a diagnosis were a result of the lack of a definitive test for diagnosing MS. However, as the following extract shows participants also felt there was a resistance by doctors to give a diagnosis of MS:

“there’s a lot of unhappiness, people seem to take a long time before they get a definite diagnosis. I don’t understand that either, it’s awful getting a nasty diagnosis so the next worst thing is having weird and wonderful symptoms and nobody telling you what it is. They just think you’re a neurotic Munchhausens person, aye? It’s better to know, especially if you’re younger, they’ve got to help you make plans and decisions, what you’re going to do about your life, you wouldn’t if you thought you had MS probably take a job in Singapore for example”, (Margaret)

This extract highlights the confusion and lack of understanding Margaret feels about why it is so difficult to receive a diagnosis of MS. She believes that doctors do not want to tell patients when they have the condition. She rationalises that although it is distressing to be diagnosed with MS, she feels that it is better to know what you are dealing with.

Other participants also felt that it was better to know that you had the condition than live in ignorance. Barry said he was *"very pleased"* to finally be diagnosed as it was *"another piece in the jigsaw"* of his health problems. In addition, Jessica stated that it was *"much easier to live with the knowledge rather than with doubt"*. These extracts suggest that the experience of being diagnosed helped these participants understand what they are experiencing. Although there is limited understanding about the condition, being able to put a label on the symptoms may have given them some relief.

This lack of understanding about the condition by health professionals can also lead to patients being misdiagnosed. In the following extract, Alison explains how she was repeatedly misdiagnosed with other conditions:

"They came back one time and said I had cancer, then they came back and said I had Lyme disease, then they told me I had epilepsy, leukaemia and I had diabetes, I had everything, honestly, and there was one time the doctor up there, Dr. XXX, I'll never forget him, he came in and told me I had cancer, and I was sitting myself with another four lasses, another three lasses in the room that I was sharing the room with, no-one of my family there or anything, and he says to me that I had cancer and he just walked away and left me. Honestly, he just walked away out the door and left me." (Alison).

In describing her experience of being misdiagnosed, Alison highlights the lack of understanding by health professionals not only about the condition itself but also about the patient's needs. Her extract focuses on her disbelief about the way she was treated in particular, the way in which the doctor told her she had cancer. This account demonstrates the severe lack of understanding by the doctor of her well-being. This unsympathetic approach by the medical profession was also reported by six other participants. Like

Alison, Jessica also felt the doctors were inconsiderate and unhelpful when she was trying to discover what was wrong with her:

"I read all the books didn't I and I was Scottish, my father was Shetlandic, I fit the personality type, I had pretty much convinced myself that I was at high risk, but no-one would talk to me, my GP just laughed." (Jessica)

As a doctor herself, Jessica was aware that there was a possibility she had MS. However, she was met with a great resistance by the medical profession to discuss the matter with her. Throughout her interview she re-iterated that no one would talk to her about whether she had the condition or not. This extract highlights how she was ignored by the medical profession and her concerns were not taken seriously.

The lack of understanding or knowledge about MS itself can undoubtedly lead to difficulties in diagnosing MS. However, what is surprising is the lack of understanding and consideration given by the medical professionals for patient's well-being. This was highlighted not only by patients discussing their diagnosis but also in their accounts of being treated for the condition:

"I go to a neurology clinic and quite frankly I think their attitude is ridiculous as far as things I've been asked to do, it makes me realise the consultant doesn't really understand the disease and yet I've been going there for years and years." (Raymond).

In describing his encounters with the clinic, Raymond highlights the lack of understanding from health professionals treating the condition. His extract focuses upon a sense of anger at the way he has been treated. There is also this sense of frustration that the people who are supposed to help him have no idea what they are doing.

Participants not only reported a lack of understanding by themselves and health professionals they also felt there was a poor understanding of MS within the wider community:

“there is not enough [media] coverage about MS because you say MS to somebody, the first thing they say to you is ‘oh is that the disease that eats all your muscles?’ and you’re like no.” (Alison)

The above extract highlights Alison’s disbelief at the lack of understanding about what MS is. She associates this to a paucity of media coverage about the condition. There is a sense of frustration from her about how others respond when she tells them she has MS. This limited understanding about the physical effects’ of the condition also led to MS participants to be misperceived as “drunk”:

“It’s quite an embarrassing condition because you look as if you’re drunk once you start to …and you think I’ve got to sit down and there’s nowhere to sit so you’re hanging on to whatever’s available.” (Margaret)

Margaret believes that other people misunderstand the physical consequences of her MS leading them to believe that she is intoxicated. This unsurprisingly gives way to feelings of embarrassment. There is also a sense of helplessness, that she can not control what is happening and is forced to simply hang on to whatever she can. This loss of control was also experienced by the other fourteen participants and will consequently, be the focus of the following section.

7.3.2.2 Loss of Control

All fifteen of the participants reported an ongoing sense of loss characterised largely by a diminishing sense of personal control. The saliency of this loss of personal control manifested itself in a broad range of areas. At the heart of this was the participants’ inability to control their bodies:

“I don’t really think I have any control over my body, I just hope from week to week that nothing serious happens.” (Christine)

Like Christine, the majority of participants felt they had no control over their body. This uncertainty about what will happen to her in the future means all she can do is hope. She feels that no matter what she does it will not make any difference and the consequences of her MS are determined by chance. There is a sense of helplessness in having to live in this constant state of uncertainty and the impending fear that something serious may happen.

This loss of control over their bodies was particularly evident in the context of their mobility. Thirteen of the participants reported problems with mobility. As the following extract highlights, this loss of control over their bodies has left participants feeling helpless, overwhelmed and distraught.

"I've had some bad episodes, real bad episodes, what do I mean by that? From doing what I do at the minute, coming from one room to another on the sticks, to not even being able to get on the sticks, not being able to stand up, devastating scenarios, me sitting here crying because I can't move. At the time, couldn't move, couldn't do anything." (Mark)

In describing his experience of relapses, Mark highlights the difficulties he faces in coming to terms with the loss of control over his body. Mark appears to be engulfed by a sense of helplessness while in the situation. The unpredictability of the condition and the loss of control leave him feeling emotional, powerless and overwhelmed. There is a real sense of distress associated with his past experiences of these incidents.

Like Mark, many of the participants have been forced to rely on physical aids including wheelchairs, walking sticks, splints and scooters, in order to remain mobile. Ten of the fifteen participants reported that they needed to rely on physical aids to move around at various times. As the following extract highlights, although these aids provide participants with a means of controlling their mobility, patients are often reluctant to use them:

"Just controlling it a little bit, it's doing that for me. I have a split that I walk with as well and a stick which I don't like, a real stigma attached to the stick but I need that although I don't really like it, but if I'm out walking now I need it, so I'm trying to overcome it sort of thing," (Garry)

Although using a stick enables Garry to exert some control over his MS he has had difficulty coming to terms with having to use a stick. This suggests that although these physical aids enable participants to become more mobile there is a mental barrier, which prevents them from using them. The perceived "stigma" attached to these aids often led participants to struggle on without them:

"I know I fight against it all the time, as I say I should use a wheelchair more especially if I'm about anywhere, I can't walk any distance, but I don't." (Davina)

Once more this highlights the resistance to use physical aids as a means of controlling the condition. Davina implies that these mobility difficulties are something which can be defeated. This suggests that by using a wheelchair she would simply be giving in to it. There is sense that only when patients feel they have no control of own bodies will they resort to using wheelchairs and sticks etc. Therefore, although using these aids can help individuals to exert greater control over their movements they are associated with the feeling that their bodies are no longer within their control. Seven of the participants reported that they felt resistant to use these physical aids. In particular, participants were reluctant to use wheelchairs.

In addition to a loss in of mobility, a loss of control over their bodies was also related to a loss of sight, sensation and incontinence. Raymond describes his own experience of being no longer about the control his bowels:

"Well you do have to plan ahead, there's always the Russian roulette element in it, but sometimes you can't account for things happening and if you're caught in the car … I have had some experiences which are embarrassing really, it can happen in the most unexpected times, so it's something you've got to cope with." (Raymond)

The above extract highlights how Raymond sees his problems with incontinence as bit of a gamble- sometimes he is ok and other times he is caught out. He tries to minimize the difficulty by planning ahead, however, this does not guarantee he will be able to prevent the incidents from occurring. He appears to be accepting that this is something which is not his fault and is out of his control. Despite feeling embarrassed he rationalises that this is something that he just has to deal with.

Like Raymond, four of the other participants highlighted this need to plan ahead in order to exert some control over their condition. This has led to a loss of spontaneity in their lives. In the following extract, Murray describes how he has to be organised and plan everything in advance.

"everything's got to be planned. Going out for the day it's not just a case of OK, grab my jacket and get out the door. I've got to plan it, take this, take that, make sure I've got to be back by a certain time, it's hard work." (Murray)

There is a sense that he is not free to simply do what he feels like, when he feels like it. The limitations of the condition have meant that he can no longer be spontaneous. Before he even leaves his house he needs to take everything into consideration from what he takes with him to when he will be back. It seems as if the process of doing anything has become an exhausting experience, even going out for the day has turned into work.

In order to exert some control, participants felt they had to change the way they went about things. In addition to planning they had to learn to take their time, not rush, be realistic about their limits and work within them. In particular, they felt that they had to reduce their exposure to stressful situations as these often led to an exacerbation of the condition. Murray highlights in his following extract how the condition has forced him to adopt a quieter lifestyle:

"I try and lead a boring life, I think if you try and keep on the level, sometimes it's the highs, the highs are great but when you come down the other side it's not so good so I try and sort of get somewhere in the middle, although it's pretty dull and there's not a lot happening, but it tends to keep you on a level, so to speak because I know people who are friends who tend to go for a high and then come down on the other side, I think that has a detrimental effect on the overall control of your MS. " (Murray)

It seems that Murray's condition has forced him to withdraw from more exciting experiences. There is a sense that he has weighed up the consequences of enjoying himself and having fun and decided that it is not worth it. By living a more sedate life he can exert more control over his condition. However, this has left him feeling that his life is dull and boring.

Planning, pacing and reducing their exposure to stressful situations were just some of the ways participants felt they could exert some control over their condition. Other methods included dietary changes and exercise. Six of the participants felt that by living a healthier lifestyle it made the condition progress better. Eight of the participants reported that they had relied on various treatments to control their condition at some point. Although there was not one particular treatment for MS they used a number of difference ones to help control their symptoms. Nine of the participants reported that other people such as family and friends helped them to cope.

7.3.2.3 Loss or change in identity

Associated with this loss of control discussed above, all fifteen of the participants subsequently experienced a loss or change in identity. As a result of participants losing control over their mobility, they were no longer able to be physically active. Many of them were forced to change their sense of identity- an identity which was previously defined by activity. They were no longer able to take part in activities, which they felt defined their sense of self:

"I was a normal guy I suppose in real terms, until I had MS, I would go to work, come back from my work, I would go to the pub before I came home, I'd go to the pub at night as well for a beer or two with the boys." (Mark)

Having MS appears to make Mark feel that he is no longer like everyone else. He is no longer able to do the types of things he perceives 'normal' people do, as though the MS has made him in some way abnormal and different from others. As Margaret's above extract highlights this often made them feel different from others:

"Before I developed these symptoms I was like everybody else, a professional, running round, for years I was getting up at the crack of dawn, I'd come back, take the kids to where they were going, just a very very full hectic life and then all of a sudden it came to an end, I mean I expected to be, well I'd made plans" (Margaret)

The above extract highlights this loss of identity that Margaret has experienced as a result of been unable to actively do what she used to. In her eyes the full and busy life she had as a professional person has come to an end. As a result of the condition, participants were no longer able to meet the goals they had set for themselves. Their experiences were framed by a sense of the disparity between the person they once were and their MS self. This change appears to have taken place quite suddenly and with this went her plans and expectations for the future. This loss of anticipated future and the uncertainty about what will happen was also reported by six other participants:

"most people have Plan A, Plan B, something goes wrong OK we go to Plan B., this is somewhere round Plan E or F for me, I thought .. I was quite looking forward to

turning forty and I was OK about that, that was a few years ago, I was OK about that and I thought there's certain things I want to do with the family, etc., and I haven't been able to do any of those things. It's really just take things as they come and just make the best of what I can do every day, you know? (Murray)

Like Margaret, Murray's expectations about the anticipated future have been dissolved as a result of his condition. The way he sees his life turning out now is clearly very different from the one he had originally planned for. There is a sense of disappointment that the things he had previously looked forward to did not come into fruition. Consequently, he feels that he can no longer plan for his future he just has to try and live day to day and make the best of this. This will make it difficult for him to think positively about what is ahead of him.

Many of the participants found it hard to accept this loss of identity and still thought of themselves as the way they were before they had MS:

"I still think of myself as a walking person, walking easily and doing things, but I just can't because I'm wheelchair dependent when I go outside." (Barry)

It appears that although Barry is aware of his limitations he still thinks of himself as someone who can move about freely as opposed to someone who is wheelchair dependent. Like Barry, four of the other participants talked about themselves as though they were still as fit and able as they once were. There is a sense that some participants did not want to accept or acknowledge their change in identity from their past self to their MS self. In the following extract Mark describes his resistance to see his condition as part of him:

" I'm getting more involved with this MY stuff, you know, everybody calls it my MS, and I was like flabbergasted the first time I heard it, a couple of years ago you know, my MS, I don't really like talking about it as my MS or my this or my the next thing, it is MS and it's a pain in the arse." (Mark)

There is a sense that Mark views his condition as some sort of external entity separate from himself. The idea that this illness is somehow part of him shocked him initially and although he is beginning to accept this, he still appears to be struggling with it. He clearly considers the condition to be something which is separate from him albeit an annoyance.

This loss and change of identity was also associated with a loss of independence. As a result of the limited control participants have over their bodies they are forced to depend on other people. They no longer see themselves as the independent individuals they were prior to their illness as they now have to rely on other people to help them. Eleven of the fifteen participants reported a loss in their independence. As the following extract highlights this loss of independence can lead to changes in participants' roles within the family:

" if I could do that independent of my wife and my son – that's been difficult becoming dependent, not dependent but if I want to go out I need someone to give me a lift there or to help me get the bus, that's been difficult because I've always driven, always been the only driver in the household for quite a long time, but now my wife has to drive everywhere, she's doing well." (Jim)

As a result of his MS, Jim feels he has lost his independence. He now sees himself as someone who is dependent of his wife and son. This dependency has meant that his role within the family has changed and this has been difficult for him to come to terms with. Like Jim many of the participants associated this loss of independence with a change in identity. In the following extract Cara describes how this loss of independence changes who you are:

"your old independence, the way you used to do things, that's gone and people say it doesn't change the person you are, you can still get out and about, that's rubbish, it's

gone, you know, you can grieve for it and you can put it to one side, you have to grow a new one, you know, that's the point, I think that's the way of coping is trying to find that new independence." (Cara)

Cara talks about her life before MS as though it is a past life. It is as if the person she once was has died. There is a sense that the life and identity she once had no longer exists and the process of accepting this is to grieve or simply let it go. She feels that the way in which to cope with this loss is to 'grow' a new independence. There is a sense that this change of identity is a process which patients must go through in order to accept the person they have become.

For participants, part of this process of developing a new independence was relying on physical aids such as wheelchairs, sticks and scooters to help them move around. This meant that they would not have to rely on other people to the same extent. However, as discussed previously patients seemed to resist using these in part, because they were seen them as a sign that the condition has beaten them and also because of the social stigma attached to them. This is closely linked with a change in identity. This failure to use these aids even though they need them to move around, may also be because participants did not want to see themselves as someone who is for example wheelchair dependent. This reflects the resistance by participants to acknowledge their change in identity from their past self to their MS self:

"… other people.......seem to cope perfectly cheerfully with being in a wheelchair, a prospect which horrifies me, I think that the big obvious thing will be the next step because people have tried to say to me you would be better using a chair than forcing yourself to walk…"(Margaret)

This extract suggests that Margaret finds it easier to cope with having to force herself to walk, than having to deal with the prospect that she needs a wheelchair. She seems surprised that other people are happy to use wheelchairs as she is so horrified by the idea. This is clearly something which she is struggling to come to terms with and highlights her resistance to accept this change in her identity- someone who is wheelchair dependent.

7.4 Discussion

This paper presented a lack of understanding and an ongoing sense of loss that this particular group of individuals with MS experienced. This lack of understanding encompassed a wide range of areas including participants, health providers and the general publics understanding of the illness. The experience of loss included a loss of personal control and a loss or change in identity.

7.4.1 MS patients experience of living with the illness

The study revealed three key themes; a lack of understanding, a loss of personal control and a loss or change in identity.

As discussed in Chapter 1 (see section 1.4) there is great controversy over what causes MS and to date, the nature and aetiology of MS remains unknown. Although previous research has suggested a number of factors, which could cause individuals to develop MS, no specific factor or factors have been identified as a definite cause. This lack of understanding about the cause MS was also reported by participants in the current study. The findings revealed that this not only led to confusion but also fear about the implications for family members if the condition is hereditary. There is a sense that it may be advantageous to believe that the condition is a result of bad luck as this will prevent feelings of blame being directed towards either the individual themselves or towards others. This is consistent with previous MS research (Eklund & MacDonald, 1991; Jopson & Moss-Morris, 2003) which found that attributing the condition to a psychological factor led to poorer adjustment whereas attributing the condition to an outside factor such as chance was beneficial.

This lack of understanding was also evident in the accounts by participants describing the physical experiences of their MS. The physical symptoms of the condition often led to feelings of confusion. MS is a condition characterised by a wide array of fluctuating symptoms, which can vary daily. The findings suggest that participants were often faced with sensations, which they found difficult to describe. This is likely to pose a problem for health professionals trying to treat the condition. Without a clear understanding of what the patient is experiencing, it can be difficult for health professionals to ascertain the best option for treating the symptoms. This highlights the importance of improving the patient's understanding of the physical symptomology of the condition.

Overall this lack of understanding reported by participants has important implications for their overall adjustment to MS. This lack of understanding is similar to the illness belief component illness coherence included in the Illness Perception Questionnaire-Revised (Moss-Morris et al, 2002) (see Chapter 2, section 2.6.7). Previous research (Jopson & Moss-Morris, 2003) investigating the role of illness coherence on adjustment to MS has found that individuals who believe they have a poor understanding of their condition experience lower psychosocial functioning and self-esteem and are more emotionally affected by the condition (see Chapter 3, section 3.2.1.3).

The findings of the study also revealed that participants felt that there was a limited understanding of the condition by the medical profession. Most notably was their lack of understanding of the patient's needs and well-being. This led to feelings of disbelief, frustration and anger. Their accounts highlight the importance of their encounters with health professionals on how well they adjust to the condition. The findings demonstrate the importance of increasing doctors understanding of the patients' needs, in order to facilitate not only better adjustment to the illness but also improved doctor-patient relationships. Participants also felt that there was limited understanding of the condition within the wider community. This led to feelings of frustration and embarrassment by participants when interacting with others. This was accounted for by the paucity of media coverage on the condition.

Overall, this lack of understanding reported by the participants was associated with poorer psychological adjustment to the condition. At present the cause of MS remains unknown, there is no one definitive test for diagnosing MS and a cure has not been developed. Consequently, there is limited opportunity for improving the understanding of the condition in relation to these aspects. However, the findings suggest that by improving health professionals understanding of the patient’s needs and promoting awareness of the condition within the general public, individuals with MS will adjust better.

Another key theme identified in the study was the loss of control characterised largely by a lack of personal control. At the heart of this was the participants’ inability to control their bodies. Difficulties with their mobility were particularly salient and lead to feelings of helplessness and distress. This loss of control was also associated with a loss of spontaneity as participants were forced to plan everything they did in advance. This led to a feeling that their life had become boring. In addition, to planning ahead participants also reported a number of other lifestyle changes they had made in order to help them control aspects of the condition. The role of control is a key component of the SRM (see Chapter 2, section 2.6 for a description of this model). Previous research applying the SRM to MS (Vaughan et al, 2003; Jopson and Moss Morris, 2002), suggests that individuals with MS who believe they have greater control over their illness, experience lower depression and higher self-esteem (see Chapter 3, section 3.2.1.3). These findings are therefore consistent with the results of the current study.

One surprising finding was that participants were reluctant to rely on physical aids as a means of controlling their mobility. These aids were associated with a stigma and relying on them was seen as a sign of defeat. One explanation for this resistance could be that participants did not want to see themselves as someone who is for example wheelchair dependent. This suggests that participants did not want to acknowledge themselves as an individual with a disability. This resistance could, therefore, reflect a reluctance to accept a change in their identity. This is linked to the final theme identified by this study - a loss or change of identity. Participants were no longer able to take part in activities which they previously associated with their sense of self. Their sense of identity, centred around being active. Furthermore, they no longer saw themselves as independent individuals. Their inability to control their bodies meant that many participants had become dependent on other people. This loss of control affected their sense of identity within their working lives, homes lives and also social lives.

Although all participants acknowledged a loss of identity, some of them were reluctant to accept a change in their new identity as someone with MS. As discussed previously they did not want to see themselves as someone who was wheelchair dependent. The failure to use physical aids was only part of this. The findings also highlighted that some participants still thought of themselves as fit and healthy even though they acknowledged that this was not their reality. Identity is one of the key illness belief components of the SRM (see Chapter 2, section 2.6 for a full description of the model). Previous research applying this model to MS, suggests that this reluctance by patients to identify with their condition may be beneficial to their psychological adjustment. Research applying the SRM to MS (Vaughan et al, 2003; Jopson and Moss Morris, 2002) found that individuals who have a strong illness identity experience greater psychological distress and physical impairment (see Chapter 3, section 3.2.1.3). This was supported by the results of the Study 1, which found that a strong illness identity was associated with greater physical disability and psychological distress concurrently and two months later. This suggests that it is beneficial for patients to not strongly identify with their condition. However, the current analysis suggests that individuals had experienced a loss in their identity as a result of being unable to be as active as they once were. This highlights the need to help individuals to redefine their sense of self so that it is not centred around activity. If patients were helped to define themselves by their principles and characteristics as opposed to their physical capabilities it would enable them to feel that the condition had not changed the person they are. Consequently, they would be less likely to experience of loss or change in identity.

The three key themes (a lack of understanding, a loss of personal control and a loss or change in identity) identified in this study are based on interviews with only 15 individuals living with MS. However, a second qualitative investigation was carried out, with a further 15 MS patients recruited from the Fife Physical Rehabilitation Service as part of Study 3. Although the results of this second qualitative investigation are not reported in the thesis the same themes emerged from the analysis suggesting that data saturation had been achieved.

7.4.2 Practical and clinical implications of the findings.

There are number of practical and clinical implications of the research. Firstly, it is essential to facilitate awareness of what it is like to live with MS in the wider community. A better understanding of what it means for the individual who lives with the condition, may reduce others misperceptions of MS. Furthermore, it is imperative to promote awareness amongst health providers diagnosing and treating MS of the patient’s needs. This study found that some of the participants had found the medical profession to be inconsiderate and unhelpful. Although some of the difficulties may be a result of the lack of understanding about the condition, according to the patients there was evidence that health providers were not taking patients’ well-being into consideration. A greater understanding and awareness of the patient's needs is, therefore, required by those working and treating individuals with the condition. This would reduce the feelings of anger, frustration and confusion reported by the participants.

The current analysis suggests that participants experienced a loss of their former identity, as a result of no longer being as physically active as they once were. This loss of identity was sometimes associated with a change in identity. Previous research has found that MS patients' who strongly identify with their condition experience greater psychological distress. Clinical interventions, therefore, need to focus on reducing patients beliefs about a loss or change in identity. The current analysis suggests that a participant's sense of self was defined by activity. They experienced a loss of identity because they were no longer physically as active. By helping patients change how they define themselves, health professionals could, therefore, reduce the psychological impact of the condition. Consequently, clinical interventions should aim to assist MS patients in defining themselves based on attributes such as their principles, which are not affected by the physical limitations of the condition. They could also help patients to identify symptoms, which are unrelated to MS, so they do not strongly identify with the condition. Furthermore, MS should be viewed as something which is separate to the patient. This should be reflected in the language used by health professionals discussing the condition. Referring to the condition as 'your MS', could have implications for adjustment, as it may result in patients defining their sense of self, based on the condition.

The loss of identity reported by participants was closely associated with a loss of control over their bodies. Interventions could, therefore, focus on assisting patients in developing a sense of control over their symptoms and the condition. One potential barrier identified in the current study for increasing patients control, was their reluctance to rely on physical aids. This could be a result of individuals not wanting to identify themselves as someone who is ‘disabled’. Reliance on these aids was seen as a sign that the condition had defeated them and that they no longer had control over their bodies. Interventions should be aimed at changing patient’s perception of these aids so they are viewed as a means for them to take back control of their physical bodies. Greater awareness and understanding within the wider community about disability may also facilitate this, by reducing some of the perceived stigma attached to using physical aids. This chapter concludes with a consideration of the limitations of the present study.

7.4.3 Limitations

With regard to the recruitment procedure, it is possible that a selection bias operated. The participants were all seen by the FVART, which is involved with rehabilitating patients with chronic conditions. Furthermore, participants were screened by the team members for emotional difficulties prior to being invited to participate. Consequently, the sample may have been better adjusted to their condition than those who were not invited or who were not seen by the FVART. Therefore, it is difficult to ascertain whether the lack of understanding and loss experienced in the present study is representative of a particular stage of the adjustment process or of a particular treatment area.

A further limitation of this study was that it did not employ an inter-rater test of agreement. Although an inductive approach was adopted to try and ensure the form of analysis adopted was data driven, the transcripts were only analysed by one researcher. It could therefore be argued that the findings reported in this chapter are based on the subjective judgements of the individual researcher and another researcher may have constructed different themes.

7.4.4 Summary

The aim of this study was to investigate the experience of living with MS from the patient’s perspective. Three key themes were identified ‘a lack of understanding’, ‘loss of control’ and a ‘loss or change in identity’. These themes were similar to three of the illness representations components identified as part of the SRM –illness coherence, personal control and illness identity. Overall the findings of the analysis provided additional support for the role of illness beliefs in determining how individuals adjust to MS. In Study 3 these relationships were investigated further using a longitudinal design. The final study, which is presented in the following chapter, assessed the role of patients’ illness beliefs on adjustment over an 8 month time period. This provides additional evidence for the role of illness perceptions in determining adjustment to MS.

Chapter 8: An Eight Month Prospective Study Investigating the Role of Illness Cognitions and Coping in Adjustment to Multiple Sclerosis.

8 Overview

This chapter discusses the third study, carried out as part of the current doctorate research. Based on the findings of Studies 1 and 2, this study was designed and implemented to further investigate the relationship between illness cognitions, coping and adjustment. The aim of this study was to test the relationships identified by the proposed model in Chapter 4 (see Figure 4-1) over an 8 month period.

The first part of this chapter describes the rational behind Study 3 and based on the research presented in the first three chapters and the findings from Study 1, a number of hypotheses were formed. The methodology employed is then discussed, expanding on the information given in Chapter 5. The findings of Study 3 are presented and these are discussed in relation to earlier research in this area and the findings of Studies 1 and 2.

8.1 Rationale

This section discusses the theory behind the design and implementation of Study 3. As highlighted in Chapter 3 (section 3.2.3.), to date, no published research has fully applied the Self Regulation Model to understanding adjustment to MS. Study 1 represented the first attempt to investigate the utility of the SRM, in predicting adjustment to MS prospectively. Based on the SRM framework a model, examining the relationship between illness representations, coping and adjustment to MS over a two month period was developed and tested (see Chapter 6, Figure 6-1). The results found support for the hypothesised relationships between these variables. Illness beliefs and coping strategies were also found to have a direct impact on adjustment to MS over time. The findings also provided support for the mediating role of coping, as proposed by the SRM. Overall, the findings suggested that the SRM is a useful framework for predicting successful adjustment to MS over time. However, one of the main limitations of Study 1 was the short follow up time period.

The aim of Study 1 was to test a range of psychological measures in adjustment to MS and based on these findings, design a second longitudinal study with a longer follow up time. In order to avoid contemporaneous contamination, participants were assessed at two time points. Study 1 was therefore designed as a 2 month follow up study. However, a limited number of relationships were identified in the longitudinal analysis, when time 1 was controlled for. It is likely that this was a result of the lack of significant change in the adjustment variables between time 1 and follow up. Study 3 therefore investigated the utility of the SRM in predicting successfully adjustment to MS over an 8 month time period.

In Study 1 illness beliefs were measured using the IPQ-Brief (Broadbent, 2007). Since Study 1 was designed to test a range of psychological measures it was felt that this short measure of illness beliefs would enable the assessment of illness beliefs along with a range of other measures at two time points. However, since it is a relatively new measure there is limited opportunity to directly compare the results with other research. Since illness beliefs were only assessed at one time point, Study 3 employed the IPQ-R, a widely recognised measure for assessing illness beliefs. Furthermore, this measure has been employed by previous MS research (Moss-Morris et al, 2006) and was found to reliably measure illness perceptions in this illness group.

In addition, to investigating the role of illness beliefs, the model proposed in Figure 6-1, extended the SRM framework to include dysfunctional attitudes and future thinking. Consistent with previous research by Shnek et al (1995) (see Chapter 3, section 3.8), the results of Study 1 found limited support for the role of dysfunctional attitudes in predicting adjustment to MS. Study 3 therefore did not assess the role of this variable any further.

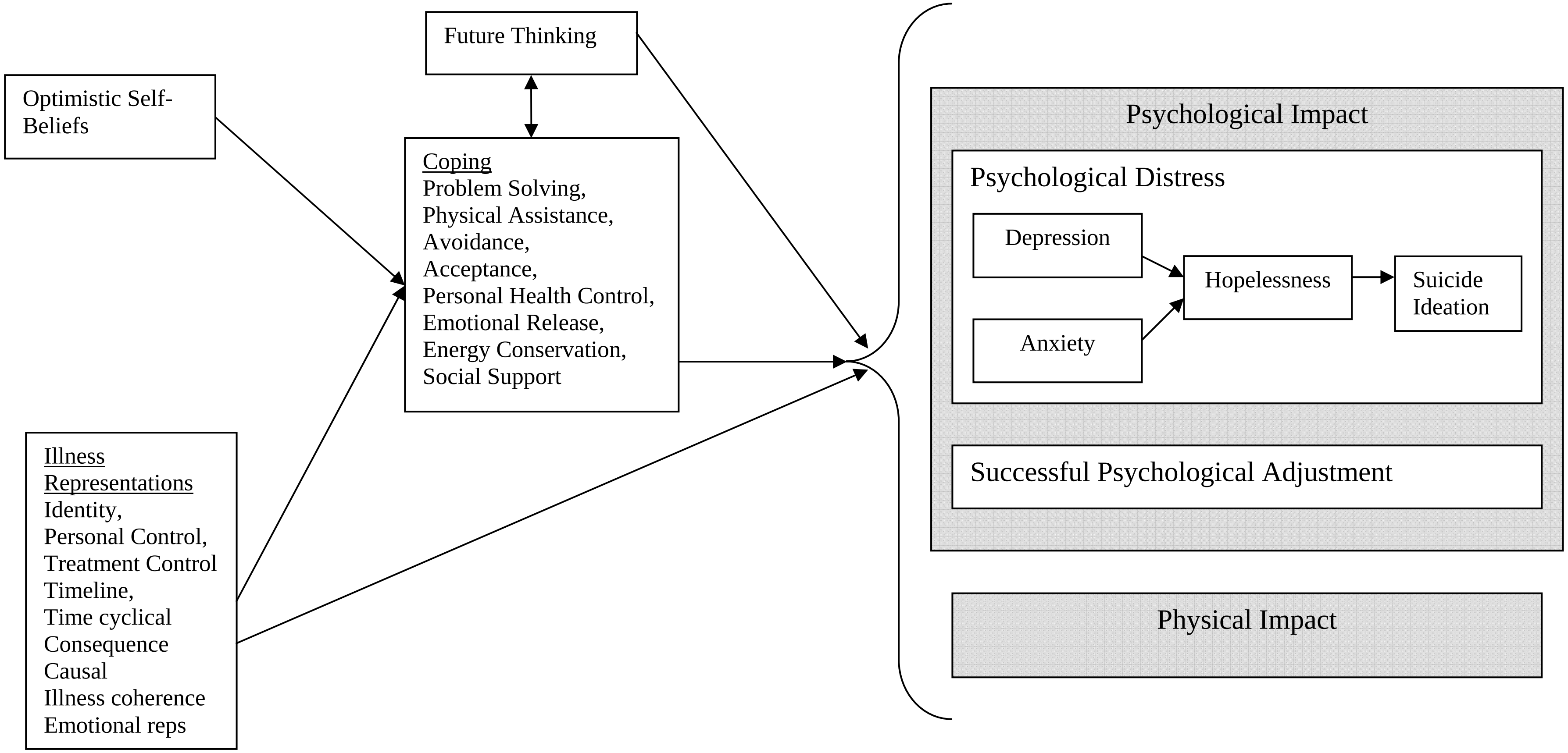
Study 1 also found limited evidence for the role of future thinking. However, previous research has suggested that future thinking plays an important role in predicting suicide ideation, which was not assessed in Study 1. Study 3 therefore included a measure of suicide ideation and further investigated the role of future thinking in MS. Furthermore, the results of the correlations examining the relationship between the future thinking components and adjustment to MS suggested that there was not a large enough sample size to have significant power. Study 3 therefore investigated these relationships further with a larger sample of MS patients.

Study 3 also included a measure of hopelessness, the construct that future thinking was derived from (see Chapter 2 section 2.11.2). Despite the high rates of suicide in MS (see Chapter 1, section 1.9.2.), to date no published research has investigated the relationship between hopelessness, depression and suicide ideation in this population. Study 3 therefore assessed the role of hopelessness in predicting suicide ideation in MS over an 8 month period.

Previous research applying the Social Cognitive Theory (see Chapter 2 section 2.3 for a full description of the model) to MS has highlighted the role of optimistic self-efficacy beliefs in successful adjustment to MS. Their findings suggest that maintaining an optimistic outlook enables MS patients to cope and adjust better to living with the condition (see Chapter 3, section 3.5.2). Using the SRM framework, Study 3 therefore investigated the role of optimistic self-efficacy beliefs in determining adjustment to MS.

The main aim of Study 3 was to investigate the relationship between illness representations, coping and adjustment to MS over 8 months, using the SRM framework. In addition, the current study also took into account the role of optimism and future thinking in predicting adjustment to MS. To date, no published research has investigated the relationship between these variables. Study 3 therefore represented the first attempt to investigate the relationship between these factors and to examine which psychological predictors (illness representations, future thinking, optimism, coping strategies) lead to successful adjustment in MS, and which lead to psychological distress. A schematic representation of the relationships, which were investigated in Study 3, is shown in Figure 8-1.

Figure 8-1 A schematic representation of the proposed relationships investigated in Study 3.



8.2 Hypotheses

Based on the findings of previous research, the following hypotheses have been developed for Study 3.

8.2.1 Hypothesis 1 (i) & (ii) - Illness representations correlations

(i) It was hypothesised that correlation analysis would indicate that illness representations are inter-related, with more negative beliefs related to each other.

(ii) It was hypothesised that correlation analysis would indicate that illness representations are related to optimism and future thinking, with more negative illness representations related to greater negative future thinking, less positive future thinking and less optimistic beliefs.

8.2.2 Hypothesis 2 (i), (ii) (iii) Self-regulation in MS

(i) It was hypothesised that correlation analysis would indicate that illness representations and coping are related, consistent with the relationships outlined in the SRM.

(ii) It was hypothesised that correlation analysis would indicate that coping strategies are related to adjustment at time 1, 2 and 3, consistent with the relationships outlined by the SRM.

(iii) It was hypothesised that correlation analysis would indicate that illness representations and adjustment to MS at time 1, 2 and 3 are related, with more negative beliefs related to poorer adjustment.

8.2.3 Hypothesis 3 (i), (ii) & (iii) - Optimism and future thinking correlations

(i) It was hypothesised that correlation analysis would indicate that optimism and future thinking are related, with greater optimism related to less negative and greater positive future thinking.

(ii) It was hypothesised that correlation analysis would indicate that optimism, coping and adjustment are related, with greater optimism related to more adaptive coping and better adjustment at time 1, 2 and 3.

(iii) It was hypothesised that correlation analysis would indicate that future thinking, coping and adjustment are statistically related, with greater negative and less positive future thinking related to more maladaptive coping and poorer adjustment at time 1, 2 and 3.

8.2.4 Hypothesis 4 (i) & (ii) - Concurrent and prospective investigation of illness representations

(i) It was hypothesised that illness representations and coping would be predictive of adjustment at time 1, 2 and 3, in line with the relationships outlined in the SRM.

(ii) It was hypothesised that coping would mediate the relationship between illness representations and adjustment to MS at time 1, 2 and 3.

8.2.5 Hypothesis 5 (i) & (ii) - Concurrent and prospective investigation of optimism

(i) It was hypothesised that optimism and coping would be predictive of adjustment at time 1, 2 and 3, with greater optimism and adaptive coping leading to better adjustment.

(ii) It was hypothesised that coping would mediate the relationship between optimism and adjustment to MS at time 1, 2 and 3.

8.2.6 Hypothesis 6 (i) & (ii) - Concurrent and prospective investigation of future thinking.

(i) It was hypothesised that future thinking components and coping would be predictive of adjustment at time 1, 2 and 3.

(ii) It was hypothesised that coping would mediate the relationship between future thinking and adjustment to MS at time 1, 2 and 3.

8.2.7 Hypothesis 7 (i) – The role of hopelessness

(i) It was hypothesised that hopelessness would mediate the relationship between anxiety/depression and suicide ideation in MS at time 1, 2 and 3.

8.3 Method

8.3.1 Design

Study 3 is a prospective study, in which MS patients (N = 150) completed a range of psychological measures at three time points. MS patients' were recruited from the Fife Physical Rehabilitation Service (FPRS), Forth Valley Area Rehabilitation Team (FVART) (details of these services are given in Chapter 5 section 5.4.1) and the Southern General Hospital in Glasgow. Those who volunteered completed a number of recognised psychological measures, which included future thinking, illness perceptions, optimism, coping, depression/anxiety, physical/psychological impact, hopelessness and suicide ideation. They were then asked if they would be willing to take part in two short telephone interviews at 4 and 8 months. Those who agreed were telephoned and asked questions about how they were adjusting to MS. Full details of the procedure followed for this study are given in Chapter 5 section 5.4.

8.3.2 Participants

8.3.2.1 Sample size

A G-Power analysis was carried out to determine the sample size, which would be required at follow-up for the results to be statistically meaningful when using a Multiple Regression. In addition to conducting the formal G-Power analysis, the sample size was also based on the follow up rate of Study 1 which had a 13% attrition rate at 2 months. Since the current study employed a 8 month follow up, the attrition rate was estimated conservatively at 20%.

A medium effect size of 0.15 was adopted, consistent with Cohen (1992). As a result, setting alpha at 0.05, power 0.8 with 8 predictors, the power calculation yielded a sample of 120. This study will therefore use a sample size of 150, assuming a 20% attrition rate that would yield a sample of 120 at follow up. Although this is greater than sample yielded by the power calculation we aimed to use a higher number in case of unforseen difficulties.

In total 150 MS patients took part in the study. To recruit participants, information about the study was sent to 60 MS patients seen by FPRS, 30 MS patients treated by the FVART and 250 treated by the Southern General hospital in Glasgow. Fifty six individuals from the FPRS, 21 from the FVART and 79 from the Southern General Hospital in Glasgow met these criteria and either telephoned or emailed agreeing to take part, yielding 93%, 70% and 32% response rates, respectively. During the course of this study, six participants recruited from Southern General Hospital dropped out. The remaining 150 took part in an interview at time 1, either in their home or at the University of Stirling.

8.3.2.2 Demographic and illness characteristics

The final sample comprised of 42 (28%) males and 108 (72%) females. The age of participants ranged from 20 to 80 years old, with a mean age of 46.18 years (SD=11.1). The onset of participants’ MS symptoms varied between 1 and 47 years and the mean length of time since onset was 14.03 (SD=10.62) years. The time since participants had received their diagnosis varied between 6 months and 46 years and the mean time since they had received their diagnosis was 9.48 (SD= 9.67) years. The results showed that 100 (66.7%) of participants were married, 27 (18%) were single, 12 (8%) were divorced, 8 (5.3%) were cohabiting, 2 (1.3) were separated and 1 (.7%) was widowed. For those MS patients recruited from the Southern General Hospital, due to data protection, information could only be accessed for those who volunteered and gave consent to take part in the research. Consequently, those who volunteered to be involved in the research could not be compared to those who declined. However, since those invited to take part from the FPRS and FVART had previously taken part in Study 1, those who volunteered from these hospitals could be compared with those who declined. Those who volunteered to take part in Study 3 did not differ significantly in terms of age, gender, marital status, time since diagnosis, time since onset or MS type from those who declined.

4 and 8 months later participants were asked to take part in follow up telephone interviews. 128 agreed to take part in the follow up at 4 months and 117 agreed at 8 months, yielding 85% and 78% response rates respectively. Those who took part at time 2 and 3 did not differ significantly from those who declined to take part in terms of age, gender, marital status, time since diagnosis, time since onset MS type, or on any of the time 1 variables.

8.3.3 Measures

8.3.3.1 Documentation and cognitive assessment.

The documentation used in this study included an information sheet, invitation letter, consent form and a questionnaire collecting patients' demographic and illness details. These measures are discussed in more detail in Chapter 5 (see section 5.3.1) and set out in the Appendices. Prior to the initial interview the *Mini-Mental State Examination (MMSE: Folstein et al, 1975)* was used to evaluate cognitive function (A full description of the MMSE is given in Chapter 5 (see section 5.3.1)

8.3.3.2 Predictor measures

The Future Thinking Task (FTT: MacLeod et al, 1997) was used to measure patients' thoughts about the future. Before administration of the FTT, all participants completed the standard verbal fluency task (Lezak, 1976) – to take into consideration participants' general cognitive fluency. A correlational analysis revealed that participants verbal fluency was not statistically related to any of the outcome variables. A full description of the scale is given in Chapter 5 (see section 5.3.2.1).

The Illness Perception Questionnaire--Revised (IPQ-R: Moss-Morris et al., 2002) was used to measure the individual's illness perceptions (see Appendix 4). The IPQ-R is a self-report measure of illness beliefs, which assess patients' cognitive and emotional representations of their condition. A full description of the scale is given in Chapter 5 Methods (see section 5.3.2.2). The internal reliability scores (Cronbach's alpha) for the subscales of the IPQ-R are shown in table 8-1. The Cronbach's α for the six-item timeline subscale, the five-item treatment control subscale and the four-item illness coherence subscale were $\alpha = 0.85$, $\alpha = 0.72$ and $\alpha = 0.86$. There was also good internal reliability for the four-item time cyclical subscale (α =.80) and for the six-item emotional representations (α =.89). However, for the five-item identity (α = 0.67), five-item consequences (α = 0.69) and five-item personal control (α = 0.69) subscale, the Cronbach alpha's were all low.

Table 8-1 Cronbach alphas for the IPQ-R.

Component	α
Identity	.67
Timeline	.85
Consequences	.69
Personal Control	.69
Treatment Control	.72
Illness Coherence	.86
Time Cyclical	.80
Emotional Representations	.89

Life Orientation Test –Revised (LOT-R: Scheier, Carver and Bridges, 1994) was used to measure participants levels of optimism (see Appendix 6). A full description of the scale is given in Chapter 5 Methods (see section 5.3.2.4).The Cronbach alpha for the ten-item LOT-R in this study was very low ((α = 0.38).

The Coping with Multiple Sclerosis (CMSS: Pakenham, 2001) was used to measure how participants' cope with their condition (see Appendix 7). The CMSS is a self-report measure of coping specific to MS requiring individuals to identify their main MS-related problem and indicate on a 5-point Likert scale how often they have used each of the 43 coping strategies. A full description of the scale is given in Chapter 5 (see section 5.3.2.5) .The Cronbach alpha for the CMSS in this study was 0.75. The internal reliability scores (Cronbach's alpha) for the subscales of the CMSS are shown in table 8-2. The Cronbach's α for the five-item problem solving subscale ($\alpha = 0.57$) the four-item personal health control subscale ($\alpha = 0.46$) and the six-item acceptance subscale ($\alpha = 0.5$) were all very low. The Cronbach alpha's were also low for the four-item avoidance subscale ($\alpha = 0.61$) and the five-item physical assistance subscales ($\alpha = 0.65$). For the six-item emotional release subscale, two-item social support subscale and the four-item energy conservation subscale the Cronbach alpha's were $\alpha = 0.75$, $\alpha = 0.77$ and $\alpha = 0.76$, respectively.

Table 8-2 Cronbach alphas for the CMSS.

Component	α
Problem Solving	.57
Physical Assistance	.65
Emotional Release	.75
Avoidance	.61
Personal Health Control	.46
Acceptance	.50
Energy Conservation	.76
Social Support	.77

8.3.3.3 Outcome measures

The Multiple Sclerosis Impact Scale (MSIS-29: Hobart et al, 2001) was used to measure the physical and psychological impact of MS (see Appendix 9). In the present study the Cronbach's α for this scale was 0.95 at time 1, 0.97 at time 2 and 0.91 at time 3.

The MSIS is a disease specific, self-report measure which contains 29 items (20 items for physical impact and 9 for psychological impact). Participants are asked their views about the impact of their MS on their day-to-day life during the past two weeks on a 5-point Likert scale (1 = not at all and 5 = extremely). A full description of the MSIS is given in Chapter 5 (see section 5.3.3.2). The physical impact scale had good internal reliability at time 1 (α = 0.95), time 2 (α = 0.92) and time 3 (α = 0.96). The psychological impact also had good internal reliability at time 1 (α = 0.90), time 2 (α = 0.96) and time 3 (α = 0.91).

Hospital Anxiety and Depression Scale (HADS: Zigmond and Snaith, 1983) was used to measure symptoms of depression and anxiety (see Appendix 8). The HADS scale is a self-rating questionnaire, which contains a fourteen items (seven for depression and seven for anxiety). The two subscales are rated depending on the extent they have been experienced over the past week. A full description of the HADS is given in Chapter 5 (see section 5.3.3.1).The anxiety subscale had good internal reliability at time 1 (α =87), time 2 (α = 0.82) and at time 3 (α = 0.85) so did the depression subscale at time 1 (α = 0.80), time 2 (α = 0.74) and at time 3 (α = 0.79).

Beck Hopelessness Scale (BHS: Beck et al., 1979) was used to measure participants' levels of hopelessness. The BHS is a 20-item measure of patients' negative expectations regarding the future (see Appendix 10). A full description of the BHS is given in Chapter 5 (see section 5.3.3.3). In the present study this scale had good internal reliability. The Cronbach alpha's for this scale were 0.86 at time 1, 0.90 at time 2 and 0.89 at time 3. Suicide Ideation subscale of the Suicide Probability Scale (Cull and Gill, 1988) was used to measure participants' suicide ideation (see Appendix 11). A full description of the SPS is given in Chapter 5 (see section 5.3.3.4). This scale had good internal reliability at time 1 (α =84), time 2 (α = 0.92) and at time 3 (α = 0.88) in the present study.

8.4 Results

This section discusses the results of Study 3. Details of the methods used and a justification for their use are outlined as appropriate throughout this chapter. However, as a result of the volume of the analysis, a brief summary of how the analyses are grouped and presented follows.

8.4.1 Analytical strategy

As with Study 1 a variety of research methods are employed. Initially the correlations between the different variables are carried out. These explore the statistical relationships between the predictor variables illness representations, optimism, future thinking and coping. They also investigate the utility of the model proposed in Figure 8-1 by examining the relationships between the predictor variables and adjustment at time 1, 2 and 3. The correlations for each of the predictors variables are presented separately in the following sequence; illness representations, coping, optimism, future thinking.

Following this a series of regressions are carried out to test the utility of the model proposed in Figure 8-1 in predicting adjustment to MS. These determine whether the predictor variables at time 1 could predict adjustment to MS at time 1, 2 and 3. In order to test the proposed model the relationships of illness representations, optimism and future thinking with coping and adjustment at time 1, 2 and 3 are presented separately. In addition, to these regression analyses, formal mediation analysis is carried out on variables showing possible mediation effects. These determine whether coping mediated the relationship between the other predictor variables and the outcome variables.

8.4.2 Illness characteristics

The illness characteristics of the sample are detailed in table 8-3. The study included individuals with all types of MS. The majority of participants suffered from the relapsing-remitting form, in total 67 (44.7%) had this type of MS. Twenty three (15.3%) had primary progressive, 43 (28.7%) had secondary progressive and 8 (5.3%) had the benign form, there was no information about MS type for 9 (6%) of the participants. The rates were similar to those from the general MS population (see Chapter 1, section 1.5). One hundred and forty six participants had taken some form of steroids since they were diagnosed with MS. 31 (20.7%) participants had had steroids intravenously injected (IV) only, 33 (22%) had only taken them orally and 40 (26.7%) had taken steroids both intravenously and orally. There was no information about steroid use from the remaining 4 (2.7%). 114 (76%) of participants had no family history of MS. There was no reliable information available regarding the treatments participants were using. Although information was gathered from both the medical case notes and from the participants themselves, there was inconsistency in terms of which treatments they were currently taking, how long they had been taking them for and which drugs they had taken previously.

Table 8-3 Illness characteristics of sample

Variable		Number (Percentage)
Current state of MS (%)	Benign	8 (5.3%)
	Relapsing Remitting	67 (44.7%)
	Secondary - Progressive	43(28.7%)
	Primary - progressive	23 (15.3%)
Steroid use	None	42 (28 %)
	IV	31 (20.7%)
	Oral	33 (22%)
	Both IV and Oral	40 (26.7%)
Relative with MS	None	114 (76%)
	Mother	6 (4%)
	Father	2 (0.3%)
	Sister	4 (2.7%)
	Daughter	2 (1.3%)
	Other	14 (9.3%)
		Number (Standard Deviation)
Mean time since	onset of symptoms	14.03 (SD=10.62) years
	diagnosis	9.48 (SD=9.67) years

IV = Steroids were intravenously injected; Oral = Steroids were taken orally

8.4.3 The nature of illness representations, optimism, future thinking, coping and adjustment.

The mean scores and standard deviations for each of the illness representations components, optimism, coping strategies, future thinking components and adjustment variables were calculated to provide a clearer understanding of these variables. Categorical analyses were also carried out to investigate participants' beliefs about what caused their MS and what their main MS-related problem had been in the last month.

8.4.3.1 The nature of illness representations, optimism and future thinking.

Mean scores were calculated for each of the IPQ-R components and are shown in table 8-6. For optimism and future thinking the means scores are shown in table 8-11. The mean score for optimism was 20.83 (SD=5.11). Since the highest score for the LOT-R scale is 50, the mean score suggests that participants were not that optimistic. The mean score for the total positive future thoughts (M= 10.03, SD=1.86) was higher than the total number of negative future thought (M=5.44, SD=3.48) suggesting they felt more positive about the future than negative.

The causal component for the IPQ-R was using categorical analysis. Participants were asked to identify three main factors they believed caused their illness. From their responses the primary cause identified by each participant was grouped into the categories given in table 8-4.

Table 8-4 The number and percentage of MS patients identifying different causal factors.

Cause	Number (Percentage) at Time 1
Unknown	9 (6.0%)
Stress	31 (20.7%)
Hereditary	19 (12.7%)
Germ	5 (3.3%)
Diet	20 (13.3%)
Chance	2 (1.3%)
Poor Medical Care	2 (1.3%)
Pollution	6 (4.0%)
Family Problems	1 (0.7%)
Overwork	9 (6.0%)
Emotional State	1 (1.7%)
Alcohol	1 (1.7%)
Smoking	1 (1.7%)
Accident	7 (4.7%)
Altered Immunity	13 (8.7%)
Geographic Location	3 (2.0%)
Childbirth	1 (1.7%)

In accordance with the IPQ-R instructions (Moss-Morris et al., 2002), the items of the causal subscale were also subjected to a principal components analysis with varimax rotation. Based on the findings of Jopson and Moss-Morris (2003) which identified three causal factors the analysis was carried out to identify three causal factors. The factor loadings of the individuals items for the causal dimensions in the current study were labelled psychological, lifestyle and physiological, are presented in table 8-5.

Table 8-5 The factor loadings of the individual items for the causal dimensions

	Psychological causes	Lifestyle causes	Physiological causes
Stress or worry	.71	-.12	.11
Hereditary	.02	.09	.45
Germ or virus	.14	-.16	.74
Diet or eating habits	.18	.33	.59
Chance or bad luck	-.041	.39	-.19
Poor medical care in the past	.11	.60	.46
Pollution	.30	.10	.03
Own behaviour	.73	.19	.15
Mental attitude	.74	.24	-.01
Family problems	.63	.34	-.03
Overwork	.73	.08	.22
Emotional state	.81	.12	.09
Ageing	.49	.57	.09
Alcohol	.28	.68	.07
Smoking	.28	.71	.10
Accident or injury	.07	.57	.28
Personality	.45	.44	.21
Altered immunity	.06	.06	.63

8.4.3.2 Coping strategies

The mean scores were calculated for each of the coping strategy categories. The mean scores for problem solving (M= 2.63, SD= 0.66), acceptance (M=2.64, SD=0.60), avoidance (M=2.23, SD=0.85) and energy conservation (M=2.50, 0.88) were higher than the other coping strategies.

Prior to completing the coping measure participants were asked to identify their main MS-related problem, in other words what it is about their MS that has bothered them the most in the past month. Participants identified a wide array of MS related problem. The most common problems (experienced by four of more individuals) are reported in table 8-

6. The majority of participants (32%) identified mobility issues as their main difficulty then fatigue (17.3%) followed by bladder/bowel dysfunctions (9.3%).

Table 8-6 Main MS-related problem

Main MS-related problem	Number (Percentage)
Mobility	48 (32%)
Fatigue	26 (17.3%)
Bladder/Bowel Problems	14 (9.3%)
Pain	11 (7.3%)
Employment/Housing Difficulties	5 (3.3%)
Tremor/Spasm	9 (6.0%)
Loss of independence	4 (2.7%)
Emotional difficulties	7 (4.2%)
Unpredictability of MS	6 (4.0%)

8.4.3.3 Adjustment variables.

The mean depression scores were 6.42 (SD=4.03) at time 1, 6.29 (SD= 3.74) at time 2 and 6.20 (SD = 4.07) at time 3. The mean anxiety scores were slightly higher at 7.51 (SD=4.72) at time 1, 7.25 (SD= 4.73) at time 2 and 6.64 (SD=4.43) at time 3. These scores suggest that the majority of patients experienced normal levels of depression symptoms and their levels of anxiety were borderline between normal and mild.

To investigate the levels of depression and anxiety further, the number of participants at time 1 which fell into the different categories (normal, mild, moderate and severe) were examined. The results showed that 103 (68.7%) of patients experienced a ‘normal’ level of depressive symptoms whereas only 82 (54.7%) had a level of anxiety within the ‘normal’ 0-7 range. A greater number of patients were found to fall in the ‘mild’ 8-10 range of anxiety compared those falling into the ‘mild’ range for depression, 35 (23.3%) and 24 (16%), respectively. Similar numbers of patients experienced ‘moderate’ levels of depression to those experiencing ‘moderate’ levels of anxiety, 24 (16%) and 22

(14.7%), respectively. However, while only 1 patient experienced severe depression, 9 (6.0%) patients suffered from severe anxiety.

8.4.4 Correlations investigating relationships between variables

In order to investigate hypotheses 1, 2 and 3 regarding the relationships between the various subscales of the measures being used, initial exploratory correlation analyses were conducted between the IPQ-R subscales, LOT-R, FTT components, CMSS, MSIS-29, HADS, SPS and the BHS. It must be remembered when interpretating the correlations that high scores on the adjustment variables indicate poorer adjustment levels.

8.4.5 Hypothesis 1 - Illness representation correlations and t-tests.

Hypothesis 1 (i) postulated that illness representations would be inter-related with one another. As shown in table 8-7, the results provide support for hypothesis 1(i) showing that more negative illness beliefs are related to each other. In addition, they were also negatively related to more positively beliefs. For example, a belief in the serious consequences was negatively related to treatment control (r = -.18, p<.05) and positively related to emotional representations (r =.34, p<.01) and identity (r = .19, p<.05). Furthermore the results suggest that positive illness beliefs are positively related to one another. For example illness coherence was positively related to personal control (r = .38, p<.05) and negatively related to emotional representations (r =-.33, p<.01) and identity (r = -.17, p<.05).

It was also hypothesised (1ii) that illness representations would be correlated with optimism and future thinking. As shown in table 8-8 the negative illness representations time cyclical, consequences, psychological cause and emotional representation components were all negatively related to optimism and positively related to negative future thoughts.

The timeline was also negatively related to total negative future thoughts (r =-.24, p<.01). These findings provide support for hypothesis 1 (ii). The results for personal control and identity provide inconsistent findings, with these components being found to positively correlate with both negative and positive future thinking components.

8.4.6 Hypothesis 2 - Self-Regulation in MS

Hypothesis 2 (i) stated that illness representations and coping would be correlated, in line with the relationships outlined in the SRM. As shown in table 8-9 the consequences components and the emotional representations components correlated with the most coping strategies. Believing MS has serious consequences was positively related to physical assistance (r =.36, p<.01), personal health control (r =.160, p<.05), energy conservation (r =.35, p<.01), seeking social support (r =.18, p<.05) and negatively related to avoidance (r =-.18, p<.05) and acceptance (r =-.18, p<.05). Emotional representations were positively related to emotional release (r =.18, p<.05), personal health control (r =.17, p<.05), energy conservation (r =.17, p<.05), seeking social support, (r =.21, p<.01) and negatively related to acceptance, (r =-.46, p<.01).

Hypothesis 2 (ii) stated that coping would be correlated to adjustment at time 1, 2 and 3, in line with the relationships outlined in the SRM. As shown in table 8-10 physical assistance and personal health control were positively related to the majority of adjustment variables at time 1, 2, and 3. On the other hand, acceptance was negatively related to all outcome variables at all three time points (except MS physical impact time 2 and overall MS impact at time 3). This suggests that physical assistance and personal health control may be maladaptive whereas acceptance is beneficial. The findings therefore provide some support for the hypothesis 2 (i) and 2 (ii).

It was also hypothesised (2iii) that illness representations would be correlated to adjustment at time 1, 2 and 3. As shown in table 8-11. The consequences, emotional representations, identity and time cyclical components were all positively related to almost all of the outcome variables at time 1, 2 and 3 (except time cyclical and MS physical impact at time 2 and identity and suicide ideation at time 2). Furthermore, a belief that MS was caused by a psychological factor was positively related to many of the adjustment variables. The more positive illness beliefs personal control, treatment control and illness coherence were negatively related to many of the adjustment variables at time 1, 2 and 3. Overall, the findings provided support for hypothesis 2(iii).

Table 8-7 Correlations among different dimensions of illness representations (N= 150).

	Timeline	Time Cyclical	Conseq	Personal Control	Treatment Control	Illness Coherence	Emotional Reps	Identity	Psychological Cause	Lifestyle Cause	Physiological Cause
Timeline		-.158*	.312**	-.386**	-.437**	.027	.096	.012	-.043	.014	-.006
Time Cyclical			.172*	.167*	.178*	-.271**	.327**	.435**	.143*	.221**	.153*
Consequence				-.100	-.179*	-.038	.342**	.187*	.089	.103	.001
Personal Control					.432**	.138*	-.123	.078	.158*	.002	.073
Treatment Control						.091	-.101	.101	.070*	-.079	-.004
Illness Coherence							-.329**	-.167*	-.201**	-.195	-.026
Emotional Representations								.402**	.262***	.144*	.180*
Identity									.256***	.056	.234**
Psychological Cause										.000	.000
Physical/ Lifestyle Cause											.000
Mean	26.54	13.78	23.89	18.91	13.71	15.40	19.31	6.37			
SD	3.52	3.41	3.66	4.20	3.54	4.42	5.46	2.41			

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

Table 8-8 Correlations of illness representations with optimism and future thinking (N=150)

	Timeline	Time Cyclical	Consequence	Personal Control	Treatment Control	Illness Coherence	Emotional Reps	Identity	Psychological Cause	Lifestyle Cause	Physiological Cause
Optimism	-.046	-.152**	-.295**	.091	.081	.107	-.347**	-.117	-.256***	-.169*	.033
Positive Week	-.011	-.067	-.081	.073	.077	-.108	.047	.149*	.138*	-.132	.067
Positive Year	.103	-.047	-.005	.012	.008	-.032	.124	.123	.116	.005	.119
Positive 5 -10 year	-.016	.026	-.043	.140*	.100	-.007	.102	.174*	.140*	-.068	.099
Positive Total	.032	-.037	-.051	.085	.071	-060	.106	.173*	.154	-.076	.111
Negative Week	.047	.121	.143*	.241**	-.024	-.065	.234**	.181*	.283***	-.076	.220***
Negative Year	.122	.109	.268*	.037	-.111	-.029	.294**	.226**	.231**	-.017	.197**
Negative 5 -10 Year	-.092	.165*	-.001	.168*	.040	-.005	.183*	.037	.127	.014	.128
Negative Total	-.235**	.168*	.172*	.193**	-.038	-.043	.300**	.187*	.273***	-.033	.232**

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

Table 8-9 Correlations among illness representations and coping (N=150)

	Timeline	Time cyclical	Consequence	Personal Control	Treatment Control	Illness Coherence	Emotional Representations	Identity	Psychological Cause	Lifestyle Cause	Physiological Cause
Problem Solving	.021	-.013	.071	.215**	.008	-.053	.119	.105	.001	.026	.095
Physical Assistance	.129	.040	.386**	-.187*	-.169*	-.020	.064	.052	-.053	.134	.021
Emotional Release	-.049	-.049	.103	.142*	.045	.107	.180*	.117	.091	.064	.118
Avoidance	-.079	.028	-.177*	.050	.005	-.180*	.058	.006	.015	-.059	-.101
Personal Health Control	-.175*	.118	.160*	.078	.065	.045	.173*	.168*	.023	.090	.167*
Acceptance	-.026	-.248**	-.182*	.189*	.056	.177*	-.459**	-.150*	-.209**	-.022	-.158*
Energy Conservation	.164*	.189*	.351**	-.026	-.072	-.041	.170*	.162*	.121	.061	-.068
Social Support	-.014	.166*	.179*	.032	.052	-.058	.213**	.184*	.127	-.013	.186

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

Table 8-10 Correlations among coping and adjustment at time 1(N=150), time 2 (N= 128) and time 3 (N=117)

	Problem Solving	Physical Assistance	Emotional Release	Avoidance	Personal Health Control	Acceptance	Energy Conservation	Social Support
Overall MS Impact Time 1	.100	.534***	.129	-.041	.313***	-.333***	.215**	.260***
Physical Impact Time 1	.116	.601***	.111	-.070	.311***	-.246***	.208**	.240**
Psychological Impact Time 1	.037	.239**	.136*	.035	.232**	-.438***	.171*	.233**
Anxiety Time 1	-.025	.082	.133	.052	.144*	-.398***	.007	.168*
Depression Time 1	-.034	.265***	.008	-.003	.157*	-.379***	.175*	.212**
Hopelessness Time 1	-.206**	.221**	-.039	-.057	.017	-.344***	.036	-.005
Suicide Ideation Time 1	-.062	.065	-.091	.202**	.079	-.277***	-.074	-.057
Overall MS Impact Time 2	.124	.518***	.142	-.012	.351***	-.230**	.150*	.176*
Psychological Impact Time 2	.047	.322***	.084	.023	.306***	-.403***	.107	.190*
Physical Impact Time 2	.146*	.556***	.137	-.026	.336***	-.128	.154*	.152*
Depression Time 2	-.021	.210**	.020	-.004	.156*	-.360***	.083	.119
Anxiety Time 2	.010	.036	.092	.030	.208**	-.433***	.034	.146
Hopelessness Time 2	-.178*	.269***	-.028	.028	.122	-.448***	.077	.134
Suicide Ideation Time 2	-.075	.185*	-.082	-.020	-.053	-.353***	-.058	-.007
Overall MS Impact Time 3	.110	.445***	-.076	-.003	.192*	-.147	.081	.056
Psychological Impact Time 3	.049	.293***	-.011	.012	.11*	.261**	.014	.058
Physical Impact Time 3	.125	.468***	-.097	.009	.183*	-.351***	.103	.049
Depression Time 3	-.081	.279***	-.019	-.070	.096	-.289***	.045	.061
Anxiety Time 3	-.006	-.011	.083	.029	.094	-.360***	.060	.032
Hopelessness Time 3	-.182*	.229**	-.061	-.079	.036	-.378***	.060	.032
Suicide Ideation Time 3	-.086	.178*	-.071	-.017	.033	-.351***	-.001	-.022

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

Table 8-11 Correlations among illness representations and adjustment at time 1(N=150), time 2 (N= 128) and time 3 (N= 117)

	Timeline	Time cyclical	Consequ	Personal Control	Treat. Control	Illness Cohe	Emotion Reps.	Identity	Psychol Cause	Lifestyle Cause	Physiol Cause
Overall MS Impact Time 1	.154*	.317**	.505**	-.164*	-.146*	-.177*	.480**	.381**	.115	.181*	.139*
Physical Impact Time 1	.180*	.219**	.476**	-.203**	-.165*	-.129	.353**	.298**	.025	.177*	.127
Psychological Impact Time 1	.054	.450**	.432**	-.033	-.062	-.236**	.635**	.464**	.288***	.141*	.126
Anxiety Time 1	.076	.345**	.370**	-.080	-.097	-.292**	.648**	.356**	.266***	.150	.183
Depression Time 1	.038	.332**	.417**	-.064	-.075	-.246**	.450**	.273**	.275***	.157*	.140*
Hopelessness Time 1	.108	.246**	.328**	-.181*	-.265**	-.170*	.413**	.181*	.183*	.198**	.023
Suicide Ideation Time 1	.005	.237**	.161*	-.023	-.107	-.099	.323**	.198**	.183*	.097	.085
Overall MS Impact Time 2	.156*	.210**	.466**	-.107	-.131	-.105	.362**	.327**	.141	.181	.017
Psychological Impact Time 2	.082	.321**	.375**	-.004	-.051	-.183*	.553**	.421**	.272***	.165*	.076
Physical Impact Time 2	.174*	.137	.461**	-.143	-.155*	-.059	.237**	.251**	.067	.170*	-.011
Depression Time 2	.118	.252**	.394**	-.053	-.071	-.033	.341**	.243**	.151	.139	.050
Anxiety Time 2	.140	.313**	.230**	-.050	-.045	-.167*	.599**	.401**	.298***	.118	.135
Hopelessness Time 2	.137	.227**	.365**	-.235**	-.176*	-.129	.425**	.242**	.229**	.181*	.050
Suicide Ideation Time 2	.231*	.249*	.241*	-.002	-.126	-.104	.429**	.120	.090	.100	.065
Overall MS Impact Time 3	.164*	.244**	.416***	-.129	-.107	-.143	.342***	.285***	.141	.181	.017
Psychological Impact Time 3	.071	.320***	.374***	-.061	-.089	-.234**	.494***	.367***	.111	.144	.020
Physical Impact Time 3	.189*	.159*	.393***	-.146	-.105	-.089	-.234**	.221**	.242**	.146	.107
Depression Time 3	.033	.251**	.434***	-.060	-.131	-.065	-.387***	.263**	.042	.129	-.020
Anxiety Time 3	.121	.288***	.291***	-.025	-.095	-.212*	.560***	.280***	.360***	.128	.222**
Hopelessness Time 3	.126	.231**	.381***	-.043	-.178*	-.190*	.361***	.174*	.187***	.223**	.093
Suicide Ideation Time 3	.118	.277***	.189*	-.012	-.104	-.043	.375***	.216**	.162*	217**	.112

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

8.4.7 Hypothesis 3 – Optimism and future thinking correlations.

It was hypothesised (3i) that optimism and future thinking would be correlated to each other. As shown in table 8-12 optimism was positively related to positive future thoughts generated for the next week (r =.32, p<.01), year (r =.15, p<.05), 5 to10 years (r =.27, p<.001) and total positive thoughts (r =.29, p<.01). This provides some support for hypothesis 3 (i). However, no statistical relationships were identified between optimism and negative future thinking.

It was also hypothesised (3ii) that optimism, coping and adjustment would be correlated. As shown in table 8-13 optimism was positively related to problem solving (r = .21, p<.01), acceptance (r = 34, p<.01) and was negatively related to physical assistance (r = -.19, p<.01) and energy conservation (r = -.16, p<.05). Furthermore, as shown in table 8-14 optimism was negatively related to all outcome variables at time 1, 2 and 3. The results therefore support hypothesis 3(ii).

Finally, it was hypothesised (3iii) that future thinking, coping and adjustment would be correlated. As shown in table 8-13 all the positive future thinking components were positively related to problem solving coping and negatively related to asking for physical assistance. In addition, negative future thinking was negatively related to acceptance. Positive future thinking was also negatively related to the majority of adjustment variables at all 3 time points, while negative future thinking was positively related to them as shown in table 8-14. The results also therefore provide support for hypothesis 3(iii).

Table 8-12 Correlations among optimism and future thoughts (N=150)

	Optimism	Positive Week	Positive Year	Positive 5-10 Year	Positive Total	Negative Week	Negative Year	Negative 5-10 Year	Negative Total
Optimism		.318**	.150*	.266**	.286**	-.022	-.054	.027	-.020
Positive Week			.585**	.603**	.864**	.250**	.236**	.266**	.319*
Positive Year				.574**	.852**	.207**	.233**	.232**	.284**
Positive 5 -10 Year					.838**	.366**	.268**	.373**	.429**
Positive Total						.318**	.288**	.337**	.400**
Negative Week							.543**	.369**	.823**
Negative Year								.372**	.801**
Mean	20.83	3.70	3.83	2.51	10.03	1.83	1.92	1.69	5.44
SD	5.11	2.16	2.13	1.88	5.25	1.57	1.40	1.46	3.48

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

Table 8-13 Correlations among future thinking, optimism and coping (N=150)

	Optimism	Positive week	Positive year	Positive 5-10yr	Positive total	Negative week	Negative year	Negative 5-10 yr	Negative total
Problem Solving	.208**	.242**	.043	.278**	.216**	.102	.005	.136*	.105
Physical Assistance	-.194**	-.249**	-.171	-.152*	-.226**	-.106	-.010	-.113	-.099
Emotional Release	.089	.029	.039	.152*	.082	.062	.074	.116	.106
Avoidance	.011	.059	-.017	.041	.032	-.020	-.071	.040	-.021
Personal Health Control	-.032	.000	.096	.154*	.094	.049	.016	.035	.043
Acceptance	.338**	.154*	-.115	.044	.032	-.192**	-.260**	-.107	-.235**
Energy Conservation	-.160*	-.027	-.065	.058	-.016	.007	.086	-.012	.033
Social Support	-.120	.016	.025	.098	.052	.099	.096	.165*	.152*

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

Table 7-14 Correlations among future thinking, optimism, and adjustment at time 1(N=150), time 2 (N= 128) and time 3 (N=117)

	Optimism	Positive week	Positive year	Positive 5-10yr	Positive total	Negative week	Negative year	Negative 5-10 yr	Negative total
Overall MS Impact Time 1	-.345***	-.184*	-.068	-.071	-.129	.044	.192**	-.045	.078
Physical Impact Time 1	-.245***	-.179*	-.082	-.089	-.139*	-.044	.127	-.093	-.00
Psychological Impact Time 1	-.477***	-.146*	-.019	-.010	-.071	.232**	.288***	.075	.252***
Anxiety Time 1	-.470***	-.148*	-.019	-.050	-.086	.290**	.310**	.139*	.314**
Depression Time 1	-.491***	-.313**	-.168	-.147*	-.249**	.197**	.231**	.047	.201**
Hopelessness Time 1	-.605***	-.318***	-.168*	-.247***	-.287**	.021	.123	.001	.059
Suicide Ideation Time 1	-.399***	-.311***	-.207**	-.187*	-.279***	.100	.208**	.048	.148*
Overall MS Impact Time 2	-.360***	-.188*	-.117	-.171*	-.184*	.002	.051	-.030	.009
Psychological Impact Time 2	-.444***	-.156*	-.062	-.103	-.126	.130	.176*	.095	.171*
Physical Impact Time 2	-.285***	.183*	-.130	-.185*	-.193*	-.057	-.011	-.084	-.065
Depression Time 2	-.441***	-.284***	-.117*	-.201*	-.259*	.067	.133	-.014	.079
Anxiety Time 2	-.381***	-.023	.108	.039	.048	.263***	.296***	.154*	.305***
Hopelessness Time 2	-.555***	-.296***	-.139	-.289***	-.280***	-.003	.175*	-.062	.045
Suicide Ideation Time 2	-.414***	-.239**	-.152	-.194*	-.228**	.041	.179*	-.042	.037
Overall MS Impact Time 3	-.402***	-.217**	-.207*	-.208*	-.245**	.014	.003	-.090	-.032
Psychological Impact Time 3	-.436***	-.179*	.153*	-.185*	-.199*	.197*	.131	-.018	.134
Physical Impact Time 3	-.347***	-.212*	-.210*	-.19*	-.241**	-.067	-.053	-.113	-.101
Depression Time 3	-.488***	-.337***	-.249**	-.259**	-.329***	.207*	.187*	-.026	.158*
Anxiety Time 3	-.442***	-.068	.008	-.091	-.056	.302***	.292**	.205*	.344***
Hopelessness Time 3	-.582***	-.278***	-.140	-.258**	-.216**	.068	.157*	-.057	.070
Suicide Ideation Time 3	-.451***	-.286***	-.085	-.166*	-.210*	.065	.098	-.022	.079

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

8.4.8 Predicting outcome: regression analyses

With reference to hypotheses 4, 5, 6 and 7 the following regression procedures were applied to test the utility of illness representations, optimism, future thinking and coping in predicting adjustment to MS. Multiple Regression analysis is a statistical procedure that assesses the determination of a criterion variable from several predictor variables. In other words, it involves the simultaneous use of two or more independent variables in ‘predicting’ a dependent variable.

Before testing the study’s hypotheses correlations between the key demographic factors (age, gender and marital status), illness characteristics (MS type, time since onset of symptoms, time since diagnosis) and the predictor and adjustment variables were calculated to determine whether these factors should be controlled for in future analyses. Gender, marital status and time since diagnosis showed no significant associations to any of the adjustment variables and were consequently not included as covariates. Those illness characteristics and demographic variables, which correlated with the dependent variable at $p<.01$ level*, were included in the analysis.

To test hypotheses 4, 5, 6 and 7 a series of hierarchical regression and mediation analyses were carried out. These investigated whether illness representations, future thinking, optimism and coping predict adjustment to MS concurrently, four and eight months later. In all the analyses, the adjustment variables acted as dependent variables. All the adjustment variables met the basic assumptions of normality. Measures of illness representations, future thinking, optimism and coping acted as predictor variables.

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* A $p <.01$ level of significance was taken as the critical level of significance to control for multiple comparisons.

8.4.9 Hypothesis 4 – Concurrent and prospective investigation of illness representations, coping and adjustment.

It is hypothesised (4i) that illness representations and coping would be predictive of adjustment at time 1, 2 and 3, consistent with the relationships outlined in the SRM. A series of regression analyses were therefore carried out to investigate whether illness representations and coping predicted adjustment concurrently, 4 and 8 months later. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn hypothesised to be predicted by illness representations. To reduce the likelihood of making a type 1 error, only those illness representations, and coping strategies which correlated with the outcome variables at a p<.01 level of significance were entered into the regression analysis. Demographic variables and illness characteristics which correlated with the dependent variable at p<.01 level were entered into step one, illness representations were entered in step two and coping strategies variables were entered in step three. It was also hypothesised (4ii) that coping mediates the relationship between illness representations and adjustment to MS at time 1, 2 and 3.

8.4.9.1 Hierarchical regression analysis to determine whether illness representations and coping predict time 1 adjustment.

A series of regression analyses were carried out to investigate whether illness representations and coping predict adjustment at time 1. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn hypothesised to be predicted by illness representations. As shown in table 8-15 all the steps in the regressions were significant (except anxiety step two). This shows that illness representations predicted all the adjustment variables at time 1 and coping positively predicted all the adjustment variables at time 1, except anxiety.

MS type was positively related to overall MS impact at time 1, in each of the steps. To investigate this further all four types of MS were compared using a one way analysis of variance (f = 9.26, 137) with post hoc Bonferroni and a significance level of p<.01. The findings revealed that overall MS impact at time 1 was significantly greater in those with secondary progressive.

Overall MS impact at time 1 was positively predicted by identity (β = .15, p < .001), consequences (β = .317, p < .001), emotional representations (β = .228, p < .01) and time cyclical (β = .170, p < .05) components in step two and these remained significant in step three when coping was added to the model. The only coping strategy related to overall MS impact was physical assistance (β = .382, p < .001). When coping was added to the model, the betas for emotional representations and time cyclical reduced to from .150 to .165 and from .170 to .141, respectively. This suggests that physical assistance mediates the relationship between these illness representation components and overall MS impact at time 1. Sobel testing confirmed that physical assistance mediated the relationship between consequences and overall MS impact at time 1 (z = 3.76, p < .001). However, Sobel testing did not confirm that the inclusion of physical assistance reduced the beta significantly for identity (z = .62, p =.53), emotional representations (z = .75, p =.45), or time cyclical (z = .47, p =.64).

Greater physical impact at time 1 was positively predicted by the consequences component (β = .396, p < .001) and physical assistance (β = .284, p <.001) and emotional release (β = .184, p < .012) coping.

Psychological impact at time 1 was positively predicted by consequences (β = .221, p < .001), emotional representations (β = .411, p < .001), identity (β = .146, p < .05) and time cyclical (β = .202, p < .01) in step one. These remained significant in step two when coping strategies were added to the model. In step three, acceptance negatively predict psychological impact at time 1 ($\underline{\beta} = -.140$, $p < .05$). When coping was added to the model, the betas for consequences, emotional representations, identity and time cyclical reduced suggesting that acceptance mediates the relationship between these illness representations components and time 1 psychological adjustment. Sobel testing confirmed that acceptance mediated the relationship between consequences ($z = 2.12$, $p < .01$), emotional representations ($z = 2.45$, $p < .01$), time cyclical ($z = 2.65$, $p < .01$) and psychological impact at time 1. However, Sobel testing did not confirm that the inclusion of acceptance reduced the beta significantly for identity ($z = 1.76$, $p = .08$).

Anxiety at time 1 was positively predicted by emotion representations ($\underline{\beta} = .493$, $p < .001$) and consequences ($\underline{\beta} = .164$, $p < .05$) in step one and these remained significant in step two.

Depression at time 1 was also positively predicted by emotional representations ($\underline{\beta} = .228$, $p < .01$), consequences ($\underline{\beta} = .294$, $p < .001$), time cyclical component ($\underline{\beta} = .161$, $p < .05$), psychological cause ($\underline{\beta} = .147$, $p < .05$) in step one and in step two when coping was added to the model, all their betas reduced and they became less significant. The only coping strategy found to be significantly related to time 1 depression was acceptance ($\underline{\beta} = -.160$, $p < .05$), suggesting this mediates the relationship between those illness representations components and depression at time 1. Sobel testing confirmed that acceptance mediated the relationship between consequences ($z = 2.04$, $p < .05$), emotional representations ($z = 2.48$, $p < .01$), time cyclical ($z = 2.68$, $p < .01$), psychological cause ($z = 2.26$, $p < .05$) and depression at time 1.

Suicide ideation at time 1 was positively predicted by emotional representations ($\underline{\beta} = .265$, $p < .01$) in step one and in step two when coping was added to the model, its beta reduced to .163 and became non-significant. The only coping strategy found to be significantly related to time 1 suicide ideation was acceptance ($\underline{\beta} = -.197$, $p < .05$), suggesting this mediates the relationship between those emotional representations and suicide ideation at time 1. However, Sobel testing did not confirm that the inclusion of acceptance reduced the beta significantly for emotional representations ($z = 1.81$, $p = .07$).

Hopelessness at time 1 was positively predicted by MS type in step one. To investigate this further all four types of MS were compared using a one way analysis of variance ($f = 1.94$, $df = 137$), with post hoc Bonferroni and a significance level of $p < .01$. However, no significant relationships were identified.

Hopelessness at time 1 was positively predicted by time cyclical ($\underline{\beta} = .190$ $p < .05$), emotional representations ($\underline{\beta} = .234$, $p < .01$) and negatively predicted by treatment control ($\underline{\beta} = -.226$, $p < .01$). When coping was added to the model in step three, all the betas reduced and problem solving coping was negatively related to concurrent hopelessness ($\underline{\beta} = -.235$, $p < .01$). This suggests that problem solving coping mediates the relationship between these illness representations components and hopelessness at time 1. However, Sobel testing did not confirm that the inclusion of problem solving reduced the beta significantly for either emotional representations ($z = -1.38$, $p = .17$) or time cyclical ($z = .19$, $p = .85$).

Table 8-15 Hierarchical regression analysis to determine whether illness representations and coping predict adjustment at time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 1						
	1	MS type	.132***	.363***	.331***	.204***
	2	Identity	.489***		.150***	.165*
		Consequence			.317***	.195**
		Emotional Representations			.228**	.230**
		Time cyclical			.170*	.141*
	3	Personal Health Control	.601***			.004
		Energy Conservation				-.114
		Social Support				-.014
		Acceptance				-.096
		Physical Assistance				.382***
Physical Impact Time 1						
	1	Age	.191***	.103	.138	.1111
		MS Type		.396***	.363***	.228***
	2	Emotional Representations	.467***		.073	.125
		Personal Control			-.157*	-.090
		Consequence			.301***	.194**
		Time cyclical			.171*	.134*
		Identity			.185*	.183*
	3	Social Support	.586***			-.019
		Personal Health Control				-.004
		Acceptance				-.032
		Physical Assistance				.428***
		Energy Conservation				-.114
Psychological Impact Time 1						
	1	Consequence	.541***	.221***	.170**	
		Emotional Representations		.411***	.357***	
		Identity		.146*	.156**	
		Time cyclical		.202**	.183**	
		Illness Coherence		.006	.007	
		Psychological Cause		.095	.090	
	2	Physical Assistance	.573*		.109	
		Personal Health Control			.027	
		Acceptance			-.140*	
		Social Support			-.001	
Anxiety Time 1						
	1	Consequence	.476***	.164*	.161*	
		Emotional Representations		.493***	.449***	
		Identity		.050	.061	
		Time cyclical		.103	.089	
		Illness Coherence		-.072	-.072	
		Psychological Cause		.080	.069	
	2	Acceptance	.484		-.105	

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Depression Time 1						
	1	Consequence	.341***	.294***	.231**	
		Emotional Representations		.228**	.167	
		Identity		.005	.017	
		Time cyclical		.161*	.138	
		Illness Coherence		-.086	-.082	
		Psychological Cause		.147*	.140	
	2	Acceptance	.383*		-.160*	
		Physical Assistance			.134	
		Social Support			.030	
Suicide Ideation Time 1						
	1	Time cyclical	.124***	.136	.105	
		Emotional Representations		.265**	.163	
		Identity		.032	.056	
	2	Acceptance	.186**		-.197*	
		Avoidance			.215	
Hopelessness Time 1						
	1	MS Type	.039*	.197*	.147*	.140*
	2	Time cyclical	.274***		.190*	.161*
		Consequence			.112	.097
		Emotional Representations			.234**	.250**
		Treatment Control			-.226**	-.216**
		Lifestyle Cause			.073	.075
	3	Problem Solving	.343**			-.235**
		Physical Assistance				.076
		Acceptance				-.058

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

8.4.9.2 Hierarchical regression analysis to determine whether illness representations and coping predict time 2 adjustment.

A series of regression analyses were also carried out to investigate whether illness representations predicted coping and adjustment to MS 4 months later. Firstly, separate regressions were carried out to investigate the relationship between illness representations and adjustment and coping and adjustment separately. This was followed by a series of hierarchical regression analyses to examine whether illness representations predicted coping, which in turn predicted adjustment to MS 4 months later.

8.4.9.3 Separate regressions (consonant with Moss-Morris et al, 1996)

Consistent with Moss-Morris et al (1996), separate regressions were initially performed, in order to investigate in greater detail the following: (1) the relationship between illness representations and the adjustment variables at time 2 and (2) between the coping responses and the adjustment variables at time 2.

8.4.9.4 Illness representations in relation to time 2 adjustment.

A series of regression analyses were carried out to investigate whether illness representations predicted adjustment 4 months later. As shown in table 8-16 illness representations positively predicted overall MS impact ($R^2 = .297$, $p<.001$), psychological impact ($R^2 = .3403$, $p< .001$), physical impact ($R^2 = .239$, $p<.001$), depression ($R^2 = .228$, $p<.001$), anxiety ($R^2 = .404$, $p<.001$), hopelessness ($R^2 = .298$, $p<.001$) and suicide ideation ($R^2 = .128$, $p<.001$) 4 months later. The consequences and emotional representation component predicted the largest of outcomes. These components positively predicted overall MS impact, psychological impact, and hopelessness at 4 months. In addition, the consequences component positively predicted physical impact ($\underline{\beta} = .414$, $p < .001$) and emotional representations positively predicted anxiety ($\underline{\beta} = .476$, $p < .001$). Personal control was also found to negatively predict hopelessness ($\underline{\beta} = -.217$, $p < .001$) and identity positively predicted psychological impact ($\underline{\beta} = .172$, $p < .05$).

Table 8-16 Hierarchal regression analysis between illness representations and time 2 adjustment

	Predictors	R^2	Final Beta
Overall MS Impact Time 2			
	Time cyclical	.297***	.027
	Consequence		.373***
	Emotional Representations		.172*
	Identity		.168
Psychological Impact Time 2			
	Time cyclical	.403***	.098
	Consequence		.202**
	Emotional Representations		.371***
	Identity		.173*
	Psychological Cause		.066
Physical Impact Time 2			
	Consequence	.239***	.414***
	Emotional Representations		.054
	Identity		.141
Depression Time 2			
	Time cyclical	.228***	.121
	Consequence		.303***
	Emotional Representations		.190*
	Identity		.055
Anxiety Time 2			
	Time cyclical	.404***	.099
	Consequence		.030
	Emotional Representations		.476***
	Identity		.141
	Psychological Cause		.083
Hopelessness Time 2			
	Time cyclical	.298***	.129
	Consequences		.227**
	Personal Control		-.217*
	Emotional Representations		.241**
	Identity		.015
	Psychological Cause		.127
Suicide Ideation Time 2			
	Emotional Representations	.128***	.357***

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

8.4.9.5 Coping in relation to time 2 adjustment

A series of regression analyses were carried out to investigate whether coping predicts adjustment 4 months later. As shown in table 7-17, coping positively predicted overall MS impact (R^2 = .319, p<.001), psychological impact (R^2 = .272, p< .001), physical impact (R^2 = .317, p<.001), depression (R^2 = .163, p<.001) and anxiety (R^2 = .217, p<.001), hopelessness (R^2 = .256, p<.001), suicide ideation (R^2 = .125, p<.001) 4 months later. Physical assistance positively predicted overall MS impact, psychological impact, physical impact, depression and hopelessness 4 months later. Acceptance negatively predicted all the adjustment variables at 4 months (excluding physical impact). In addition, personal health control was found to positively predict psychological impact (β = .178, p < .05) and anxiety (β = .174, p < .05) at 4 months.

Table 8-17 Hierarchal regression analysis to determine whether coping predicts time 2 adjustment.

	Predictors	R2	Final Beta
Overall MS Impact Time 2			
	Physical Assistance	.319***	.443***
	Personal Health Control		.132
	Acceptance		-.185*
Psychological Impact Time 2			
	Physical Assistance	.272***	.212*
	Personal Health Control		.178*
	Acceptance		-.372***
Physical Impact Time 2			
	Physical Assistance	.317***	.509***
	Personal Health Control		.103
Depression Time 2			
	Physical Assistance	.163***	.183*
	Acceptance		-.346***
Anxiety Time 2			
	Personal Health Control	.217***	.174*
	Acceptance		-.418***

	Predictors	R2	Final Beta
Hopelessness Time 2			
	Physical Assistance	.256***	.235***
	Acceptance		-.430***
Suicide Ideation Time 2			
	Acceptance	.125***	-.353***

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

8.4.9.6 Hierarchical regression analysis testing the relationship between illness representations, coping and outcomes at time 2 controlling for time 1.

A series of regression analyses were carried out to investigate the relationship between illness representations, coping and adjustment at time 2. The steps reflect a model in which adjustment is assumed to be predicted by coping, which in turn, is predicted by illness representations. For this analysis only those illness representations and coping strategies, which correlated with the adjustment variables at a p<.01 level of significance were included in the analysis. The scores for the outcome variables measured at time 1 were first controlled for, along with any illness characteristics variables or demographic variables, which correlated with the dependent variable at p<.01 (step one). The illness representation variables, which correlated with the outcome variable at p<.01 significance level were then entered into step two and the coping strategies variables, which correlated with the outcome variable were entered in step three. As table 8-18 shows only step one was significant in each of the regressions. The consequences component positively predicted physical impact ($\underline{\beta}$ = .114, p <.05) in step two however, this became insignificant when coping was added to the model. No significant relationships were identified. This suggests there may not have been long enough period of time between time 1 and time 2 to allow identification of a change.

Table 8-18 Hierarchical regression analysis testing the relationship between illness representations, coping and outcomes at time 2, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 2						
	1	MSIS Time 1	.711***	.812***	.774***	.735***
		Age		.017	.022	.012
		Onset		.027	.036	.031
		MS type		.057	.057	.053
	2	Identity	.719		.059	.059
		Time cyclical			-.027	-.028
		Consequence			.087	.075
		Emotional Representations			-.041	-.038
	3	Physical Assistance	.728			.046
		Personal Health Control				.076
		Acceptance				-.001
Psychological Impact Time 2						
	1	Psychological Impact Time 1	.628***	.792***	.716***	.658***
	2	Time cyclical	.639		-.049	-.046
		Consequence			.053	.013
		Emotional Representations			069	.070
		Identity			.076	.092
		Psychological Cause			-.008	-.018
	3	Physical Assistance	.657			.118
		Acceptance				-.061
		Personal Health Control				.030
Physical Impact Time 2						
	1	Physical Adjustment Time 1	.713***	.808***	.761***	.730***
		MS Type		.073	.081	.082
		Age		.013	.017	.009
		Onset of MS		.007	.019	.011
	2	Emotional Representations	.726		-.073	-.081
		Consequence			.114*	.105
		Identity			.047	.043
	3	Personal Health Control	.735			.094
		Physical assistance				.025

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2						
	1	Anxiety Time 1	.568***	.754***	.623***	.601***
	2	Identity	.599		.099	.112
		Emotional Representations			.145	.103
		Time cyclical			.026	.011
		Consequence			-.062	-.062
		Psychological Cause			.029	.011
	3	Personal Health Control	.609			.034
		Acceptance				-.116
Depression Time 2						
	1	Depression Time 1	.526***	.693***	.643***	.642***
		MS Type		.148*	.150*	.183**
	2	Identity	.535		.019	.031
		Time cyclical			.033	.022
		Emotional Representations			-.008	-.074
		Consequence			.092	.139
	3	Physical Assistance	.555			-.117
		Acceptance				-.117
Suicide Ideation Time 2						
	1	Suicide Time 1	.552***	.743***	.708***	.691***
	2	Emotional Representations	.560		.093	.061
	3	Acceptance	.565			-.083
Hopelessness Time 2						
	1	Hopelessness Time1	.589***	.768***	.678*	.641**
	2	Time cyclical	.620		-.022	-.041
		Consequence			.087	.084
		Emotional Representations			.062	.017
		Identity			.039	.056
		Personal Control			-.095	-.074
		Psychological Cause			.067	.038
	3	Physical Assistance	.637			.033
		Acceptance				-.152

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

8.4.9.7 Hierarchical regression analysis to determine whether illness representations and coping predict outcomes at time 2, when time 1 is not controlled for.

Due to the small number of significant results found from these regressions another series of regression analyses were carried. As shown in table 8-19, these regression analyses included the same outcome variables. However, the outcome measure taken at time 1 for each outcome variable was not controlled for. If any illness characteristics or demographic variables correlated with the adjustment variables at a $p<.01$ then these were entered at step one. The correlated illness representation variables were entered in the subsequent step and the correlated coping strategies were entered in the final step.

As shown in table 8-19, all the steps in each of the regressions were significant. This shows that illness representations and coping positively predicted all the adjustment variables at time 2.

MS type was positively related to overall MS impact at time 2 in each of the steps. To investigate this further all four types of MS were compared using a one way analysis of variance ($f = 6.77$, $df = 120$) with post hoc Bonferroni and a significance level of $p<.01$. The findings revealed that overall MS impact at time 2 was significantly greater in those with secondary progressive MS.

Overall MS impact at time 2 was positively predicted by time cyclical ($\underline{\beta} = .317$, $p < .001$) and emotional representations ($\underline{\beta} = .207$, $p < .05$) in step two. These components remained significant when coping was added to the model and physical assistance was positively related to overall MS impact ($\underline{\beta} = .289$, $p < .001$). In step three the betas for time cyclical and emotional representations reduced to .209 ($p<.05$) and .206 ($p<.05$) respectively, suggesting that physical assistance mediates the relationships between these components and overall MS adjustment at 2 months. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for emotional representations (z = .75, p =.46) or time cyclical (z = .75, p = .46).

Greater psychological impact at time 2 was positively predicted by the consequences component (β = .202,p < .01), emotional representations (β = .371, <.001) and identity (β = .172p < .05) in step one. When coping was added to the model the betas for the consequences and emotional representations component reduced to .110 and .305 (p<.001) respectively with consequences becoming non- significant. In addition, physical assistance was positively (β = .205 p < .05) related and acceptance was negatively related (β = -.170, p < .05) to psychological dysfunction at time 2. This suggests that these coping strategies mediate the relationship between the illness representation components consequences and emotional representation and psychological impact at time 2. Sobel testing did confirm that physical assistance mediated the relationship between consequences (z = 2.12, p <.05) and psychological impact at time 2. Sobel testing also confirmed that acceptance mediated the relationship between illness representations consequences (z = 2.06, p <.05) and emotional representations (z = 2.12, p <.05) and psychological impact at time 2. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for emotional representations (z = .74, p =.46).

MS type was positively related to physical impact at time 2 in each of the steps. To investigate this further all four types of MS were compared using a one way analysis of variance (f = 9.67, df = 120) with post hoc Bonferroni and a significance level of p<.01. The findings revealed that physical impact at time 2 was significantly greater in those with secondary progressive MS.

Physical impact at time 2 was positively predicted by emotional representations (β = .221, p < .01) and identity (β = .361, p < .001) in step two. These components became less significant when coping was added to the model and their betas reduced to .204 ($p<.05$) and .236 ($p<.01$). This suggested that personal health control mediated the relationship between these components and physical impact at 2 months as it was significant in step three ($\beta = .321$, $p < .001$). However, Sobel testing did not confirm that the inclusion of personal health control significantly reduced the beta for either emotional representations ($z = 1.89$, $p =.06$) or identity ($z = 1.80$, $p = .07$).

Anxiety at time 2 was positively predicted by emotion representations ($\beta = .476$, $p < .001$) in step one. When coping strategies were added to the model acceptance was found to negatively predict anxiety ($\beta = -.198$, $p < .05$). In step two the beta for emotional representations reduced to .389 ($p<.001$) suggesting that acceptance mediates the relationship between this component and time 2 anxiety. This was confirmed by Sobel testing ($z = 2.31$, $p<.05$).

Depression at time 2 was positively predicted by MS type in each of the steps. To investigate this further all four types of MS were compared using a one way analysis of variance ($f = 6.19$, $df = 120$) with post hoc Bonferroni and a significance level of $p<.01$. The findings revealed that depression at time 2 was significantly greater in those with secondary progressive MS.

Emotion representations ($\beta = .181$, $p < .05$) and the consequences component ($\beta = .259$, $p < .01$) were both positively related to depression at 4 months. The beta for emotional representations dropped to .070 and became insignificant when coping was added to the model and acceptance was found to be negatively related to depression ($\beta = -.232$, $p < .05$) suggesting that coping strategies play a mediating role. Sobel testing did confirm that acceptance acted as a mediator between depression at time 2 and emotional representations ($z = 2.55$, $p < .01$).

Suicide ideation at time 2 was also positively predicted by emotional representations (β = .357, p < .001) and again the beta reduced and became less significant (β = .246, p < .01) when acceptance was added to the model. Acceptance coping was found to be negatively related to suicide ideation (β = -.239, p < .05) suggesting that it may play a mediating role between emotional representations and suicide ideation at 2 months. Sobel testing did confirm that acceptance acted as a mediator between suicide ideation at time 3 and emotional representations (z = 2.40, p < .05).

Hopelessness at time 2 was positively predicted by emotional representations (β = .241, p < .01), consequences (β = .227, p < .01) and negatively predicted by personal control (β = -.217, p < .05) in step one. In step two, acceptance was found to be negatively related to hopelessness (β = -.274, p < .01) and all the betas for these three illness representations components reduced, the consequences component became less significant and emotion representations became non-significant. This suggests that acceptance also mediated the relationship between these illness representations components and hopelessness at time 2. Sobel testing did confirm that acceptance mediated the relationship between consequences (z = 2.12, p < .05), emotional representations (z =3.20, p <.001), personal control (z = - 2.07, p < .05) and hopelessness at time 2.

Table 8-19 Hierarchical regression analysis to determine whether illness representations and coping predict outcomes at time 2, when time 1 is not controlled for.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 2						
	1	MS type	.135***	.298***	.257***	.183*
		Onset		.092	.100	.100
		Age		.059	.125	.063
	2	Identity	.420***		.124	.085
		Time Cyclical			.317***	.209**
		Consequence			.127	.110
		Emotional Representations			.207*	.206*
	3	Physical Assistance	.507***			.289***
		Personal Health Control				-.082
		Acceptance				.068
Psychological Impact Time 2						
	1	Time Cyclical	.403***	.098	.074	
		Consequence		.202**	.110	
		Emotional Representations		.371***	.305***	
		Identity		.172*	.192*	
		Psychological Cause		.066	.029	
	2	Physical Assistance	.475***		.205*	
		Acceptance			-.170*	
		Personal Health Control			.061	
Physical Adjustment Time 2						
	1	MS Type	.175***	.348***	.300***	.223**
		Onset of MS		.063	.081	.065
		Age		.093	.129	.078
	2	Emotional Representations	.389***		.221**	.204*
		Consequence			.017	.037
		Identity			.361***	.236**
	3	Personal Health Control	.486***			.321***
		Physical assistance				.070

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2						
	1	Identity	.404***	.141	.160	
		Emotional Representations		.476***	.389***	
		Time Cyclical		.099	.060	
		Consequence		.030	.024	
		Psychological Cause		.083	.050	
	2	Personal Health Control	.433*		.056	
		Acceptance			-.198*	
Depression Time 2						
	1	MS Type	.052**	.229*	.211*	.211*
	2	Identity	.256***		.030	.058
		Time Cyclical			.170	.136
		Emotional Representations			.181*	.070
		Consequence			.259**	.269**
	3	Physical Assistance	.297*			-.011
		Acceptance				-.232*
Suicide Ideation Time 2						
	1	Emotional Representations	.128***	.357***	.246**	
	2	Acceptance	.172*		-.239*	
Hopelessness Time 2						
	1	Time Cyclical	.298***	.129	.077	
		Consequence		.227**	.179*	
		Emotional Representations		.241**	.149	
		Identity		.035	.049	
		Personal Control		-.217*	-.158*	
		Psychological Cause		.127	.065	
	2	Physical Assistance	.365***		.133	
		Acceptance			-.247***	

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

8.4.9.8 Hierarchical regression analysis to determine whether illness representations and coping predict time 3 adjustment.

A series of regression analyses were also carried out to investigate whether illness representations predicted coping and adjustment to MS, 8 months later. Firstly, separate regressions were carried out to investigate the relationship between illness representations and adjustment and coping and adjustment separately. This was followed by a series of hierarchical regression analyses to examine whether illness representations predicted coping, which predicted adjustment to MS, 8 months later.

8.4.9.9 Separate regressions for time 3 (consonant with Moss-Morris et al, 1996).

As carried out with time 2 and consistent with Moss-Morris et al (1996), separate regressions were initially performed in order to investigate, in greater detail, the following relationships: (1) the relationship between illness representations and adjustment variables at time 3 and (2) between coping responses and adjustment variables at time 3.

8.4.9.10 Illness representations in relation to time 3 adjustment.

A series of regression analyses were carried out to investigate whether illness representations predicted adjustment 8 months later. As shown in table 8-19 individual's illness representations positively predicted overall MS impact ($R^2 = .248$, $p<.001$), psychological impact ($R^2 = .344$, $p< .001$), physical impact ($R^2 = .196$, $p<.001$), depression ($R^2 = .276$, $p<.001$), anxiety ($R^2 = .386$, $p<.001$), hopelessness ($R^2 = .247$, $p<.001$) and suicide ideation ($R^2 = .163$, $p<.001$), 8 months later. Emotional representations, consequences and physical/ lifestyle cause were the only illness representations to be related to adjustment at time 3. Consequence and emotional representations positively predicted psychological impact, depression and hopelessness at 8 months. In addition, the consequences component positively predicted overall MS impact ($\underline{\beta} = .327$, $p < .001$) and physical impact ($\underline{\beta} = .357$, $p < .001$) at time 3, the emotional representations component positively predicted anxiety ($\underline{\beta} = .423$, $p < .001$) and suicide ideation ($\underline{\beta} = .266$, $p < .01$) and physical/lifestyle cause positively predicted hopelessness ($\underline{\beta} = .180$, $p < .05$).

Table 8-20 Hierarchal regression analysis between illness representations and time 3 adjustment.

	Predictors	R^2	Final Beta
Overall MS Impact Time 3	Time Cyclical	.248***	.055
	Consequence		.327***
	Emotional Representations		.166
	Identity		.151
Psychological Impact Time 3			
	Time Cyclical	.344***	.114
	Consequence		.221**
	Illness Coherence		-.028
	Emotional Representations		.320***
	Identity		.164
Physical Impact Time 3			
	Consequence	.196***	.357***
	Emotional Representations		.105
	Identity		.155
	Psychological Cause		-.109
Depression Time 3			
	Time Cyclical	.276***	.089
	Consequence		.331***
	Emotional Representations		.719*
	Identity		.096
Anxiety Time 3			
	Time Cyclical	.386***	.116
	Consequence		.009
	Emotional Representations		.423***
	Identity		-.011
	Psychological Cause		.173
	Genetic/Physiological Cause		.124
Hopelessness Time 3			
	Time Cyclical	.247***	.065
	Consequences		.295**
	Emotional Representations		.201*
	Identity		.019
	Psychological Cause		.021
	Lifestyle Cause		.180*
Suicide Ideation Time 3			
	Time Cyclical	.163***	.074
	Emotional Representations		.266**
	Identity		.089
	Lifestyle Cause		.167

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

8.4.9.11 Coping in relation to time 3 adjustment.

A series of regression analyses were carried out to investigate whether coping predicts adjustment 8 months later. As shown in table 8-21 coping positively predicted overall MS impact (R^2 = .198, p<.001), psychological impact (R^2 = .151, p< .001), physical impact (R^2 = .224, p<.001), depression (R^2 = .159, p<.001), anxiety (R^2 = .130, p<.001), hopelessness (R^2 = .192, p<.001) and suicide ideation (R^2 = .123, p<.001) 8 months later. Physical assistance positively predict overall MS impact (β = .445, p < .001), psychological impact (β = .288, p < .001), physical impact (β = .466, p < .001), depression (β = .274, p < .01), and hopelessness (β = .221, p < .01) 8 months later. Acceptance negatively predicted all the adjustment variables at 8 months (excluding overall MS impact).

Table 8-21 Hierarchal regression analysis to determine whether coping predicts time 3 adjustment.

		R2	Final Beta
Overall MS Impact Time 3	Physical Assistance	.198***	.445***
Psychological Impact Time 3	Physical Assistance	.151***	.288***
	Acceptance		-.255**
Physical Impact Time 3	Physical Assistance	.224***	.466***
	Acceptance		-.073
Depression Time 3	Physical Assistance	.159***	.274**
	Acceptance		-.284***
Anxiety Time 3	Acceptance	.130***	-.360***
Hopelessness Time 3	Physical Assistance	.192***	.221**
	Acceptance		-.373***
Suicide Ideation Time 3	Acceptance	.123***	.351***

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

8.4.9.12 Hierarchical regression analysis to determine whether illness representations and coping predict adjustment at time 3, when time 1 is controlled for.

A series of regressions analyses were carried out to investigate the relationship between illness representations, coping and adjustment at time 3. The steps reflect a model in which adjustment ia assumed to be predicted by coping, which in turn is assumed to be predicted by illness representations. For this analysis only those illness representations and coping strategies, which correlated with the adjustment variables at a $p<.01$ level of significance were included in the analysis. The scores for the outcome variables measured at time 1 were first controlled for, along with any illness characteristics variables or demographic variables, which correlated with the dependent variable at $p<.01$ (step one). The illness representation variables, which correlated with the outcome variable at $p<.01$ significance level, were then entered into step two and the coping strategies variables, which correlated with the outcome variable were entered in step three. As shown in table 8-22 in addition to step one in each regression, the only significant relationship was between psychological cause and anxiety at time 3 in step two($\underline{\beta} = .135$, $p < .05$) and step three($\underline{\beta} = .138$, $p < .05$). No other significant relationships were identified. This suggests there may not have been a long enough period of time between time 1 and time 3 to notice a change.

Table 8-22 Hierarchical regression analysis testing the relationship between illness representations, coping and outcomes at time 3, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 3						
	1	Overall MS Impact Time 1	.615***	.774***	.772***	.755***
		MS type		.027	.036	.032
	2	Time Cyclical	.620		.037	.039
		Emotional Representations			-.071	
		Identity			.028	.029
		Consequence			.027	.020
	3	Physical Assistance	.621			.032
Physical Impact Time 3						
	1	Physical Impact Time 1	.570***	.744***	.716***	.705***
	2	MS Type	.577	.025	.034	.029
		Emotional Representations			-.046	-.021
		Identity			.054	.051
		Consequence			.068	.060
		Psychological Cause			-.053	-.047
	3	Physical Assistance	.579			.029
		Acceptance				.049
Psychological Impact Time 3						
	1	Psychological Impact Time 1	.552***	.743***	.695***	.686***
	2	Emotional Representations	.561		-.081	.041
		Identity			.044	.030
		Consequence			.063	.022
		Time Cyclical			-.012	.008
		Illness coherence			.077	-.071
	3	Physical Assistance	.575			.101
		Acceptance				.087
Anxiety Time 3						
	1	Anxiety Time 1	.634***	.796***	.744***	.750***
	2	Time Cyclical	.659		.057	.060
		Consequence			-.013	-.013
		Emotional Representations			.013	.020
		Identity			-.007	-.070
		Psychological Cause			.135*	.138*
		Genetic/Physiological cause			.074	.076
	3	Acceptance	.659			..025

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Depression Time 3						
	1	Depression Time 1	.565***	.752***	.683***	.679***
	2	Time Cyclical	.579		.001	.007
		Consequence			.117	.100
		Emotional Representations			.004	.019
		Identity			.049	.045
	3	Acceptance	.580			.019
		Physical Assistance				.041
Hopelessness Time 3						
	1	Hopelessness Time1	.553***	.695***	.624***	.594***
		MS Type		.160*	.166*	.177*
	2	Time Cyclical	.578		.047	.027
		Consequence			.107	.121
		Emotional Representations			-.008	.-.050
		Identity			.028	.048
		Psychological Cause			.070	.049
		Lifestyle Cause			.038	.056
	3	Physical Assistance	.589			-.018
		Acceptance				-.120
Suicide Ideation Time 3						
	1	Suicide Time 1	555***	.704***	.664***	.636***
		MS Type		.156*	.162*	.168**
	2	Time Cyclical	.572		.027	.004
		Emotional Representations			.009	-.037
		Identity			.079	.095
		Physical/ Lifestyle Cause			.090	.103
	3	Acceptance	583			-.121

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

8.4.9.13 Hierarchical regression analysis to determine whether illness representations and coping predict outcomes at time 3, when time 1 is not controlled for.

Due to the small number of significant results found by these regressions, a second series of regression analyses were carried out, not controlling for time 1. As shown in table 8-23 these regression analyses included the same outcome variables. However, the outcome measure taken at time 1 for each outcome variable was not controlled for. If any illness characteristic or demographic variables correlated with the adjustment variables at a p<.01 then these were entered at step one. The correlated illness representation variables were entered in the subsequent step and the correlated coping strategies were entered in the final step. As shown in table 8-23, all the steps in each of the regressions were significant. This indicates that illness representations and coping positively predicted all the adjustment variables at time 3.

MS type was positively related to overall MS impact at time 3, in steps 2 and 3. To investigate this further all four types of MS were compared using a one way analysis of variance (f = 4.37, df = 109) with post hoc Bonferroni and a significance level of p<.01. The findings revealed that overall MS impact at time 3 was significantly greater in those with secondary progressive MS.

Overall MS impact was positively predicted by consequences (β = .263, p < .01) in step one only and emotional representations (β = .185, p < .05) and physical assistance (β = .306, p < .001) in step two. The beta for the consequences component dropped to .139 and became non-significant when coping was added to the model. This suggested that physical assistance mediates the relationship between consequences and overall impact at time 3. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for the consequences component (z = .73, p =.46).

MS type was positively related to physical impact at time 3 in all the steps. To investigate this further all four types of MS were compared, using a one way analysis of variance (f = 6.05, df = 109), with post hoc Bonferroni and a significance level of p<.01. The findings revealed that physical impact at time 3 was significantly greater in those with secondary progressive and those with primary progressive MS.

Physical impact at time 3 was positively predicted by identity (β = .208, p < .05) and consequences (β = .298, p < .001) in step one. When coping strategies were added to the model their betas reduced to .134 (non-significant) and .184 (p<.05) respectively and physical assistance coping was found to positively predict physical impact (β = .316, p < .001). This suggests that physical assistance mediates the relationship between these illness beliefs components and physical impact at time 3. The Sobel test revealed that physical assistance acted as a mediator for the consequences component (z = 3.22, p <.001) but not for identity (z = .62, p =.53).

Psychological impact at time 3 was positively predicted by emotion representations (β = .320, p < .001) and the consequences component (β = .221, p < .01) in step one. When coping strategies were added to the model emotional representations remained significant and the beta increased (β = .348, p < .001). However, the beta for the consequence component reduced to .119 and became non-significant. In addition, physical assistance was found to positively predict psychological impact (β = .221, p < .01) at time 3. This suggests that physical assistance mediates the relationship between the consequences component and psychological impact at time 3. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for the consequences component (z = .69, p =.49).

Anxiety at time 3 was positively predicted by emotion representations (β = .423, p < .001) in step one and step two (β = .391, p < .001). Psychological cause also positively predicted anxiety in step one (β = .173, p < .05) and step two (β = .164, p < .05). No other illness representations or coping strategies significantly predict anxiety at time 3.

The consequences component (β = .331, p < .001) in step one was positively related to depression, at 8 months. In step two, the beta reduced to .255 (p<.01) and physical assistance was positively related to depression (β = .159, p < .05), suggesting this coping strategy plays a mediating role. However, the Sobel test did not confirm that the inclusion of physical assistance significantly reduced the beta for the consequences component (z = 1.29, p = .20).

MS type was positively related to hopelessness at time 3 in all the steps. To investigate this further all four types of MS were compared using a one way analysis of variance (f = 3.84, df = 108) with post hoc Bonferroni and a significance level of p<.01. The findings revealed that hopelessness at time 3 was significantly greater in those with secondary progressive MS.

Hopelessness at time 3 was positively predicted by consequences (β = .237, p < .05) in step one. When coping was added to the model the consequences beta dropped to .227 (p<.05) and acceptance was found to be negatively related to hopelessness (β = -.269, p < .01) at time 3. This suggests that acceptance mediated the relationship consequences and hopelessness at time 3. Sobel testing did confirm this (z = 1.96, p <.05).

MS type was positively related to suicide ideation at time 3 in all the steps. To investigate this further all four types of MS were compared using a one way analysis of variance (f = 3.52, df = 109) with post hoc Bonferroni and a significance level of p<.01. The findings revealed that suicide ideation at time 3 was significantly greater in those with secondary progressive MS.

Suicide ideation at time 3 was also positively predicted by emotional representations (β = .232, p < .05) and the beta dropped to .108 and became non-significant when acceptance was added to the model. Acceptance coping was found to be negatively related to suicide ideation (β = -.271, p < .01) suggesting that it plays a mediating role between emotional representations and suicide ideation at 8 months. Sobel testing confirmed that acceptance mediated the relationship between suicide ideation at time 3 and emotional representations (z = 2.38, p <.05).

Table 8-23 Hierarchical regression analysis testing the relationship between illness representations, coping and outcomes at time 3, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Time 3						
	1	MS type	.092***	.303	.294***	.202*
	2	Time Cyclical	.320***		.125	.124
		Emotional Representations			.137	.185*
		Identity			.173	.154
		Consequence			.263**	.139
	3	Physical Assistance	.389***			.306***
Physical Impact Time 3						
	1	MS Type	.119***	345***	318***	223**
	2	Emotional Representations	.284***		.081	.134
		Identity			.208*	.184*
		Consequence			.298***	.167
		Psychological Cause			-.112	-.094
	3	Physical Assistance				.316***
		Acceptance	.358***			.017
Psychological Impact Time 3						
	1	Emotional Representations	344***	.320***	.348***	
		Identity		.164	.151	
		Consequence		.221**	.119	
		Time Cyclical		.114	.122	
		Illness coherence		-.020	-.012	
	2	Physical Assistance	.384*		.221**	
		Acceptance			-.020	
Anxiety Time 3						
	1	Time Cyclical	.386***	.116	.104	
		Consequence		.019	.079	
		Emotional Representations		.423***	.391***	
		Identity		-.011	-.001	
		Psychological Cause		.173*	.164*	
		Physiological Cause		.124	.117	
	2	Acceptance	.351		-.079	
Depression Time 3						
	1	Time Cyclical	.276***	.089	.077	
		Consequence	.307	.331***	.255**	
		Emotional Representations		.219	.189	
		Identity		.096	.095	
	2	Acceptance			-.120	
		Physical Assistance			.159*	

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Hopelessness Time 3						
	1	MS Type	.089***	.299***	.258***	.257**
	2	Time Cyclical	.302***		.124	.072
		Consequence			.237*	.227*
		Emotional Representations			.179	.074
		Identity			.030	.069
		Psychological Cause			.041	.000
		Physical/Lifestyle Cause			.131	.115
	3	Physical Assistance	.300*		.043	.019
		Acceptance				-.269**
Suicide Ideation Time 3						
	1	MS Type	.071**	.267**	.265**	.269**
	2	Time Cyclical	.281***		.138	.188
		Emotional Representations			.232*	.108
		Identity			.097	.131
		Lifestyle Cause			.120	.147
	3	Acceptance	.287**			-.271**

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

8.4.10 Hypothesis 5 - Concurrent and prospective investigation of optimism, coping and adjustment.

Hypothesis 5 (i) postulated that optimism and coping are predictive of adjustment at time 1, 2 and 3. A series of regression analyses were therefore carried out, to investigate whether optimism and coping predict adjustment concurrently and at 4 and 8 months later. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn hypothesised to be predicted by optimism. If any demographic variables or illness characteristics correlated with the dependent variable at p<.01 level they were entered into step one, optimism was entered in the next step and coping strategies variables were entered in the final step. It was also hypothesised (5ii) that coping mediates the relationship between optimism and adjustment to MS at time 1, 2 and 3.

8.4.10.1 Hierarchical regression analysis to determine whether optimism and coping predict time 1 adjustment

As shown in table 8-24, all the steps in the regressions were significant. This shows that optimism and coping positively predicted all the adjustment variables at time 1.

MS type was found to be positively related to overall MS impact, physical impact and hopelessness at time 1. These were investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.1.

In each of the regressions, optimism was found to be negatively related to all of the adjustment variables. When coping was added into these regressions, all of the betas for optimism reduced in each of the regressions, suggesting that coping plays a mediating role. For overall MS impact and physical impact, the coping strategy physical assistance was positively related to these adjustment variables and acceptance was negatively related. This suggests that physical assistance and/or acceptance, mediates the relationship between optimism and these adjustment variables. Sobel testing did confirm that acceptance mediated the relationship between optimism and overall MS impact (z = -2.52, p <.01) however, physical assistance did not (z = -.099, p = .32). Sobel testing also confirmed that acceptance mediated the relationship between physical impact at time 1 and optimism (z = -1.98, p <.05) however, again physical assistance did not play a mediating role (z = -.99, p = .32).

Acceptance negatively predicted all the other adjustment variables, including psychological impact, anxiety, depression and suicide ideation. In addition to acceptance, avoidance also negatively predicted suicide ideation at time 1. Sobel testing confirmed that acceptance mediated the relationship between optimism and the other adjustment variables, psychological impact (z = -3.09, p <.001), anxiety (z = -2.82, p <.01), and depression (z = -2.63, p <.01). However, Sobel testing did not confirm that the inclusion of either acceptance (z = -1.84, p = .07) or avoidance (z = 1.42, p = .89) significantly reduced the beta for optimism when predicting suicide ideation at time 1.

Table 8-24 Hierarchical regression analysis to determine whether optimism and coping predict physical and psychological impact at time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 1						
	1	MS Type	.132***	.363***	.322***	.201**
	2	Optimism	.223**		-.305***	-.157*
	3	Physical Assistance	.424***			.342***
		Personal Health Control				.092
		Energy Conservation				.000
		Acceptance				-.225**
		Social Support				.040
Physical Impact Time 1						
	1	MS Type	.191***	.396***	.364***	.231**
		Age		.103	.116	.049
	2	Optimism	.231**		-.204**	-.063
	3	Physical Assistance	.447***			.448***
		Personal Health Control				.048
		Energy Conservation				-.014
		Acceptance				-.160*
		Social Support				.018
Psychological Impact Time 1						
	1	Optimism	.227***	-.477***	-.355***	
	2	Physical Assistance	.362***		.028	
		Personal Health Control			.137	
		Acceptance			-.295***	
		Social Support			.108	
Anxiety Time 1						
	1	Optimism	.221***	-.470***	-.378***	
	2	Acceptance	.285***		-.271***	
Depression Time 1						
	1	Optimism	.241***	-.491***	-.376***	
	2	Social Support	.327***		.109	
		Acceptance			-.228**	
		Physical Assistance			.125	
Hopelessness Time 1						
	1	MS Type	.039*	.197*	.108	
	2	Optimism	.367***	.118	-.515***	
	3	Problem Solving	.366	-.597***	-.052	
		Acceptance			-.123	
		Physical Assistance			.054	

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Suicide Ideation Time 1						
	1	Optimism	.159***	-.399***	-.336***	
	2	Acceptance	.235***		-.194*	
		Avoidance			-.231**	

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

8.4.10.2 Hierarchical regression analysis to determine whether optimism and coping predict time 2 adjustment.

A series of regression analyses were carried out to investigate whether optimism predicted coping and adjustment to MS 4 months later. Firstly, separate regressions were carried out to investigate the relationship between optimism and adjustment. This was followed by a series of hierarchical regression analyses to examine whether optimism predicts coping, which in turn predicts adjustment to MS 4 months later.

8.4.10.3 Separate regressions for the relationship between optimism and time 2 adjustment.

Separate regressions were initially performed to investigate, in greater detail, the relationship between optimism and adjustment at 4 months. As shown in table 8-25, each of the steps were significant including overall MS impact (R^2 = .129, p<.001), psychological impact (R^2 = .197, p< .001), physical impact (R^2 = .081, p<.001), depression (R^2 = .194, p<.001), anxiety (R^2 = .145, p<.001), hopelessness (R^2 = .306, p<.001) and suicide ideation (R^2 = .194, p<.001) 4 months later. Optimism was found to negatively predict all the adjustment variables at 4 months at a p<.001 level.

Table 8-25 Hierarchal regression analysis between optimism and time 2 adjustment.

	Predictors	R^2	Final Beta
Overall MS Impact Time 2			
	Optimism	.129***	-.360***
Psychological Impact Time 2			
	Optimism	.197***	-.444***
Physical Impact Time 2			
	Optimism	.081***	-.285***
Depression Time 2			
	Optimism	.194***	-.441***
Anxiety Time 2			
	Optimism	.145***	-.381***
Hopelessness Time 2			
	Optimism	.306***	-.553***
Suicide Ideation Time 2			
	Optimism	.194***	-.441***

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

8.4.10.4 Hierarchical regression analysis to determine whether optimism and coping predict adjustment at time 2, when time 1 is controlled for.

A series of regressions analyses were carried out to investigate the relationship between optimism, coping and adjustment at time 2. The steps reflect a model in which adjustment are assumed to be predicted by coping, which is in turn predicted by optimism. For this analysis only those coping strategies, which correlated with the adjustment variables at a p<.01 level of significance were included in the analysis. The scores for the outcome variables measured at time 1, were first controlled for along with any illness characteristics variables or demographic variables, which correlated with the dependent variable at p<.01 (step one). Optimism was then entered into step two and the coping strategies variables, which correlated with the outcome variables were entered in step three. As table 8-25 shows, for overall MS impact, physical impact, psychological impact, depression and anxiety, only step one was significant in these regressions. MS type was positively related to depression at time 2. This relationship was investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.1.

Optimism negatively predicted hopelessness (β = -.174, p < .05) in step one. When coping was added to the model, acceptance negatively predicted hopelessness at time 2 and the beta for optimism reduced to -.135 and became non-significant. This suggests that acceptance mediates the relationship between optimism and hopelessness, at time 2. This was confirmed by a Sobel test (z = -2.85, p <.01).

Optimism also negatively predicted suicide ideation (β = -.181, p < .01) in step one. When coping was added to the model, this beta also reduced to -.163 (p<.05) however, acceptance was not found to be significantly related to suicide ideation, at time 2. The limited number of relationships identified by these regressions, may be a result of a lack of significant change between the adjustment variables at time 1 and time 2.

Table 8-26 Hierarchal regression analysis between optimism and time 2 adjustment controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 2	1	MSIS Time 1	.711***	.812***	.779	.747***
		Age		.017	.021	.015
		Onset of MS		.027	.037	.026
		MS Type		.057	.051	.044
	2	Optimism	.717		-.083	-.89
	3	Physical Assistance	.727			.050
		Acceptance				.044
		Personal Health Control				.073

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Physical Impact Time 2						
	1	Physical Impact Time 1	.713***	.808***	.786***	.739***
		Age		.013	.016	.007
		Onset of MS		.007	.015	.009
		MS Type		.073	.068	.067
	2	Optimism	.717		-.071	.739
	3	Physical Assistance	.727			.053
		Personal Health Control				.079
Psychological Impact Time 2						
	1	Psychological Impact Time 1	.628***	.792**	.748***	.697***
	2	Optimism	.634		-.094	-.069
	3	Physical Assistance	.649			.094
		Personal Health Control				.048
		Acceptance				-.053
Anxiety Time 2						
	1	Anxiety Time 1	.568***	.754***	.724***	.672***
	2	Optimism	.572		-.070	-.037
	3	Acceptance	.588			-.133*
		Personal Health Control				.783
Depression Time 2						
	1	Depression Time 1	.526***	.698***	.138*	.164*
		MS Type		.148*	.632***	.632***
	2	Optimism	.538		-.126	-.119
	3	Acceptance	.549			-.068
		Physical Assistance				-.085
Hopelessness Time 2						
	1	Hopelessness Time 1	.589***	.768***	.669***	.616***
	2	Optimism	.610*		-.174*	-.135
	3	Physical Assistance	.630*			.056
		Acceptance				-.150*
Suicide Ideation Time 2						
	1	Suicide Ideation Time 2	.552***	.743***	.673***	.658***
	2	Optimism	.580**		-.181**	-.163*
	3	Acceptance	.583			-.063

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

8.4.10.5 Hierarchical regression analysis to determine whether optimism and coping predict outcomes at time 2, when time 1 is not controlled for.

Due to the small number of significant results found from these regressions a second series of regression analyses were carried out, not controlling for time 1. As shown in table 8-27, these regression analyses included the same outcome variables however, the outcome measure taken at time 1, for each outcome variable, was not controlled for. If any illness characteristic or demographic variables correlated with the adjustment variables at a $p<.01$, then these were entered at step one. Optimism was entered in the subsequent step and the correlated coping strategies were entered in the final step.

As shown in table 8-27, all the steps in each of the regressions were significant. This shows that illness representations and coping positively predicted all the adjustment variables at time 2. MS type was found to be positively related to overall MS impact, physical impact and depression, at time 2. These were investigated previously using a one way analysis of variance and the results are reported in section 7.5.9.8.

Overall MS impact at time 2 was negatively predicted by optimism ($\underline{\beta} = -.359$, $p < .001$) in step one. When coping was added to the model, physical assistance was positively related to overall MS impact ($\underline{\beta} = .310$, $p < .001$) and the beta for optimism reduced to -.225 ($p<.01$). This suggests that physical assistance mediated the relationship between optimism and overall impact, at time 2. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for optimism ($z = -.99$, $p = .32$).

Physical impact at time 2 was also negatively predicted by optimism ($\underline{\beta} = -.274$, $p < .001$) in step one. When coping was added to the model, physical assistance was positively related to physical impact ($\underline{\beta} = .365$, $p < .001$) and the beta for optimism reduced to -.176 ($p<.05$). This suggests that physical assistance mediated the relationship between optimism and physical impact, at time 2. However, again Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for optimism ($z = -.99$, $p = .32$).

Psychological impact at time 2 was also negatively predicted by optimism ($\underline{\beta} = -.444$, $p < .001$) in step one. When coping was added to the model, the beta for optimism reduced to -.284 ($p<.001$). In step two, psychological impact at time 2 was positively predicted by personal health control ($\underline{\beta} = .177$, $p < .05$) and negatively predicted by acceptance ($\underline{\beta} = -.272$, $p < .001$). This suggests that personal health control and/or acceptance mediated the relationship between optimism and psychological impact, at time 2. Sobel testing confirmed that this relationship was mediated by acceptance ($z = -2.75$, $p <.01$) but not personal health control ($z = -.38$, $p = .70$).

Anxiety at time 2 was also negatively predicted by optimism ($\underline{\beta} = -.381$, $p < .001$) in step one. When coping was added to the model, acceptance was found to be negatively related to anxiety ($\underline{\beta} = -.333$, $p < .001$) and the beta for optimism reduced to -.239 ($p<.01$). This suggests that acceptance mediated the relationship between optimism and anxiety at time 2. Sobel testing confirmed that acceptance mediated the relationship between optimism and anxiety at time 2 ($z = -2.99$, $p <.01$).

Depression at time 2 was also negatively predicted by optimism ($\underline{\beta} = -.435$, $p < .001$) in step one. When coping was added to the model, acceptance was found to be negatively related to depression ($\underline{\beta} = -.207$, $p < .001$) and the beta for optimism reduced to -.352 ($p<.001$). This suggests that acceptance mediates the relationship between optimism and depression at time 2. Sobel testing confirmed that acceptance mediated the relationship between optimism and depression, at time 2 ($z = -2.33$, $p <.01$).

Hopelessness at time 2 was also negatively predicted by optimism ($\underline{\beta} = -.553$, $p < .001$) in step one. When coping was added to the model, the beta for optimism reduced to -

.413 (p<.001). In step two, hopelessness at time 2 was positively predicted by physical assistance (β = .147, p < .05) and negatively predicted by acceptance (β = -.285, p < .001). This suggests that physical assistance and/or acceptance mediated the relationship between the optimism and hopelessness at time 2. Sobel testing confirmed that this relationship was mediated by acceptance (z = -2.85, p <.01) but not physical assistance (z = -.88, p = .38).

Suicide ideation, at time 2, was also negatively predicted by optimism (β = -.441, p < .001) in step one. When coping was added to the model, acceptance was negatively related to suicide ideation (β = -.221, p < .05) and the beta for optimism reduced to -.359 (p<.001). This suggests that acceptance mediated the relationship between the optimism and suicide ideation at time 2. This was confirmed by Sobel test (z = -2.26, p <.05).

Table 8-27 Hierarchal regression analysis between optimism and time 2 adjustment, not controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 2						
	1	Age	.135***	.059	.066	-.012
		Onset of MS		.092	.125	.120
		MS Type		.298***	.234**	.162*
	2	Optimism	.260***		-.359***	-.225**
	3	Physical Assistance				.310***
		Acceptance	.401***			-.122
		Personal Health Control				.139
Physical Impact Time 2						
	1	Age	.175***	.093	.098	.029
		Onset of MS		.063	.088	.070
		MS Type		.348***	.299***	.213**
	2	Optimism	.247***		-.274***	-.176*
	3	Physical Assistance	.410***			.365***
		Personal Health Control				.114
Psychological Impact Time 2						
	1	Optimism	.197***	-.444***	-.284***	
	2	Physical Assistance	.338***		.151	
		Personal Health Control			.177*	
		Acceptance			-.272***	

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2						
	1	Optimism	.145***	-.381***	-.239**	
	2	Acceptance	.66***		-.333***	
		Personal Health Control			.149	
Depression Time 2						
	1	MS Type	.052*	.229*	.170*	.164*
	2	Optimism	.238***		-.435***	-.352***
	3	Acceptance	.275*			-.207*
		Physical Assistance				.029
Hopelessness Time 2						
	1	Optimism	.306***	-.553***	-.413***	
	2	Physical Assistance	.381***		.147*	
		Acceptance			-.285***	
Suicide Ideation Time 2						
	1	Optimism	.194**	-.441***	-.359***	
	2	Acceptance	.236*		-.221*	

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

8.4.10.6 Hierarchical regression analysis to determine whether optimism and coping predict time 3 adjustment.

A series of regression analyses were also carried out to investigate whether optimism predicts coping and adjustment to MS, 8 months later. Firstly, separate regressions were carried out to investigate the relationship between optimism and adjustment. This was followed by a series of hierarchical regression analyses to examine whether optimism predicts coping, which in turn predicts adjustment to MS, 8 months later.

8.4.10.7 Separate regressions for the relationship between optimism and time 3 adjustment.

Separate regressions were initially performed in order to investigate, in greater detail, the relationship between optimism and adjustment 8 months later. As shown in table

8-28, each of the steps were significant including overall MS impact (R^2 = .161, p<.001), psychological impact (R^2 = .190, p< .001), physical impact (R^2 = .120, p<.001), anxiety (R^2 = .195, p<.001), depression (R^2 = .239, p<.001), hopelessness (R^2 = .338, p<.001) and suicide ideation (R^2 = .190, p<.001) 8 months later. Optimism was found to negatively predict all the adjustment variables at 8 months at a p<.001 level.

Table 8-28 Hierarchal regression analysis between optimism and time 3 adjustment.

	Predictors	R^2	Final Beta
Overall MS Impact Time 3			
	Optimism	.161***	-.402***
Psychological Impact Time 3			
	Optimism	.190***	-.436***
Physical Impact Time 3			
	Optimism	.120***	-.347***
Depression Time 3			
	Optimism	.239***	-.442***
Anxiety Time 3			
	Optimism	.195***	-.442***
Hopelessness Time 3			
	Optimism	.338***	-.582***
Suicide Ideation Time 3			
	Optimism	.190***	-.436***

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

8.4.10.8 Hierarchical regression analysis to determine whether optimism and coping predict adjustment at time 3, when time 1 is controlled for.

A series of regressions analyses were carried out to investigate the relationship between optimism, coping and adjustment, at time 3. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn predicted by optimism.

For this analysis only those coping strategies, which correlated with the adjustment variables at a p<.01 level of significance, were included in the analysis. The scores for the outcome variables measured at time 1 were first controlled for, along with any illness characteristics variables or demographic variables which correlated with the dependent variable at p<.01 (step one). Optimism was then entered into step two and the coping strategies variables, which correlated with the outcome variable, were entered in step three. As table 8-29 shows, with the exception of hopelessness, only step one was significant for each of the regressions. Optimism negatively predicted hopelessness in step one (β = -.231, p < .01). In step two, when coping was added to the model, optimism negatively predicted hopelessness (β = -.208, p < .01) and physical impact (β = -.146, p < .05). None of the coping strategies significantly predicted hopelessness at time 3.

MS type positively predicted suicide ideation at time 3. MS type was found to be positively related to suicide ideation at time 3. This relationship was investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.13.

Table 8-29 Hierarchal regression analysis between optimism and time 3 adjustment, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 3						
	1	MS Impact Time 1	.052***	.774***	.737***	.717***
		MS Type		.027	.022	.014
	2	Optimism	.622		-.090	-.089
	3	Physical Assistance	.623			.045
Psychological Impact Time 3						
	1	Psychological Impact time 1	.552***	.743***	.698***	.711***
	2	Optimism	.558		-.091	-.100
	3	Physical Assistance	.573			.066
		Acceptance				.091

	Step/Predictors		R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Physical Impact Time 3						
	1	Physical Impact	.570***	.744**	.709***	.705***
		MS type		.025	.017	.002
	2	Optimism	.580		-.110	-.146*
	3	Physical Assistance	.590			.028
		Acceptance				.102
Anxiety Time 3						
	1	Anxiety Time 1	.634***	.746	.767***	.766***
	2	Optimism	.637		-.059	-.058
	3	Acceptance	.637			-.004
Depression Time 3						
	1	Depression Time 1	.565***	.752***	.691***	.685***
	2	Optimism	.574		-.112	-.113
	3	Acceptance	.578			.030
		Physical Assistance				.060
Hopelessness Time 3						
	1	Hopelessness Time 1	.553***	.695***	.566***	.541***
		MS type		.160*	.140*	.148*
	2	Optimism	.588**		-.231**	-.208**
	3	Physical Assistance	.595			-.011
		Acceptance				-.091
Suicide Ideation Time 3						
	1	Suicide Time 1	.555***	.704***	.652***	.629***
		MS Type		.156*	.142*	.151*
	2	Optimism	.565		-.112	-.089
	3	Acceptance	.570			-.085

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

8.4.10.9 Hierarchical regression analysis to determine whether optimism and coping predict outcomes at time 3, when time 1 is not controlled for.

Due to the small number of significant results found from these regressions a second series of regression analyses were carried out not controlling for time 1. As shown in table 8-29, these regression analyses included the same outcome variables however, the outcome measure taken at time 1, for each outcome variable, was not controlled for. If any illness characteristic or demographic variables correlated with the adjustment variables at $p<.01$ then these were entered at step one. Optimism was entered in the subsequent step and the correlated coping strategies were entered in the final step.

As shown in table 8-30, all the steps in each of the regressions were significant. This shows that illness representations and coping positively predicted all the adjustment variables at time 3.

MS type was found to be positively related to overall MS impact, physical impact, hopelessness and suicide ideation, at time 3. These were investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.13.

Overall MS impact at time 3 was also negatively predicted by optimism ($\beta = -.367$, $p < .001$) in step one. When coping was added to the model, physical assistance was positively related to overall MS impact ($\beta = .322$, $p < .001$) and the beta for optimism reduced to -.308 ($p<.001$). This suggests that physical assistance mediated the relationship between optimism and overall MS impact, at time 3. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for optimism ($z = -.98$, $p =.33$).

Psychological impact at time 3 was also negatively predicted by optimism ($\beta = -.436$, $p < .001$) in step one. When coping was added to the model physical assistance was positively related to psychological impact ($\beta = .214$, $p < .05$) and the beta for optimism reduced to -.340 ($p<.001$). This suggests that physical assistance mediated the relationship between optimism and psychological impact, at time 3. However, again Sobel testing did not confirm that physical assistance reduced the beta for optimism ($z = -1.19$, $p =.24$).

Physical impact at time 3 was also negatively predicted by optimism ($\beta = -.299$, $p < .001$) in step one. When coping was added to the model, physical assistance was positively related to physical impact ($\beta = .350$, $p < .001$) and the beta for optimism reduced to -.243

(p<.01). This suggests that physical assistance mediated the relationship between the optimism and physical impact, at time 3. However, Sobel testing did not confirm that physical assistance significantly reduced the beta for optimism (z = -.98, p =.33).

Anxiety at time 2 was also negatively predicted by optimism (β = -.442, p < .001) in step one. When coping was added to the model acceptance was negatively related to anxiety (β = -.225, p < .05) and the beta for optimism reduced to -.356 (p<.001). This suggests that acceptance mediated the relationship between optimism and anxiety at time 3. This was confirmed by Sobel testing (z = -1.67, p<.05).

Depression at time 3 was also negatively predicted by optimism (β = -.488, p < .001) in step one. When coping was added to the model, physical assistance was positively related to depression (β = .189, p < .05) and the beta for optimism reduced to -.352 (p<.001). This suggests that physical assistance mediated the relationship between the optimism and depression, at time 3. However, Sobel testing did not confirm that physical assistance significantly reduced the beta for optimism (z = -.91, p =.36).

Hopelessness at time 3 was also negatively predicted by optimism (β = -.547, p < .001) in step one. When coping was added to the model, acceptance was negatively related to hopelessness (β = -.206, p < .05) and the beta for optimism reduced to -.458 (p<.001). This suggests that acceptance mediated the relationship between the optimism and hopelessness, at time 3. This was confirmed by Sobel testing (z = -2.05, p <.05).

Suicide ideation at time 3 was also negatively predicted by optimism (β = -.424, p < .01) in step one. When coping was added to the model, acceptance was negatively related to suicide ideation (β = -.233, p < .01) and the beta for optimism reduced to -.333 (p<.001). This suggests that acceptance mediated the relationship between optimism and suicide ideation at time 3. This was confirmed by Sobel testing (z = -2.10, p <.05).

Table 8-30 Hierarchal regression analysis between optimism and time 3 adjustment, not controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 3						
	1	MS Type	.092***	.303***	.229**	.133
	2	Optimism	.221***		-.367***	-.308***
	3	Physical Assistance	.310***			.322***
Psychological Impact Time 3						
	1	Optimism	.190***	-.436***	-.340***	
	2	Physical Assistance	.244*		.214*	
		Acceptance			-.127	
Physical Impact Time 3						
	1	MS type	.119***	.345***	.285***	.178*
	2	Optimism	.204***		-.299***	.243**
	3	Physical Assistance	.310***			.350***
		Acceptance				.021
Anxiety Time 3						
	1	Optimism	.195***	-.442**	-.356***	
	2	Acceptance	.238*		-.225*	
Depression Time 3						
	1	Optimism	239***	-.488***	-.395***	
	2	Acceptance	.285**		-.135	
		Physical Assistance			.189*	
Hopelessness Time 3						
	1	MS type	.089***	.299***	.197*	.196*
	2	Optimism	.378***		-.547***	-.458***
	3	Physical Assistance	.414*			.047
		Acceptance				-.206*
Suicide Ideation Time 3						
	1	MS Type	.071**	.67**	.182*	.202*
	2	Optimism	.255***		-.424**	-.333***
	3	Acceptance	.290**			-.233**

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

8.4.11 Hypothesis 6 - Concurrent and prospective investigation of future thinking, coping and adjustment.

Hypothesis 6 (i) postulates that future thinking and coping are predictive of adjustment at time 1, 2 and 3. A series of regression analyses were therefore carried out to investigate whether future thinking and coping predict adjustment concurrently and at 4 and 8 months later. The steps reflect a model in which adjustment is assumed to be predicted by coping, which in turn is hypothesised to be predicted by future thinking. To reduce the likelihood of making a type 1 error, only those future thinking components and coping strategies, which correlated with the outcome variables at a p<.01 level of significance, were entered into the regression analysis. It was also hypothesised (6 ii) that coping mediates the relationship between future thinking and adjustment to MS at time 1, 2 and 3.

8.4.11.1 Hierarchical regression analysis to determine whether future thinking and coping predict time 1 adjustment.

A series of regression analyses were carried out to investigate whether future thinking and coping predict adjustment at time 1. These are shown in table 8-31. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn hypothesised to be predicted by future thinking. If any demographic variables or illness characteristics correlated with the dependent variable at p<0.01 level, they were entered into step one, future thinking was entered in the next step and coping strategies variables were entered in the final step. As shown in table 8-30, all the steps in the regressions were significant. This shows that future thinking and coping positively predicted all the adjustment variables at time 1.

MS type was positively related to overall MS impact and hopelessness at time 1. These were investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.1.

Overall MS impact at time 1 was positively predicted by negative future thoughts over the next year ($\underline{\beta}$ = .246, $p < .01$) and this beta reduced to .182 ($p<.01$) in step two, when coping was added to the model. The results suggest that physical assistance coping plays a mediating role, as it positively predicted overall MS impact ($\underline{\beta}$ = .384, $p < .001$) at time 1. However, Sobel testing did not confirm that the inclusion of physical assistance significantly reduced the beta for negative thoughts over the next year ($z = -.12$, $p = .90$).

Psychological impact at time 1 was positively predicted by negative future thoughts over the next year ($\underline{\beta}$ = .303, $p < .05$). In step two when coping was added to the model, this beta reduced to .222 and became non-significant and acceptance negatively predicted psychological impact at time 1 ($\underline{\beta}$ = -.351, $p < .001$). The results suggest that acceptance coping plays a mediating role between negative future thinking for the next year and psychological impact at time 1. This was confirmed by Sobel testing ($z = 2.76$, $p <.01$).

Negative future thoughts about the next year was also found to be positively related to time 1 anxiety ($\underline{\beta}$ = .217, $p < .01$) in step one. This became non-significant when coping acceptance was added to the model. However, acceptance did not significantly predict time 1 anxiety.

For depression and hopelessness at time 1, only acceptance significantly predicted these adjustment variables ($\underline{\beta}$ = -.241, $p < .01$ and $\underline{\beta}$ = -.275, $p < .001$, respectively).

Suicide ideation at time 1 was positively predicted by negative future thoughts over the next year ($\underline{\beta}$ = .310, $p < .001$), in step one. When coping was added to the model, the beta for this component reduced to .273 ($p<.001$). In step two suicide ideation at time 3 was negatively predicted by acceptance ($\underline{\beta}$ = -.202, $p < .05$) and positively predicted by avoidance (β = .265, p < .001). The results suggest that acceptance and/or avoidance coping plays a mediating role, between negative future thinking for the next year and suicide ideation at time 1. Sobel testing confirmed that this relationship was mediated by acceptance (z = 2.14, p <.05) but not avoidance (z = -.82, p =.41).

Table 8-31 Hierarchical regression analysis to determine whether future thinking and coping predict adjustment impact at time 1

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 1						
	1	MS Type	.132***	.363***	.383***	.223**
	2	Negative Year	.192***		.246**	.182**
	3	Physical Assistance	.433***			.384***
		Personal Health Control				.084
		Acceptance				-.229
		Energy Conservation				-.006
		Social Support				.027
Psychological Impact Time 1						
	1	Negative Week	.094**	.188	.175	
		Negative Year		.303*	.222	
		Negative Total		-.146	-.166	
	2	Physical Assistance	.288***		.107	
		Acceptance			-.351***	
		Social Support			.127	
		Personal Health Control			.085	
Anxiety Time 1						
	1	Negative Week	.117***	.175	.151	
		Negative Year		.217*	.146	
		Negative total		-.006	-.005	
	2	Acceptance	.295***		-.324	
Depression Time 1						
	1	Positive Week	.219***	-.356	-.204	
		Positive Total		-.069	-.142	
		Negative Week		.162	.166	
		Negative Year		.223	.166	
		Negative total		.030	-.013	
	2	Physical Assistance	.315***		.114	
		Acceptance			-.241**	
		Social Support			.137	

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Hopelessness Time 1						
	1	MS type	.039*	.197*	.175*	.143
	2	Positive Week	.130**		-.315	-.105
		Positive 5-10 year			.277	-.187
		Positive total			.241	.015
	3	Problem Solving	.223**			-.046
		Physical Assistance				.087
		Acceptance				-.275***
Suicide Ideation Time 1						
	1	Positive Week	.186***	-.281	-.237	
		Positive Year		-.030	-.072	
		Positive Total		-.100	-.092	
		Negative Year		.310***	.273***	
	2	Acceptance	.249***		-.202*	
		Avoidance			.265***	

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

8.4.11.2 Hierarchical regression analysis to determine whether future thinking and coping predict time 2 adjustment.

A series of regression analyses were carried out to investigate whether future thinking predicts coping and adjustment to MS, 4 months later. Firstly, separate regressions were carried out to investigate the relationship between future thinking and adjustment. This was followed by a series of hierarchical regression analyses to examine whether illness representations predict coping, which in turn predict adjustment to MS, 8 months later.

8.4.11.3 Separate regressions for the relationship between future thinking and time 2 adjustment.

Separate regressions were initially performed in order to investigate, in greater detail the relationship between future thinking and adjustment, 4 months later. As shown in table 8-32 future thoughts were positively related to depression (R^2 = .081, p<.001), anxiety (R^2 = .082, p< .01), hopelessness (R^2 = .114, p<.01) and suicide ideation (R^2 =

.059, p<.001) 4 months later. Positive future thoughts negatively predicted depression at 4 months (β = -.284, p < .001). However, no other significant relationships were identified.

Table 8-32 Hierarchal regression analysis between future thinking and time 2 adjustment.

	Predictors	R^2	Final Beta
Depression Time 2			
	Positive Week	.081***	-.284***
Anxiety Time 2			
	Negative Week	.082**	.102
	Negative Year		.178
	Negative Total		.079
Hopelessness Time 2			
	Positive Week	.114**	-.358
	Positive 5-10 Year		-.318
	Positive Total		.302
Suicide Ideation Time 2			
	Positive Week	.059*	-.161
	Positive Total		-.082

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

8.4.11.4 Hierarchical regression analysis to determine whether future thinking and coping predict adjustment at time 2, when time 1 is controlled for.

A series of regression analyses were carried out to investigate the relationship between future thinking, coping and adjustment at time 2, controlling for time 1 adjustment. The steps reflect a model in which adjustment is assumed to be predicted by coping, which is in turn assumed to be predicted by future thinking. For this analysis only those future thinking components and coping strategies, which correlated with the adjustment variables at a p<.01 level of significance, were included in the analysis. The scores for the outcome variables measured at time 1 were first controlled for, along with any illness characteristics variables or demographic variables, which correlated with the dependent variable at p<.01 in step one. Any future thinking components, which correlated with the outcome variable at p<.01 level were entered into step two and the coping strategies variables, which correlated with the outcome variable were entered in step three. As shown in table 8-33, only step one was significant in each of the regressions.

MS type was positively related to depression at time 2. This relationship was investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.7.

Table 8-33 Hierarchal regression analysis between future thinking and time 2 adjustment, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2						
	1	Anxiety Time 1	.561***	.749***	.738***	.673***
	2	Negative Week	.564		-.046	-.047
		Negative Year			-.054	-.064
		Negative Total			.130	.132
	3	Personal Health Control	.583			.083
		Acceptance				-.141*
Depression Time 2						
	1	Depression Time 1	.526***	.693***	.680***	.660***
		MS Type		.1488	.143*	.167*
`	2	Positive Week	.528		-.041	-.047
	3	Physical Assistance	.541			-.089
		Acceptance				.-.080
Hopelessness Time 2						
	1	Hopelessness Time 1	.584***	.764***	.732***	.660***
	2	Positive Week	.593		-.118	-.021
		Positive 5 Year			.119	-.090
		Positive Total			.127	.025
	3	Physical Assistance	.618*			.051
		Acceptance				-.171
Suicide Ideation Time 2						
	1	Suicide Ideation Time 2	.598***	.773***	.774***	.742***
	2	Positive Week	.601		.100	.144
		Positive Total			-.177	-.156
	3	Acceptance	.609			-.101

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

8.4.11.5 Hierarchical regression analysis to determine whether future thinking and coping predict outcomes at time 2, when time 1 is not controlled for.

Due to the small number of significant results found from these regressions, a second series of regression analyses were carried out, not controlling for time 1. As shown in table 8-34, these regression analyses included the same outcome variables. However, the outcome measure taken at time 1, for each outcome variable, was not controlled for. If any illness characteristic or demographic variables correlated with the adjustment variables at a $p<.01$ then these were entered at step one. Any future thinking components, which correlated with the outcome variable at a $p<.01$ level of significance, were entered in the subsequent step and the correlated coping strategies were entered in the final step.

As shown in table 8-34, all the steps in each of the regressions were significant. This shows that future thinking and coping positively, predicted anxiety, depression, hopelessness and suicide ideation, at time 2.

Anxiety at time 2 was negatively predicted by acceptance ($\underline{\beta} = -.360$, $p < .001$) and positively predicted by personal health control ($\underline{\beta} = .167$, $p < .05$). Hopelessness at time 2 was negatively predicted by acceptance ($\underline{\beta} = -.402$, $p < .001$) and positively predicted by physical assistance ($\underline{\beta} = .173$, $p < .05$). Suicide ideation at time 2 was also negatively predicted by acceptance ($\underline{\beta} = -.331$, $p < .001$). None of the future thinking components positively predicted anxiety, hopelessness and suicide ideation, at time 2.

MS type was positively related to depression at time 2. This relationship was investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.7.

Depression at time 2 was also negatively predicted by positive future thoughts over the next week ($\underline{\beta} = -.255$, $p < .01$) in step one. When coping was added to the model, acceptance was negatively related to depression ($\underline{\beta} = -.298$, $p < .001$) and the beta for positive future thoughts over the next week reduced to -.181 (p<.05). This suggests that acceptance mediated the relationship between this future thinking component and depression at time 2. However, Sobel testing did not confirm that the inclusion of acceptance significantly reduced the beta for positive future thoughts over the next week (z = -1.67, p =.09).

Table 8-34 Hierarchal regression analysis between future thinking and time 2 adjustment, not controlling for time 1.

	Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Anxiety Time 2					
	1 Negative Week	.104**	.102	.064	
	Negative Year		.178	.100	
	Negative Total		.079	.099	
	2 Personal Health Control	.262***		.167*	
	Acceptance			-.360***	
Depression Time 2					
	1 MS Type	.052*	.229*	.190*	.172*
	2 Positive Week	.116**		-.255**	-.181*
	3 Physical Assistance	.204**			.057
	Acceptance				-.298***
Hopelessness Time 2					
	1 Positive Week	.114**	-.358	-.067	
	Positive 5 Year		-.318	-.209	
	Positive Total		.302	.037	
	2 Physical Assistance	.291***		.173*	
	Acceptance			-.402***	
Suicide Ideation Time 2					
	1 Positive Week	.059*	-.167	.013	
	Positive Total		-.082	-.215	
	2 Acceptance	.160***		-.331***	

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

8.4.11.6 Hierarchical regression analysis to determine whether future thinking and coping predict time 3 adjustment.

A series of regression analyses were also carried out to investigate whether future thinking predicted coping and adjustment to MS, 8 months later. Firstly, separate regressions were carried out to investigate the relationship between future thinking and adjustment. This was followed by a series of hierarchical regression analyses to examine whether future thinking predicted coping, which in turn predicted adjustment to MS, 8 months later.

8.4.11.7 Separate regressions for the relationship between future thinking and time 3 adjustment.

Separate regressions were initially performed in order to investigate, in greater detail the relationship between future thinking and adjustment 8 months later. As shown in table 8-35 individual's future thoughts were positively related to overall MS impact (R^2 = .060, p<.05), physical impact (R^2 = .058, p<.01), depression (R^2 = .118, p<.01), anxiety (R^2 = .112, p< .01), hopelessness (R^2 = .093, p<.05) and suicide ideation (R^2 = .082, p<.01), 8 months later. Positive total future thoughts negatively predicted physical impact at 8 months (β = -.241, p < .01). Positive future thoughts for the next five to ten years negatively predicted depression at 8 months (β = -.658, p < .05). Positive future thoughts for the next week negatively predicted suicide ideation at 8 months (β = -.286, p < .01).

Table 8-35 Hierarchal regression analysis between future thinking and time 3 adjustment.

	Predictors	R^2	Final Beta
Overall MS Impact Time 3			
	Positive Week	.060*	-.012
	Positive Total		-.235
Physical Impact Time 3			
	Positive Total	.058**	-.241**
Depression Time 3			
	Positive Week	.118**	.207
	Positive Year		.179
	Positive 5-10 Years		-.658*

	Predictors	R^2	Final Beta
Anxiety Time 3			
	Negative Week	.112**	.094
	Negative Year		.071
	Negative Total		.211
Hopelessness Time 3			
	Positive Week	.093*	-.324
	Positive 5-10 Years		-.255
	Positive Total		.241
Suicide Ideation Time 3			
	Positive Week	.082**	-.286**

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

8.4.11.8 Hierarchical regression analysis to determine whether future thinking and coping predict adjustment at time 3, when time 1 is controlled for.

A series of regressions analyses were carried out to investigate the relationship between future thinking, coping and adjustment at time 3. The steps reflect a model in which adjustment are assumed to be predicted by coping, which is in turn assumed to be predicted by future thinking. For this analysis only those future thinking components and coping strategies, which correlated with the adjustment variables at a p<.01 level of significance, were included in the analysis. The scores for the outcome variables measured at time 1 were first controlled for, along with any illness characteristics variables or demographic variables, which correlated with the dependent variable at p<.01 in step one. Future thinking components, which correlated with the outcome variable at p<.01 level, were entered into step two and the coping strategies variables, which correlated with the outcome variable were entered in step three. As shown in table 8-36, only step one was significant in each of the regressions. MS type positively predicted suicide ideation at time 3. MS type was positively related to suicide ideation at time 3. This relationship was investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.13.

Table 8-36 Hierarchal regression analysis between future thinking and time 3 adjustment, not controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Overall MS Impact Time 3						
	1	MS Impact Time 1	.615***	.774***	.765***	.753***
		MS type		.027	.021	.071
	2	Positive Week	.624		.081	.082
		Positive Total			-.157	-.153
	3	Physical Assistance	.624			.027
Physical Impact Time 3						
	1	Physical Impact Time 1	.570***	.744***	.732***	.732***
		MS type		.025	.020	.012
	2	Positive total	.575		-.074	-.073
	3	Physical Assistance	.579			.024
		Acceptance				.058
Depression Time 3						
	1	Depression time 1	.560***	.748***	.711***	.705***
	2	Positive Week	.562		-.055	-.049
		Positive Year			-.056	-.047
		Positive 5 Year			-.046	-.049
	3	Physical Assistance	.578			-043
		Acceptance				.007
Anxiety Time 3						
	1	Anxiety Time 1	.620***	.787***	.760***	.756***
	2	Negative Week	.635		-.036	-.035
		Negative Year			-.099	.-100
		Negative Total			.222	.222
	3	Acceptance	.635			-.011
Suicide Ideation Time 3						
	1	Suicide Time 1	.555***	.104***	.686***	.651***
		MS Type		.156*	.148*	.156*
	2	Positive Week	560			-.063
	3	Acceptance	.568			-.098
Hopelessness Time 3						
	1	Hopelessness Time 1	.553***	.695***	.675***	.629***
		MS type		.160*	.159*	.162*
	2	Positive Week	.557		-.120	-.047
		Positive 5-10 Year			-.095	-.060
		Positive Total			-.151	-.063
	3	Acceptance	.569			-.122
		Physical Assistance				.031

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

8.4.11.9 Hierarchical regression analysis to determine whether future thinking and coping predict outcomes at time 3, when time 1 is not controlled for.

Due to the small number of significant results from these regressions, a second series of regression analyses were carried out, not controlling for time 1. As shown in table 8-37 these regression analyses included the same outcome variables however, the outcome measure taken at time 1, for each outcome variable, was not controlled for. If any illness characteristic or demographic variables correlated with the adjustment variables at a $p<.01$, then these were entered at step one. Any future thinking components, which correlated with the outcome variable at a $p<.01$ level of significance were entered in the subsequent step and the correlated coping strategies were entered in the final step.

As shown in table 8-37, for depression, anxiety, hopelessness and suicide ideation all the steps in each of the regressions were significant. However, only step one and three were significant in the regressions for overall MS impact and physical impact. None of the future thinking components predicted overall MS impact, physical impact, hopelessness or anxiety, at time 3. MS type was positively related to overall MS impact, physical impact, suicide ideation and hopelessness, at time 3. These relationships were investigated previously using a one way analysis of variance and the results are reported in section 8.4.9.13.

In addition to MS type, physical assistance also positively predicted overall MS impact ($\underline{\beta} = 358$, $p < .001$) and physical impact ($\underline{\beta} = .377$, $p < .001$), at time 3. Furthermore, acceptance negatively predicted hopelessness ($\underline{\beta} = -.348$, $p < .001$) and anxiety ($\underline{\beta} = -.294$, $p < .001$), at time 3.

Depression at time 3 was negatively predicted by total positive future thoughts ($\underline{\beta} = -.658$, $p < .001$) in step one and this beta reduced to -.355 and became non-significant when coping was added to the model. In step two, depression was positively predicted by physical assistance (β = .192, p < .05) and negatively predicted by acceptance (β = -.261, p <.01). This suggests that physical assistance and/or acceptance, mediated the relationship between total positive future thoughts and depression, at time 3. However, Sobel testing did not confirm that the inclusion of physical assistance (z = 1.64, p =.10) or acceptance (z = -.44, p =.66) significantly reduced the beta for total positive future thoughts.

Suicide ideation at time 3 was negatively predicted by positive future thoughts over the next week (β = -.244, p < .01) in step one and this beta reduced to -.180 (p<.05) when coping was added to the model. In step two, suicide ideation was negatively predicted by acceptance (β = -.322, p <.001), which suggests that acceptance mediated the relationship between positive future thoughts for the week and suicide ideation at time 3. However, Sobel testing did not confirm that the inclusion of acceptance significantly reduced the beta for positive future thought for the week (z = -1.56, p =.12).

Table 8-37 Hierarchical regression analysis between future thinking and time 3 adjustment, not controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
MS Impact Time 3						
	1	MS type	.092***	303***	.278**	.171
	2	Positive Week	.124		-.006	.027
		Positive Total			-.176	-.118
	3	Physical Assistance	.230***			.358***
Physical Impact Time 3						
	1	MS type	.119***	.345***	.321***	.208*
	2	Positive total	.147		-.170	-.073
	3	Physical Assistance	.269***			.377***
		Acceptance				-.063

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Depression						
	1	Positive Year	.118**	.207	.018	
		Positive 5-10 Years		.179	.102	
		Positive Total		-.658*	-.355	
	2	Physical Assistance	.211**		.192*	
		Acceptance			-.261**	
Anxiety Time 3						
	1	Negative Week	.122**	.094	.079	
		Negative Year		.071	.013	
		Negative Total		.211	.216	
	2	Acceptance	.204***		-.294***	
Suicide Ideation Time 3						
	1	MS Type	.071**	.267**	.230**	.242**
	2	Positive Week	.129*		-.244**	-.180*
	3	Acceptance	.229***			-.322***
Hopelessness Time 3						
	1	MS type	.089***	.299***	.271**	.253**
	2	Positive Week	.158*		.010	.098
		Positive Year			.312	.157
		Positive Total			-.488	-.276
	3	Acceptance	.174***			-.348***
		Physical Assistance				.009

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

8.4.12 Hypothesis 7 – The role of hopelessness

A regression analysis was carried out to investigate the relationship between anxiety, depression, hopelessness and suicide ideation, at time 1. The steps reflect a model in which suicide ideation is assumed to be predicted by hopelessness, which is in turn assumed to be predicted by anxiety and depression. As shown in table 8-38 suicide ideation at time 1 was positively predicted by anxiety (β = .365, p < .001) and depression (β = .207, p < .05) in step one and the betas reduced to .218 (p<.01) and .075 (non-significant) respectively when hopelessness was added to the model. In step two suicide ideation was positively predicted by hopelessness (β = .418, p < .001), suggesting that hopelessness may act as mediator between these variables and suicide ideation at time 1. Sobel testing confirmed this for the anxiety (z = 4.64, p =.001) and depression (z = 4.83, p =.001).

Table 8-38 Hierarchical regression analysis between anxiety, depression, hopelessness and time 1 suicide ideation.

	Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Suicide Ideation Time 1					
1	Anxiety Time 1	.277**	.365***	.218**	
	Depression Time 1		.207*	.075	
2	Hopelessness Time 1	.387		.418***	

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

A series of regression analyses were also carried out to investigate the relationship between anxiety, depression, hopelessness and suicide ideation at time 2 and 3 controlling for time 1 suicide ideation. The steps reflect a model in which suicide ideation over time is assumed to be predicted by hopelessness, which is in turn assumed to be predicted by anxiety and depression. Suicide ideation at time 1 was controlled for in step one, anxiety and depression were entered in step two and hopelessness was entered at step three. As shown in table 8-39, only hopelessness was found to predict suicide ideation at time 2. Suicide ideation at 8 months however, was predicted by depression (β = .225, p < .05) in step two and hopelessness (β = .253, p < .01) in step three. Furthermore, when hopelessness was added to the model the beta for depression reduced to .164 and became non-significant. This suggests that hopelessness mediates the relationship between depression and suicide ideation, at time 3. This was confirmed by Sobel testing (z = 2.53, p =.01).

Table 8-39 Hierarchical regression analysis between anxiety, depression, hopelessness and suicide ideation at time 2 and 3, controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)	Beta (Step 3)
Suicide Ideation Time 2						
	1	Suicide Ideation Time 1	.552***	743***	.740***	.623***
	2	Anxiety Time 1	.553		.036	.050
`		Depression Time 1			-.027	-.108
	3	Hopelessness Time 1	.606***			.318***
Suicide Ideation Time 3						
	1	Suicide Ideation Time 1	.449***	.670***	.585***	.494***
	2	Anxiety Time 1	.480*		-.053	-.102
		Depression Time 1			.225*	.164
	3	Hopelessness Time 1	.515**			.253**

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

A series of regression analyses were also carried out to investigate the relationship between anxiety, depression, hopelessness and suicide ideation at time 2 and 3 not controlling for time 1 suicide ideation. As shown in table 8-40 anxiety predicted suicide ideation at time 2 (β = .225, p < .05). In step two hopelessness was also found to predict suicide ideation at time 2 (β = .225, p < .05) and the beta for anxiety reduced to .065 and became non-significant. This suggests that hopelessness mediates the relationship between anxiety and suicide ideation, at time 2. This was confirmed by Sobel testing (z = 5.23, p =.001).

The results also found that depression predicted suicide ideation at time 3 (β = .381, p < .05). In step two hopelessness was also found to predict suicide ideation at time 2 (β = .444, p < .001) and the beta for depression reduced to .230 (p<.05). This suggests that hopelessness may mediate the relationship between depression and suicide ideation at time 3. This was confirmed by Sobel testing (z = 4.26, p =.001).

Table 8-40 Hierarchical regression analysis between anxiety, depression, hopelessness and suicide ideation at time 2 and 3, not controlling for time 1.

		Step/Predictors	R2	Beta (Step 1)	Beta (Step 2)
Suicide Ideation Time 2					
	1	Anxiety Time 1	.171***	.243*	.065
		Depression Time 1		.211	.004
`	2	Hopelessness Time 1	.376***		.577***
Suicide Ideation Time 3					
	1	Anxiety Time 1	.245***	.153	.009
		Depression Time 1		.381***	.230*
	2	Hopelessness Time 1	.371***		.444***

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

8.5 Discussion

This section discusses the results of Study 3. The design of this study was based primarily of the SRM framework, and its aim was to investigate the relationship between illness representations, coping and adjustment to MS over an 8 month period. As discussed in Chapter 3, other psychological models have identified the illness cognitions cognitive schema, optimism and future thinking as important predictors of psychological distress. However, Study 1 found limited evidence for the role of cognitive schema and consequently, this was not assessed in Study 3. Based on the SRM framework, an extended SRM was proposed in Figure 8-1, which included optimism and future thinking. In addition to discussing the main findings of this study, the methodological limitations are also outlined, along with the clinical implications.

8.5.1 Summary of emergent relationships

In Chapter 4 section 4.3, a series of research questions were proposed based on the findings and limitations of previous research. Study 3 was designed to address some of these research questions and consequently, determine the utility of the extended SRM model (see Figure 8-1) in predicting adjustment to MS. Using the results from Study 3, this section addresses each of the following proposed research questions.

8.5.1 Question 1 – What is the relationship between the illness representation components?

Previous MS research by Vaughan et al (2003) and also Study 1 found that some of the illness representation components were inter-related. These findings provided support for Heijman et al’s (1998) proposition that these components could be conceptualisedn as groups of beliefs, as opposed to single cognitions. They also provided support for Hagger and Orbell's (2001) view that some of these beliefs are inter-dependent. The results of Study 3 provide further evidence for these proposals. Negative illness beliefs were found to be inter-related, as were more positive ones. Furthermore, negative beliefs were associated with lower levels of positive beliefs. Consistent with previous research (Hampson et al., 1990; Heijmans, 1998; Moss-Morris et al., 1996; Schiaffino et al., 1998; Vaughan et al., 2003; Weinman et al., 1996) and the results of Study 1, the relationship between a strong illness identity and serious consequences was identified, suggesting that patients who strongly identify with their MS also believe their condition has a considerable impact on their lives. Study 3 also found evidence for the relationship between the timeline component, serious consequences and lower levels of control, which was identified by Vaughan et al (2003). The findings suggest that believing the condition will last a long time, compromises the individual's sense of control over their MS and makes them feel that the illness has a severe impact on the life. Overall the findings of Study 3 provided support for the hypothesis (1i) that illness representations are inter-related.

The results also provided support for hypothesis 2ii that illness representations would be correlated to optimism and future thinking. Consistent with Study 1 the findings suggest that illness representations are not only inter-dependent with one another, they are also inter-dependent with other illness cognitions. Study 3 found that the negative illness representation components time cyclical, consequences and emotional representations, were related to lower levels of optimism and greater negative future thoughts. These findings suggest that individuals who had a more negative view of their condition, found it difficult to be optimistic and felt more negative about their future.

Overall the findings provide support for hypothesis 1 (i) and (ii). In addition, to investigating the relationship between the different illness representation components and their relationship with optimism and future thinking, Study 3 also examined whether they were related to how individuals cope and adjust with MS. This is the focus of the following section.

8.5.1.2 Question 2– What is the relationship between illness representations, coping and adjustment at time 1, 2 and 3?

According to the SRM (Leventhal et al, 1980), illness representations are directly related to coping, which in turn is related to adjustment (see Chapter 2, section 2.6.2). Study 1 represented the first attempt to fully examine the relationships between SRM components in MS. The results revealed that illness beliefs, coping and adjustment were statistically related, which is consistent with relationships outlined by this model. Study 3 examined these relationships further, using a larger sample and measuring adjustment at three time points.

Based on the findings of Study 1, it was hypothesised (2i & ii) that illness representations would be correlated with coping and coping would be correlated with adjustment, which is consistent with the relationships outlined in the SRM. Those with greater personal control employed greater problem-solving. This is consistent with previous research by Hagger and Orbell (2001), who found that control beliefs were related to more active coping. The findings suggest that those who felt more in control of their condition felt more confident about relying on more active forms of coping. The current study also found that problem-solving was associated with lower levels of hopelessness at all three time points. These findings are consistent with previous research which has found a persistent relationship between problem-focused coping and well-being (Folkman & Lazarus, 1986; Pakenham, 1999). The findings suggest that those who feel more in control of their MS are more likely to engage in greater problem solving strategies and those employing these strategies feel more hopeful over time.

The results also revealed that those who felt their condition had serious consequences were more likely to ask for physical assistance, whereas those who felt they could control their condition were less likely to rely on this coping strategy. Individuals who rely on physical assistance are more likely to feel dependent on others, or have to rely on physical aids to move around. It is therefore expected that they would feel the condition has more serious consequences. Moreover, those who feel that they have no control over their bodies are more likely to feel they need physical assistance, in order to manage. This type of coping was also found to be associated with poorer adjustment, at all three time points. This suggests firstly, that individuals who are more physically disabled are more likely to rely on more physical assistance and secondly, those who have to rely on this as a means of coping experience greater psychological distress.

Study 1 found that the more negative illness beliefs (identity, emotional representations, consequences, psychological cause, time cyclical) were associated with lower levels of acceptance whereas, the more positively beliefs (personal control, illness coherence) were related to greater acceptance. Consistent with previous research by Pakenham et al (2001) and the results of Study 1, acceptance was found to be associated with better adjustment to MS. This current study found acceptance was related to better outcomes at all three time points. The results suggest that those with more negative illness perceptions are less likely to accept their condition and those who rely on this type of coping, experience greater physical disability and psychological distress.

Personal health control was found to be positively related to identity, emotional representations and consequences and was negatively associated with timeline. Furthermore, this coping strategy was found to be associated with poorer adjustment at all three time points. This is inconsistent with previous research by Pakenham et al (2001) who found that this type of coping was beneficial. However, the results for personal health control in the current study must be considered with caution, as this subscale was found to have a low internal reliability (see section 8.4.3.2, table 8-2). Previous research has found a persistant relationship between personal control beliefs and better adjustment. Greater personal control has been found to lead to lower depression and greater self-esteem (Jopson & Moss-Morris, 2003; Shnek et al., 1995; Vaughan et al., 2003). Furthermore, research based on the health locus of control theory, suggests that individuals who are more internally control orientated experience lower levels of depression (Halligan & Rezinikoff, 1985), a milder MS course (Wassem, 1991) and lower levels of hopelessness (Hickey & Greene, 1989). These findings suggest that the inconsistent results of the current study may be unreliable. Personal health control coping was assessed in the current study using the CMSS. This is a relatively new instrument, designed to measure MS-specific coping. To date the only published study, which has reported the reliability and validity of the CMSS is by the researchers who developed the measure. Pakenham (2001) found that this subscale had a reliability of .57 and was associated with better subjective health status. The inconsistency between Pakenham et al (2001) and the current findings may be a result of the difference in the study samples. Participants for Pakenham et al’s (2001) study were recruited from MS societies in Australia, as opposed to the clinical samples of MS patients recruited from Scotland in the current research.

This current study also found that more negative illness beliefs were associated with greater energy conservation strategies, which in turn was related to poorer adjustment, in particular greater overall and physical dysfunction at time 1 and 2. The findings suggest that individuals who hold a more negative view of their condition will be more likely to pace themselves as a means of coping. In addition, those who employ energy conservation strategies are also more physically disabled.

Previous research by Pakenham et al (2001) found that social support was beneficial to MS. However, the current study found that this type of coping was associated with poorer adjustment at time 1 and 2. In addition, those with more negative illness beliefs were found to rely on this type of coping.

Although the SRM identifies coping as the mediator between illness representations and adjustment, the findings of the previous MS research (Vaughan et al., 2003) and the results of Study 1, suggest that illness representations have a direct impact on adjustment. Individuals who hold a more negative view of their condition have been shown to experience greater psychological distress. Consistent with this, Study 3 found that the negative illness beliefs, consequences, emotional representations, identity, psychological cause and time cyclical were all related to poorer adjustment and greater psychological distress concurrently, 4 and 8 months later. Whereas, the positive illness representation components personal control, treatment control and illness coherence were associated with better adjustment at all three time points. The results therefore support the hypothesis (2iii) that illness representations and adjustment to MS at time 1, 2 and 3 would be correlated.

Overall the findings of the correlations provide support for hypothesis 2 (i),(ii) and (iii). To investigate these relationships further, Study 3 also carried out a series of regression and mediation analysis to determine whether illness representations and coping could predict adjustment to MS, over 8 months. These findings are discussed in the following section.

8.5.1.3 Question 3 – Do illness representations and coping predict adjustment to MS?

According to the SRM (Leventhal et al 1980) illness representations predict coping, which in turn predicts adjustment to illness. Study 1 represented the first attempt to fully apply the SRM to understanding adjustment to MS, over time. However, Study 1 was only designed to assess adjustment over a two month time frame. Study 3 addressed this limitation by examining the utility of the SRM in predicting adjustment to MS over a period of 8 months. The results supported the hypothesis (4i) that illness representations and coping would be predictive of adjustment at time 1, 2 and 3, in line with the relationships outlined in the SRM.

Consistent with the findings of Study 1, Study 3 found that negative illness representations (consequences, emotional representations, identity) predicted poorer psychological and physical adjustment and greater psychological distress, at time 1. These findings are also consistent with previous MS research by Vaughan et al (2003) and Jopson and Moss-Morris (2003) who also found that negative illness beliefs predicted poorer outcome. One of the main limitations of this previous research was that it did not provide evidence for the role of illness beliefs in predicting adjustment to MS over time. In Study 1 illness representations were found to predict adjustment to MS, 2 months later. The current study provides additional support for ability of illness beliefs to predict adjustment to MS over time. This study found that the illness representations consequences, identity and emotional representations, not only predicted poor adjustment to MS at time 1, they also predicted poorer outcomes 4 and 8 months later. In addition to highlighting the importance of these negative illness representation components in predicting adjustment, the current study also found that the individual’s control beliefs had an influence on how well they adjusted. The results revealed that those who believed they could control their condition with treatment were, more hopeful at time 1. Moreover, those who believed they could personally control their illness felt more hopeful four months later. This is consistent with previous research by Hickey and Greene (1989) who found that those individuals with more internal control beliefs experienced lower levels of hopelessness.

Previous research investigating adjustment to MS has not only investigated the role of illness beliefs in predicting adjustment, it has also assessed the impact of coping. Consistent with the results of Study 1, the current study found that the way in which individuals coped with their MS predicted how well they adjusted. This study found that physical assistance predicted poorer adjustment to MS. Previous research by Pakenham et al (2001), found that this subscale was related to illness variables such as disease course, number of symptoms and time since diagnosis and was therefore confounded with the level of participant’s disability. Those who were more disabled, relied more on physical assistance. The results of Study 2 suggest that the reliance on physical aids is associated with the feeling that the individual no longer has control over their body and is associated with a change in identity, to someone who is ‘disabled’. These findings suggest that it is the patient’s perceptions of this type of coping, which may lead to the high levels of psychological distress identified in the current study.

As discussed previously, research provides mixed findings about whether emotional release is adaptive or maladaptive. However, the findings of Study 3 are consistent with those from Study 1 and with Hagger and Orbell (2003), which suggest this strategy is maladaptive.

Also consistent with Study 1 was the finding that problem solving coping and acceptance was beneficial. The results suggest that individuals who engaged in more problem-solving as a means of coping felt less hopeless at time 1. This finding supports previous research, which found a persistant relationship between problem-focused coping and greater well-being (Folkman & Lazarus, 1986; Pakenham, 1999; Pakenham, 2001). Study 3 also showed that those who accepted their condition experienced lower levels of depression, psychological dysfunction and suicide ideation. Of all the coping subscales in Pakenham et al's (2001) study, acceptance was most strongly and consistently related to better adjustment across all but one domain. In addition, Brooks and Matson (1982) found that acceptance in MS was predictive of better self concept, 7 years later.

Inconsistent with Pakenham's (2001) findings (see Chapter 3, section 3.2.2.4), personal health control coping predicted greater physical impact. This is also inconsistent with the earlier findings that personal control (measured by the IPQ-R) predicted better adjustment at 4 months. One explanation for this inconsistency (as discussed in section 8.5.1.2) is that the internal reliability coefficient for this subscale was very low (see section 8.3.3.2, table 8-2). Consequently, this finding should be interpretated with caution.

It is important to note that the findings reported for the longitudinal analysis are based on the regressions not controlling for time 1. The only significant relationship identified in those controlling for time 1 was between the consequences component and physical impact at time 2. This finding suggested that a belief that MS has serious consequences, predicted an increase in the patient's level of physical disability over 4 months. The results therefore only provided limited support for the hypothesis 4 (i) that illness representations and coping predict adjustment, consistent with the relationships outlined in the SRM. There are two possible explanations for this. Firstly, this could reflect a limitation in the design of the current research. As discussed previously, MS is a life long condition and since many patients had suffered from the condition for many years, changes in adjustment are likely to occur over a long time period. It was hoped that 8 months would be a long enough time in which to notice a significant change, however, results do not support this. It could therefore be argued that the current research did not employ a long enough follow up time in which to notice a significant change. However an alternative explanation is that the limited support for the SRM reflects a limitation in this theoretical model for predicting adjustment to MS prospectively. To date the current research represents the attempt to fully apply the SRM to understand adjustment prospectively. Further research is therefore required to determine whether the limited support identified for the model is a result of a limitation in the current research design or if it reflects a limitation in the theoretical model.

According to the SRM, coping mediates the relationship between illness representations and adjustment to illness. Previous research however, has investigated the role of illness beliefs and coping independently. The results of Study 1 supported the SRM, that coping mediates the relationships between illness beliefs and adjustment. The current study did provide further support for this. Physical assistance mediated the relationship between consequences and overall impact at time 1 and psychological impact at 4 months. The results suggest that individuals who believe their MS has serious consequences, are more likely to ask for physical assistance and as a result, experience greater overall dysfunction concurrently and greater psychological dysfunction 4 months later. Consistent with the results of Study 1, acceptance was found to mediate the largest number of relationships. The findings revealed that those with more negative illness beliefs (consequences, emotional representations, time cyclical) were less likely to accept their condition and as a result, experienced greater psychological distress concurrently, 4 and 8 months later. Furthermore, those with who felt they could personally control their condition were more likely to accept their MS and as a result experienced less hopelessness 4 months later. These findings suggest that changing how an individual copes with their condition, will affect the impact of their illness beliefs on the way in which they adjust. These findings however are based on the analysis not controlling for time 1. The results therefore only provide limited support for the hypothesis (4ii), that coping mediates the relationship between illness representations and adjustment.

Overall these findings provide limited support for the relationships between illness representations, coping and adjustment to MS as proposed in Figure 8-1 and the hypotheses 4 (i)(ii).

8.5.1.4 Question 4– What is the relationship between optimism, future thinking, coping and adjustment to MS?

One of the main aims of this Study 3 was to investigate the model proposed in Figure 8-1, in order to identify its effectiveness in predicting adjustment to MS. Based on the SRM framework, the proposed model extends the SRM to include optimism and future thinking. The results provided some support for the hypothesis (3i) that optimism and future thinking would be correlated. Study 3 found that individuals who were more optimistic generated more positive thoughts about their future. However, they did not generate more negative future thoughts. This finding is similar to that of Study 1, which found that dysfunctional attitudes were associated with less positive future thinking but had no relationship with negative future thinking.

The results also supported the hypothesis (3ii) that optimism, coping and adjustment would be correlated. As expected, optimism was associated with greater adaptive coping and less maladaptive coping. The results showed that individuals who were optimistic employed more problem solving and acceptance coping and lower levels of physical assistance and energy conservation. Furthermore, optimism was related to better outcome on all the adjustment variables, at all three time points. This is consistent with previous research, which has found that individuals who are optimistic experience greater physical and psychological well-being (Brenner et al., 1994; Carver et al., 1993; Carver & Scheier, 1985).

Finally, it was hypothesised (3iii) that future thinking, coping and adjustment would be correlated. The findings also supported this hypothesis. Positive future thinking was related to more adaptive coping and less maladaptive coping. Those who were more positive about their future employed more problem-solving coping and were less likely to ask for physical assistance. In addition, those who were more negative about their future were less likely to accept their condition.

Positive future thinking was also associated to better adjustment at all 3 time points and the opposite was true for negative future thinking. This is consistent with previous research by Moore et al (2006), who found that depressed individuals generated less positive future thoughts, compared to non-depressed ones. However, unlike the current study Moore et al (2006) found that there was no increase in negative future thinking. Similarly, previous research has found that suicide ideation can be predicted by a decrease in positive future thinking, which made no difference in negative future thoughts (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004).

Overall, the results of the correlations suggest that, as expected, optimism and future thinking are related to how individuals cope and adjust to MS. To investigate these relationships further, a series of regression analyses were carried out, to test whether these illness cognitions can predict how MS patients cope and adjust. The subsequent sections will discuss these findings by examining role of optimism first, followed by the role of future thinking.

8.5.1.5 Question 5 - Does optimism and coping predict adjustment to MS?

Previous research suggests that optimistic self-beliefs are associated with better adjustment (Brenner et al., 1994; Carver et al., 1993; Carver & Scheier, 1985). Consistent with this, Study 3 found that optimism predicted better adjustment on all of the outcome variables at time 1. The regression analysis controlling for time 1 revealed that optimism could predict a decrease in suicide ideation 4 months later, physical dysfunction 8 months later and hopelessness 4 and 8 months later. They suggest that an optimistic outlook is protective, reducing patient’s risk of experiencing greater physical dysfunction or psychological distress. The results of Study 3 therefore support the hypothesis (5i) that optimism and coping would be predictive of adjustment at time 1, 2 and 3.

Although the regressions controlling for adjustment at time 1 identified a number of important relationships, the correlations analysis suggested that optimism was related to all the outcome variables at each time point. This suggested that these regressions were only identifying a limited number of relationships. As discussed previously this may have been a result of the lack of significant change between the adjustment variables over the 8 months. Another series of regressions were therefore carried out not controlling for time 1. Consistent with the findings of the cross-sectional analysis, optimism predicted better adjustment on all of the outcome variables at 4 and 8 months later. The results also revealed that acceptance mediated the relationship between optimism and adjustment at all three time points. The results suggest that individuals, who are more optimistic, are more accepting of their condition and as result experience lower levels of physical dysfunction and psychological distress, concurrently, 4 and 8 months later. The results therefore provide support for hypothesis 5(ii) that coping mediates the relationship between optimism and adjustment to MS at time 1, 2 and 3. Similarly, previous research by Fournier et al (2002a) found that coping mediated the relationship between optimism and adjustment to MS. Their findings however, suggested that optimistic individuals were less likely to employ emotion-focused coping and as a result, experienced lower levels of psychological distress 6 and 12 months later. Since acceptance is considered as an emotion-focused coping strategy this finding appears to be inconsistent with the results from the current study. However, Fournier (2002a) did not differentiate between the different types of emotion-focused strategies. As discussed previously some emotion-focused strategies, such as acceptance, have been found to be more beneficial that others (Pakenham, 1999). This highlights the importance of identifying specific types of coping, as opposed to examining the broad categories problem-focused and emotion-focused.

Overall the findings provide evidence for the role of optimism and coping in predicting adjustment to MS, as proposed by Figure 8-1. In addition to examining the role of optimism in predicting adjustment to MS, this study also investigated the role of future thinking.

8.5.1.6 Question 6 - Does future thinking and coping predict adjustment to MS?

Study 1 found limited evidence for the role of future thinking in predicting adjustment to MS. However, it only included a limited number of outcome measures. Study 3 was therefore designed to further examine the role of future thinking in predicting adjustment to MS further.

The results provided support for the hypothesis (6i) that future thinking and coping are predictive of adjustment at time 1, 2 and 3. The findings revealed that negative future thinking for the next year predicted greater anxiety, suicide ideation, psychological and overall impact, at time 1. Furthermore, acceptance was found to act as a mediator in some of these relationships. The results suggest that individuals who have more negative future thoughts about the next year are less likely to accept their condition and as a result experience greater psychological dysfunction and suicide ideation at time 1.

Study 3 also investigated whether future thinking could predict adjustment to MS over time. Previous research (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; Moore et al., 2006; O'Connor et al., 2004) has found that non-suicidal individuals can be differentiated from suicidal individuals, by their positive future thoughts (they have fewer positive future thoughts and they do not differ in negative thoughts). Consistent with these findings, Study 3 found no relationship between greater negative future thinking and poorer adjustment however, lower levels of positive future thinking was found to predict greater psychological distress, 4 and 8 months later. The results suggest that MS patients who are more positive about their future will experience lower levels of depression, anxiety and suicide ideation over time, irrespective of how many negative future thoughts they have.

It is important to note however, that these findings are based on the regressions not controlling for time 1 adjustment. The results therefore do not indicate that positive future thinking could predict a decrease in psychological distress over 8 months. The results revealed that none of the future thinking variables could predict a change in patient’s adjustment over time.

The findings from the longitudinal analysis also suggest that future thinking has a direct impact on adjustment prospectively, as opposed to being mediated by coping. Although there was some evidence that coping mediates this relationship cross-sectionally, this does not persist over time. The findings therefore only provide some support for hypothesis 6(ii).

8.5.1.7 Question 7 - Does hopelessness mediate depression and suicide ideation in MS?

The model proposed in Figure 7-1 postulated that hopelessness mediates the relationship between anxiety depression and suicide ideation. This is based on previous research which suggests that hopelessness is the pernicious link between depression and suicide (O’Connor and Sheehy, 2000). The current research was consistent with this previous research and found that hopelessness mediated the relationship between depression and suicide ideation. In addition, hopelessness also acted as a mediator between anxiety and suicide ideation. The results suggested that those MS patients who felt more depressed or anxious were more likely to feel hopelessness and consequently experienced greater suicide ideation, both cross-sectionally and over time.

8.5.2 Methodological criticisms and future research

Despite finding support for the hypotheses in the present investigation, it is important to take into consideration the limitations of the research. Firstly, Study 1 was designed to investigate the efficacy of the SRM in predicting adjustment to MS prospectively. Based on the limited time frame used in Study 1 a longer follow up time period was employed for Study 2 and adjustment was measured at three time points over an 8 month period. It was felt that this would be a long enough time period in which to notice a change. However, the results from the longitudinal analysis suggest that there was not enough of a difference between adjustment at time 1 and follow up to notice a change. MS is a life long condition with a wide array of fluctuating symptoms consequently, 8 months may not be a long enough time frame to notice a change. This highlights the need to for research to investigate these relationships further over a longer time period.

Another limitation of Study 1 was the low internal reliability alpha coefficients (see section 8.3.3.2, table 8-2) for personal health control and acceptance subscales of the CMSS. To date the only published study, which has reported the reliability and validity of the CMSS is by the researchers who developed the measure. Participants for Pakenham et al’s (2001) study were recruited from MS societies in Australia as opposed to the clinical samples of MS patients recruited from Scotland in the current research. The differences in the study samples may therefore account for the low internal reliabilities identified in the current study for these subscales.

A further limitation of the research was with the sample used. As a result of the recruitment procedure, it is possible that a selection bias operated. Therefore, it is difficult to ascertain whether the findings in the present study are representative of a particular stage of the adjustment process. In the current study only 1 participant experienced severe depression and 9 suffered from severe anxiety. Consequently, the sample may not be as representative of those suffering from more severe psychological distress. Another limitation in relation to the sample was that the number of participants suffering from each type of MS varied within the sample, making it difficult to interpretate the results of the analysis. Moreover, due to the lack of accurate data, the influence of treatment on the results could not be controlled for.

Finally, the current research did not take into account the impact of patients' relapses. The majority of participants (44.7%) suffered from the relapsing-remitting form of the condition and therefore were prone to experiencing sporadic exacerbations of symptoms. During some of the assessments patients may have been experiencing a flare up of symptoms as a result of a relapse. Inevitably this may have impacted the findings.

8.5.3 Clinical implications

The findings of Study 3 have a number of implications for health professionals working with MS patients. Consistent with Study 1, the findings suggest that individuals at risk of developing psychological distress could be identified by their illness beliefs and coping strategies. Patients with a more negative view of their MS reported higher levels of psychological distress over the 8 month time period. Interventions could therefore aim to target these beliefs in order to improve adjustment to the condition. In particular, they could focus on reducing the patient's illness identity. MS is a condition characterised by a wide array of symptoms, which can fluctuate daily. It is therefore easy to understand how patients can mis-attribute everyday symptoms such as headaches to their MS. This can lead to patients having a strong illness identity. Health professionals could therefore help patients to identify those symptoms, which are unrelated to their MS. Interventions could also aim to increase the patient's sense of control over their condition. One way in which patients can exert greater control over their bodies is by the use of assistance aids. The current research however, found that physical assistance coping led to greater psychological distress. The analysis in Study 2, suggested that a reliance on these aids was seen as a sign of defeat. Interventions could therefore focus on changing patients perceptions of these aids, so they are seen as a way of increasing the control they have over their bodies. The results of Study 3, suggest that illness beliefs components were inter-related to each other. Interventions which reduce patients' illness identity and increased their sense of control would also therefore affect their beliefs about the consequences of the condition. This suggests that health professionals would be able to change the patient's perception of their condition by targeting beliefs, which are more amenable to change.

In addition to identifying the importance of illness beliefs in determining adjustment to MS, Study 3 also found that coping played a role. Interventions could therefore teach individuals how to cope by using more adaptive strategies, such as problem-solving and acceptance coping. One of the key findings of Study 3, was that coping mediated the relationship between illness cognitions and adjustment. Interventions aimed at teaching individuals how to cope effectively would therefore reduce the likelihood, that those with a more negative view of their condition would experience psychological distress. In particular, the research highlighted the importance of acceptance in successful adjustment to the condition. Interventions designed to help individuals accept their MS, would therefore have a considerable impact on patients overall quality of life. A full discussion of the clinical implications of the research, are given in Chapter 9.

8.5.4 Summary

The findings for Study 3 provide some support for the utility of the SRM in predicting adjustment to MS over an 8 month period. The results revealed that, the beliefs an individual has about their MS and the coping strategies they employ, can have a direct impact on how well they adjust. The findings also provided some support for the mediating role of coping, as proposed by the SRM. However, as with Study 1, there may not have been enough of a difference between time 1 and follow up to notice a change. The model in Figure 8-1, extends the SRM framework to include the role of optimism and future thinking. The findings showed that optimism can predict successful adjustment to MS over an 8 month period, even when time 1 is controlled for. Furthermore, the results provided support for the mediating role of coping between optimism and adjustment to MS, as proposed by the model in Figure 7-1. The study also found evidence for the role of future thinking in predicting adjustment in MS. Positive future thinking was found to predict lower levels of depression and suicide ideation over time. However, again these results were based on the regressions not controlling for time one. Although there was evidence that acceptance mediated this relationship cross-sectionally, the longitudinal analysis revealed that future thinking directly impacts adjustment to MS, over time.

Chapter 9: General Discussion

9 Overview

The following chapter discusses the results of the current doctoral research and the implications of these findings for MS research and theory. The arising methodological limitations are outlined and proposals for future research are presented. Finally, the clinical implications of this research for health professionals working with MS patients are proposed.

9.1 Summary of emergent relationships

The main aim of the current doctoral research was to identify the psychological factors which predict quality of life and psychological distress in MS. To do so, psychological models were applied to samples of MS patients and indices of adjustment were assessed over time. The model in Chapter 4, Figure 4-1 illustrates the relationships which were investigated. A series of research questions were also proposed in Chapter 4 (see section 4.3) based on the findings and limitations of previous research. Studies 1 and 3 were designed specifically to address these research questions and consequently, to determine the utility of the extended SRM model (see Chapter 4, Figure 4-1) in predicting adjustment to MS. Furthermore, Study 2 was designed to investigate the experience of living with MS from the patient’s perspective, using a qualitative research design. Based on the results from Studies 1 and 3, this chapter addresses each of the proposed research questions presented in Chapter 4 (see section 4.3). Although Study 2 was not designed to address any specific research question, the findings of this study are also taken into consideration. Based on the results a revised version of the proposed model is presented in Figure 9-1.

9.1.1 Question 1 - What is the relationship between the illness representations components in MS?

Previous MS research (Vaughan et al, 2003) found that patient's illness beliefs were inter-related to one another (see Chapter 3, section 3.2.1.2). As hypothesised the results of Studies 1 and 3 were consistent with this. The current research found that negative illness perceptions were associated with one another as were positive beliefs. These findings provide support for Hagger and Orbell's (2001) proposition that illness beliefs are inter-related as opposed to orthogonal. In particular, a belief that MS has serious consequences appears to be dependent on having a strong illness identity. Evidence for this was found in the current research and in previous studies (Hampson et al., 1990; Heijmans, 1998; Moss-Morris et al., 1996; Schiaffino et al., 1998; Vaughan et al., 2003; Weinman et al., 1996). Overall, the findings provide support for Heijman et al's (1998) suggestion that the illness belief components could be conceptualised as groups of beliefs as opposed to single cognitions.

The current research also found that illness beliefs were inter-dependent with other illness cognitions. Illness representations were found to be associated with dysfunctional attitudes, optimism and future thinking. The findings suggest that individuals who hold a more negative view of their condition find it difficult to be optimistic, tend to have more dysfunctional attitudes, think more negatively about their future and find it difficult to generate more positive future thoughts. The findings suggest that similar to the illness belief components, these illness cognitions do not act independently but are inter-dependent. Furthermore, they could be conceptualized as groups of cognitions or schemata

Another key finding from the current research in terms of illness beliefs was that some of the patients' perceptions of their condition changed over time. The current research found that patients' understanding of their illness and feelings of personal control increased over the 2 month period. As discussed in Chapter 2 (see section 2.6.3) an individual's perceptions of their condition may change and develop over time as a result of the experience of living with the condition, social messages and increased contact with the medical profession. The current findings suggest that these factors may have helped patients to gain a greater understanding of MS and feel more in control.

9.1.2 Question 2 – What is the relationship between illness representations, coping and concurrent and prospective adjustment in MS?

The aim of the current research was to fully apply the SRM to understand adjustment to MS. Previous MS research has investigated the relationship between illness beliefs and adjustment (see Chapter 3, section 3.2.1), while others have assessed the role of coping on adjustment to MS (see Chapter 3, section 3.2.2). The current doctoral research represented the first attempt to fully investigate the relationships between all the SRM components in MS. As hypothesised illness representations were correlated with coping and coping was correlated with adjustment, consistent with the relationships outlined in the SRM.

Problem-solving coping involves strategies such as thinking about how to solve the problem, planning ahead, or just trying to get something positive out of the situation (Pakenham et al, 2001). Previous research has found a persistant relationship between problem-focused coping and greater physical and psychological well-being (Folkman & Lazarus, 1986; Pakenham, 1999; Pakenham). Consistent with this, the current research found that problem-solving coping was associated with better psychological adjustment at time 1 and lower levels of hopelessness concurrently, 4 and 8 months later. Hagger and Orbell (2003), in their meta-analysis, found that control beliefs were related to more active coping in a range of chronic illnesses. Similarly, the current research found that MS patients who believed they had more personal control employed more problem-solving coping. The findings suggest that those individuals who believed they had some control over their MS felt more confident in employing active forms of coping and in turn, these strategies were associated with lower levels of hopelessness over time.

Another coping strategy found to be associated with better adjustment to MS was acceptance. This strategy occurs via direct acceptance, humour, and/or downward comparisons (Pakenham, 2001) and is a form of emotion-focused coping. Previous research has found that emotion-focused coping is consistently related to greater psychological and emotional distress (Arnett et al, 2002). However, as discussed in Chapter 3 (see section 3.2.2.3) instead of considering a range of strategies within the broad category of emotion-focused, Pakenham (1999) argued that the more constructive forms of this type of coping including acceptance (Carver, Scheier, & Weintraub, 1989) may be more useful in helping individuals adjust to MS. In 2001, Pakenham found that acceptance was related to better adjustment in MS across all but one domain. The current research provides additional support for this relationship demonstrating that acceptance was associated with lower levels of psychological distress and physical disability 2, 4 and 8 months later. According to Carver et al (1989), acceptance of a stressor is adaptive when the stressor is not amenable to change and must be accommodated. MS is a condition which at present has no cure available, patients must therefore learn to live with the illness. Acceptance of the condition therefore is a key in order to facilitate a greater sense of well-being. The results of the current research suggest that patients who had more negative illness beliefs (identity, emotional representations, consequences, time cyclical) were less likely to accept their condition. Those who believed that they could control the condition and felt they had a better understanding of the illness were more accepting of it. This highlights the need to facilitate a better understanding of the condition and increase patients’ sense of control over their illness.

One method of helping patients to control the physical limitations of the condition is through the use of physical assistance coping. This type of coping involves strategies aimed at alleviating the practical difficulties associated with MS such as using assistance equipment, respite services, asking for financial or material aids and/or modifying living environments. Pakenham (2001) found that this type of coping was associated with greater physical dysfunction. His findings suggested that this subscale may have been confounded by the level of patient’s disability, with more disabled individuals relying more on physical assistance. Study 1 and 3 also found that this type of coping was associated with greater physical dysfunction over time. However, the results of Study 3 also revealed that it was associated with greater suicide ideation, depression and hopelessness. It could be argued therefore that this type of coping is maladaptive for adjustment to MS. However, closer consideration of the findings suggests that it is the patient’s perception of this type of coping, which may determine the levels of psychological distress associated with this strategy. The qualitative analysis from Study 2 suggested that a reliance on physical aids was seen as a sign of defeat. There was a sense that using physical aids was related to the feeling that participants no longer had control over their bodies. This was consistent with the results of Study 3, which found those who believed they had greater personal control used lower levels of physical assistance. The qualitative analysis suggested that this resistance to use physical aids may be a result of patients not wanting to see themselves as someone who was for example wheelchair dependent. Their resistance to using this type of coping therefore may reflect a reluctance to accept a change in their identity. Consistent with this, Study 3 found that those with a strong illness identity were more likely to employ physical assistance coping strategies. Moreover, Study 1 and 3 found this kind of coping was related to a belief that MS has serious consequences.

Previous research by Pakenham (2001) found that that avoidance was associated with better physical adjustment but greater psychological distress. This was consistent with the current research, which found that this type of coping was related to greater physical adjustment at 2 months but greater suicide ideation concurrently. Avoidance coping involves the individual keeping others from knowing about their problems, pushing themselves to get things done and putting things to the back of their mind (Pakenham, 2001). The findings suggest that on a physical level these types of strategies are beneficial. This may be because patients keep their bodies active as a result of not acknowledging the condition. However, psychologically they can lead to greater distress. This may be a result of them not dealing with problems when they arise or sharing them with others. The current research also found that avoidance coping was negatively associated with a belief that MS has serious consequences and illness coherence. It is likely that since this type of coping involves patients putting the condition to the back of their minds they will not feel it has serious consequences. In addition, they will just keep pushing themselves to carry out the things they need to do so they are unlikely to feel it stops them from doing anything. In terms of illness coherence, if they cope by not wanting to acknowledge the condition or its limitations it is likely they do not spend time trying to understand the illness by reading about it or talking about it with others.

The results of the current research for the role of problem-solving coping, acceptance and avoidance on adjustment were consistent with previous research by Pakenham (2001). However a number of inconsistent findings were also identified for the role of the other coping strategies - energy conservation, personal health control and emotional release.

Energy conservation coping involves behaviours, which are designed to use what little energy is available carefully and is considered advantageous in an illness like MS where fatigue is the most common complaint (Pakenham, 2001). However, the results of the current research were inconsistent with this. Greater energy conservation strategies were found to be related to poorer adjustment, in particular greater overall and physical dysfunction. Study 3 also found that individuals with a more negative view of their condition were more likely to pace themselves as a means of coping. Furthermore, the qualitative analysis suggested that pacing and energy conservation strategies were associated with the feeling that life had become boring.

Mixed results were identified for the role of personal health control in the current research. Study 1 found that, as expected, treatment control was positively related to this type of coping. However, Study 3 found that the more negative illness beliefs identity, emotional representations, consequences and timeline were positively associated with this type of coping. Furthermore, Study 3 found that this coping strategy was associated with poorer adjustment at all three time points. This finding was inconsistent with Pakenham et al (2001) who found that personal health control coping was beneficial. Furthermore, previous research has found a persistant relationship between personal or internal control beliefs and better adjustment (Halligan & Rezinikoff, 1985; Hickey & Greene, 1989; Jopson & Moss-Morris, 2003; Shnek et al., 1995; Vaughan et al., 2003; Wassem, 1991) in MS. The current study also found that personal control was beneficial when assessed by the IPQ-R. One explanation for the inconsistency of the results of Study 3 with the other findings is that the coping subscale was assessed using the CMSS and had a low internal reliability (see section 8.3.3.2, table 8-2). The results for personal health control in Study 3, therefore must be considered with caution.

The CMSS is a relatively new instrument designed to measure MS-specific coping. As discussed in Chapter 8 (see section 8.5.2.) the only published study which has reported the reliability and validity of the CMSS is by the researchers who developed the measure.

Furthermore, there were a number of differences between the sample used in Pakenham's (2001) study and the current research.

The correlation analysis of the current research revealed that social support was associated with poorer adjustment at time 1 and 2. In addition, those with more negative illness beliefs were found to rely on this type of coping. These findings are surprising as social support would be expected to be beneficial for adjustment. Pakenham et al (2001) in the development of the CMSS found that although this strategy emerged from the content analyses it was not confirmed by factor analyses. He concluded that this coping strategy may need further work in future research on the CMSS.

Previous findings by Hagger and Orbell (2003) revealed that a strong illness identity was associated with expressing emotion. This relationship between identity and emotional release was also found in the current study. Previous research by Pakenham (2001) suggested emotional release was beneficial and was related with better adjustment. The results of the current research were inconsistent with this as emotional release was associated with greater psychological and physical dysfunction. According to Hagger and Orbell (2003) however, this strategy is maladaptive as it reduces the patient's motivation to seek help or acknowledge their condition.

Taken together the correlations of Study 1 suggest that negative illness beliefs were associated with greater maladaptive coping and lower levels of adaptive coping, which in turn were associated with greater psychological distress and physical disability. These findings are therefore consistent the relationships outlined in the SRM.

Although the SRM proposes that coping mediates the relationship between illness representations and adjustment, previous MS research (see Chapter 3 section 3.2.1.3) suggests that illness representations may also have a direct impact on how MS patients adjust (Jopson and Moss-Morris, 2003, Vaughan et al, 2003). Their findings suggested that those who held a more negative view of their illness, also experienced greater levels of psychological distress. Both studies found that as hypothesised, the more negative illness beliefs –identity, concern, consequences, emotion, time cyclical - were related to poorer concurrent and prospective adjustment to MS. In addition, Study 3 found that the more positive illness representation components personal control, treatment control and illness coherence were associated with better adjustment concurrently, 4 and 8 months later.

Overall, the findings of the correlations in Studies 1 and 2 provide support for the relationship between illness beliefs, coping and adjustment to MS, in line with the SRM. In addition, the findings also suggest that illness beliefs may be directly related to adjustment. To investigate these relationships further, a series of regression and mediation analysis were carried out to determine whether illness representations and coping predict adjustment to MS, over time. These findings are discussed in the following section.

9.1.3 Question 3 – Do illness representations and coping predict adjustment to MS?

The aim of the current research was to examine the efficacy of the SRM framework in predicting adjustment to MS over time. According to the SRM (Leventhal et al 1980), illness representations predict coping, which in turn, predicts outcome. The current research represents the first attempt to fully apply the SRM to MS patients prospectively.

The results for the cross-sectional analyses of both studies provides support for the hypothesis that illness representations and coping would be predictive of adjustment at time 1. Negative illness representation components (consequences, identity, emotion, concern, timeline/time cyclical, psychological cause) were found by the current research to predict poorer concurrent adjustment. These findings are consistent with previous MS research (Vaughan et al 2003, Jopson and Moss-Morris, 2003) who also found evidence that negative illness beliefs predicted poorer adjustment. One of the main limitations of this previous research was that it did not investigate these relationships over time. The current research addresses this limitation by assessing indices of psychological distress over 2, 4 and 8 months. The findings provided support for the ability of illness beliefs to predict adjustment to MS prospectively. The results from these regressions showed that the negative illness representation components, emotion and consequences predicted poorer adjustment on almost all the outcome measures 2, 4 and 8 months later. Furthermore, the results from the current research suggest that the emotion and consequences components could predict adjustment over time even when time 1 adjustment was controlled for. The findings suggest that believing that MS has serious consequences could predict an increase in psychological dysfunction, depression and anxiety over 2 months and an increase in physical disability over 4 months. Furthermore, the emotion component predicted an increase in psychological dysfunction over 2 months.

The emotional representation component assesses how much the individual feels they are emotionally affected by the condition. As discussed in Chapter 2 (section 2.6.2) illness representations are made up of cognitive dimensions and an emotional representation (Diefenbach & Leventhal, 1996). It is believed that the emotional aspect increases or decreases the intensity of symptoms and creates symptoms. These symptoms can be confused with those caused by the illness. As a result, individuals may focus on the negative outcomes of the condition, therefore having a reciprocal relationship to the cognitive processing (Leventhal et al., 1984b). This is supported by the results of the current research. The findings revealed that those individuals who felt their condition had a strong emotional effect also reported greater psychological distress. Those who believe their MS has a strong emotional impact may feel the symptoms of the condition are more intense and consequently, will focus more on the negative impact of their MS. One interesting finding was that acceptance mediated the relationship between emotional representations and the adjustment variables psychological dysfunction and depression concurrently and 4 months later, anxiety 4 months later, and hopelessness and suicide ideation 4 and 8 months later. These results suggest that those individuals who believe their condition has a strong emotional impact are less likely to accept their MS and as a result are more likely to experience greater psychological distress over time. These findings are consistent with previous research which has found that acceptance in beneficial for adjustment to MS (Pakenham, 2001). Furthermore, they suggest that by helping those individuals who believe their condition had strong emotional impact to accept their MS the likelihood they will experience psychological distress will be reduced. In addition to the relationship between emotional representations and adjustment, acceptance was found to act as a mediator between a number of the other illness representations and adjustment variables including the consequences, time cyclical and personal control components.

The results of the current research revealed that individuals who believed their condition had serious consequences, also experienced poorer adjustment over time. MS affects many aspects of patients’ lives socially, at work and also at home. The condition can therefore have a serious impact on their everyday activities. The current research highlights how their beliefs about the impact of the condition can have considerable implications for how well they adjust. The relationship between the consequences component and adjustment was mediated by acceptance coping and also physical assistance. MS patients who believed their MS had serious consequences were less likely to accept their condition and as a result experienced greater depression at time 1, psychological dysfunction concurrently and 4 months later and hopelessness 4 and 8 months later. Furthermore, they were more likely to ask for physical assistance and as a result experienced greater physical and overall dysfunction concurrently, greater physical dysfunction 2 months later and greater psychological dysfunction 4 months later.

The relationship between physical assistance and greater physical disability is consistent with the results of both the correlation analysis of the current research and the findings of previous research by Pakenham (2001). It would be expected that individuals who need to rely on physical assistance would also be more physically disabled however, this type of coping also predicted greater psychological dysfunction 4 months later. As discussed previously, consideration of the qualitative analysis suggests that the psychological distress associated with this coping strategy may be a result of the patient's perception of these strategies, such as having to rely on assistance aids. This highlights the need for interventions to target patients' perceptions of these types of strategies so that they are seen as a way for them to control their bodies, as opposed to a sign that the condition has beaten them. Since physical assistance coping mediates the relationship between the consequences component and adjustment, these interventions would also reduce the negative impact of this illness belief on adjustment.

The current research found that believing MS is a cyclical condition predicted psychological dysfunction and depression at time 1 and greater overall MS impact at 4 months. Although MS is a chronic condition patients often experience relapses or exacerbations of symptoms. In particular those suffering from relapsing-remitting or secondary-progressive MS experience relapses with varying degrees of severity. The findings suggest that believing the condition is characterised by relapses predicts greater levels of psychological distress concurrently. Since patients are diagnosed with having a specific type of MS, interventions could not change their beliefs about the type of MS they have. However, the findings of the mediation analysis suggest that by helping patients to accept their condition, their levels of psychological distress concurrently would be reduced. The time cyclical component was also found to predict greater overall dysfunction prospectively. Overall dysfunction was assessed by the MSIS (Hobart et al, 2001) and the majority of the items relate to patients physical dysfunction. The findings therefore suggest that relapses are leading to greater physical disability.

The negative illness belief concern was also found to predict greater psychological distress in MS. Furthermore, this was mediated by acceptance coping. The results suggested those individuals who were more concerned about their condition were less likely to accept their illness and as a result experienced greater levels of depression.

Previous research by Jopson and Moss-Morris (2003) found that illness identity or the tendency to attribute a wide range of symptoms to MS predicted greater anxiety. Consistent with this the current research found that those with a strong illness identity experienced greater anxiety at 4 months. This research also found identity predicted greater psychological and physical dysfunction 4 months later. According to Leventhal et al (1984), people are inclined to move towards symmetry. In other words they are motivated to find a label for their symptoms or motivated to identify symptoms which are consistent with the label they have been given (see Chapter 2, section 2.6.5). Since MS is unpredictable and the symptoms can fluctuate daily, it is easy for patients to mis-attribute to everyday symptoms such as a headache or sore throat to their MS. These symptoms could also signal that the condition is active or progressing resulting in anxiety (Jopson and Moss-Morris, 2003). Furthermore, illness identity may be related to internal somatic focus whereby those focusing on their bodily sensations experience a wider range of symptoms. This is consistent with previous research which found that MS patients who have more internal somatic focus experience greater subjective fatigue (Vercoulen et al, 1996).

Previous research by Jopson and Moss-Morris (2003) found that attributing the condition to a psychological factor led to poorer adjustment. The results of the current research provided support for this. A belief that MS was caused by something psychological such as stress, mental attitude or overwork was found to lead to greater psychological distress. Furthermore, the current research found that acceptance mediated the relationship between a belief in a psychological cause and depression. Believing that MS is caused by something psychological, therefore led individuals to be less accepting of the illness and consequently, they experienced greater depression.

In addition to highlighting the importance of the negative illness belief components in predicting psychological distress, the current research found that control beliefs were important predictors of well-being. Previous MS research by Hickey and Green (1989) found those with greater internal control beliefs experienced lower levels of hopelessness. Similarly, the current research found that those with greater personal control felt more hopeful 4 months later. In Study 2 a loss of control was one of the key themes identified during the analysis. This was found to lead to a loss of spontaneity as participants felt they had to plan everything in advance. Planning ahead is considered within the CMSS as a problem-solving coping strategy. It would therefore be expected that the relationship between control beliefs and adjustment may be mediated by problem-solving coping. As discussed in Chapter 3 section 3.4.1 individuals who feel they have more control would also be expected to feel more confident in employing more active coping. Although the results of the correlations provided support for this, the regression and mediation analyses did not. Consistent with previous research (Aikens et al., 1997; McCabe et al., 2004; Mohr et al., 1997), problem-solving coping was found to be beneficial for adjustment predicting lower levels of hopelessness at time 1, however it did not act as a mediator. The relationship between personal control and hopelessness however, was mediated by acceptance. Those who believed they could control their condition were more likely to accept their illness and as a result felt more hopeful 4 months later.

Also relating the role of control the current study found personal health control coping predicted greater physical impact. This is inconsistent with the finding that personal control led to better adjustment at 4 months and with Pakenham's (2001) findings that this type of coping is beneficial. As discussed previously this subscale was found to have low internal reliability and should be interpretated with caution. Consequently, no conclusions with be drawn about the role of this particular coping strategy in the current research.

Overall the findings revealed that the only illness beliefs which predicted a change in patients' adjustment to MS over time were the consequences and emotion representation components. Although a number of other relationships are discussed these are based on the analyses not controlling for time 1. The research therefore only provides limited support for the hypothesis that illness representations and coping will predict concurrent and prospective adjustment to MS, in line with the relationships outlined by the SRM. As discussed in Chapter 8 (see section 8.5.1.3) there are two possible explanations for this. Firstly, this could reflect a limitation in the design of the current research. Since MS is life long condition which many patients have suffered from for many years, changes in their adjustment may only be noticeable over a long period of time. It therefore could be that 8 months may not be a long enough time in which to notice a significant change. An alternative explanation for the findings is that there is a limitation in theoretical model. It could be that the SRM may not be a useful framework for predicting adjustment to MS prospectively. Since the current research represents the only attempt to fully apply the SRM to MS over time, further research is required to investigate the relationships further. This will help to determine whether the limited support identified for the model is a result of a limitation in the current research design or if it reflects a limitation in the SRM.

Despite the limited support for the SRM in predicting adjustment to MS overall, the findings do suggest that the consequences and emotional representations components of the model are key predictors of psychological distress over time. In addition, the findings highlight the importance of acceptance for protecting individuals from psychological distress. One of the key findings of the current research was that acceptance mediated the relationship between a number of the illness belief components and adjustment. Acceptance may protect those with more negative illness beliefs from experiencing psychological distress.

Overall the findings provided some evidence for role of illness representations and coping in predicting adjustment, and for the mediating role of coping, proposed by Figure 4-1 (see Chapter 4). These relationships will therefore remain the same in the model proposed in Figure 9-1. However, consistent with previous MS research (Vaughan et al, 2003; Moss-Morris et al, 2003) illness beliefs were found to have a direct impact of adjustment. The model in proposed in Figure 9-1 has therefore been revised to indicate this.

9.1.4 Question 4 – What is the relationship between dysfunctional attitudes, optimism, future thinking, coping and adjustment to MS?

The model proposed in Figure 4-1 (see Chapter 4) was based on the SRM framework, however it was extended to include cognitive schema (dysfunctional attitudes), optimism and future thinking. In Study 1 the relationship between dysfunctional attitudes and the other variables were examined. As expected, greater dysfunctional attitudes were found to be related to less positive future thinking. These findings suggest that those with more maladaptive beliefs or cognitive distortions find it difficult to think more positively about their future. However, no relationship was identified between dysfunctional attitudes and negative future thinking. In Study 2 the relationship between optimism and future thinking was investigated. As predicted, optimism was found to be related to greater positive future thinking, however no significant relationships were found between optimism and lower negative future thinking. Overall, the findings suggest that negative future thinking may not play as important a role as positive future thinking. This is similar to the findings of previous research which has found that suicidal individuals can be differentiated from non-suicidal by a reduction in positive future thinking with no difference in negative future thinking (see Chapter 2, section 2.2.3.2).. To investigate this further the present research examined the role of future thinking in predicting adjustment to MS. The findings of these analyses will be the discussed in the following section

9.1.5 Question 5 – Does future thinking and coping predict adjustment to MS?

As discussed in the previous section, research (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004) has found that non-suicidal individuals can be differentiated from suicidal individuals by their positive future thoughts (they have fewer positive future thoughts and they do not differ in negative thoughts) (see Chapter 2, section 2.11.2). Despite the high suicide rates in MS, to date no published research has investigated the role of future thinking in predicting suicide ideation in MS.

The correlational analyses of the current research revealed that positive future thinking was related to greater problem solving coping, which was found to be related to better outcomes. Problem-solving coping involves planning ahead and trying to get something positive out of the situation (Pakenham, 2001). It would therefore be expected that those individuals who are more positive about their future would also employ more problem-solving coping. The result also found that positive future thoughts were related to lower levels of physical assistance. Positivity may lead patients to feel more in control of their bodies and as a result they may not feel the need to rely on physical assistance strategies. The results also found that negative future thinking was associated with lower levels of acceptance. This is consistent with the earlier findings that those with more negative illness beliefs were less likely to accept their condition. As expected those who were more positive about their future reported better prospective adjustment, while the opposite was found for those with greater negative future thinking.

Previous research has found that suicide ideation could be predicted by a decrease in positive future thinking, with no difference in negative future thoughts (Hunter & O'Connor, 2003; MacLeod et al., 1997; MacLeod et al., 1993; O'Connor et al., 2004). A similar pattern of relationships has been identified with MS patients. Moore et al (2006) found that depressed individuals with MS generated less positive future thoughts compared to non-depressed ones. Furthermore, they did not report an increase in negative future thinking. Similarly, the current research found that positive future thinking predicted lower levels of anxiety at time 1, depression at 4 and 8 months and suicide ideation 8 months later. Although negative future thinking was found to predict greater anxiety, suicide ideation, psychological and overall dysfunction in the current study, all these relationships were cross-sectional. Only positive future thinking was found to predict adjustment to MS over time.

The extended model proposed in Chapter 4 (Figure 4-1) is based on the SRM framework and consequently, identifies coping as a mediator. No previous research has investigated the relationship between future thinking, coping and adjustment to MS. The results of the current study found some support for the mediating role of coping but only cross-sectionally. The analysis suggested that those with more negative future thinking were less likely to accept their condition and as a result experienced greater psychological impact and suicide ideation at time 1. There was however, no evidence that coping mediated any of the relationships prospectively.

Overall the results of the future thinking analysis provide some support for the role of future thinking in predicting how individuals cope and adjust to MS. However, the results of the longitudinal analysis suggest that future thinking may have a direct impact on adjustment over time. The model proposed in Chapter 4 (Figure 4-1) has therefore been revised in line with these findings and can be seen in Figure 9-1.

9.1.6 Question 6 – Do dysfunctional attitudes and coping predict adjustment to MS?

According the Beck's Cognitive Theory of Depression, maladaptive cognitive schemas play a key role in the development of depression (see Chapter 2, section 2.9 for a full description of the model). Based on this theory when an individual is faced with a critical event any dysfunctional attitudes they have are triggered. These typically lead to the negative thought patterns, which cause psychological distress. Consistent with this the correlation analysis of the current research found that those with dysfunctional attitudes experienced greater anxiety and depression. Furthermore, they also employed lower levels of problem-focused coping, acceptance and energy conservation.

Due to the small number of correlated relationships between dysfunctional attitudes and adjustment to MS only a limited number of regressions were carried out. However, the results showed that greater dysfunctional attitudes predicted greater concurrent depression and concurrent and prospective anxiety. These findings support Beck's theory suggesting that MS patients with more maladaptive beliefs experience greater psychological distress. This highlights the need for interventions to challenge patients' maladaptive beliefs in order to improve their sense of well-being. The current research also found that acceptance mediated these relationships. This suggests that those with dysfunctional attitudes were less likely to accept their condition and as a result experienced greater anxiety and depression. The findings highlight how acceptance may protect those with maladaptive schemas from experiencing psychological distress.

The finding that future thinking predicted anxiety is based on the regressions not controlling for time 1. Future thinking was not found to predict the change in anxiety over 2 months. As discussed previously this may have been a result of the lack of significant change in adjustment over this time frame. MS is a life long condition and consequently 2 months may not have been a long enough period of time in which to notice a change.

Overall the findings provided some support for hypothesised relationship between dysfunctional attitudes, coping and adjustment to MS, as proposed in Chapter 4, Figure 4-1. Although, the results of Study 1 only provided limited evidence for the role of dysfunctional attitudes in predicting adjustment to MS, prospectively. The revised model in Figure 9-1 therefore still includes the role of dysfunctional attitudes however, it must be noted that they were only found to predict anxiety, over time. Due to the limited number of relationships identified the second study carried out did not asses the role of dysfunctional attitudes and instead investigated the role of optimism. The findings of these analyses are discussed in the following section.

9.1.7 Question 7 – Does optimism and coping predict adjustment to MS?

Previous research suggests that optimistic self-beliefs may protect MS patients from becoming vulnerable to psychological distress (Brenner et al., 1994; Carver et al., 1993; Carver & Scheier, 1985). Consistent with this the correlation analysis of the current research revealed that individuals who were more optimistic experienced better adjustment on all domains at all three times points. The regression analysis revealed that optimism could predict a decrease in suicide ideation 4 months later, physical dysfunction 8 months later and hopelessness 4 and 8 months later. This highlights the importance of positive mind states in protecting individuals from psychological distress and greater physical disability over time.

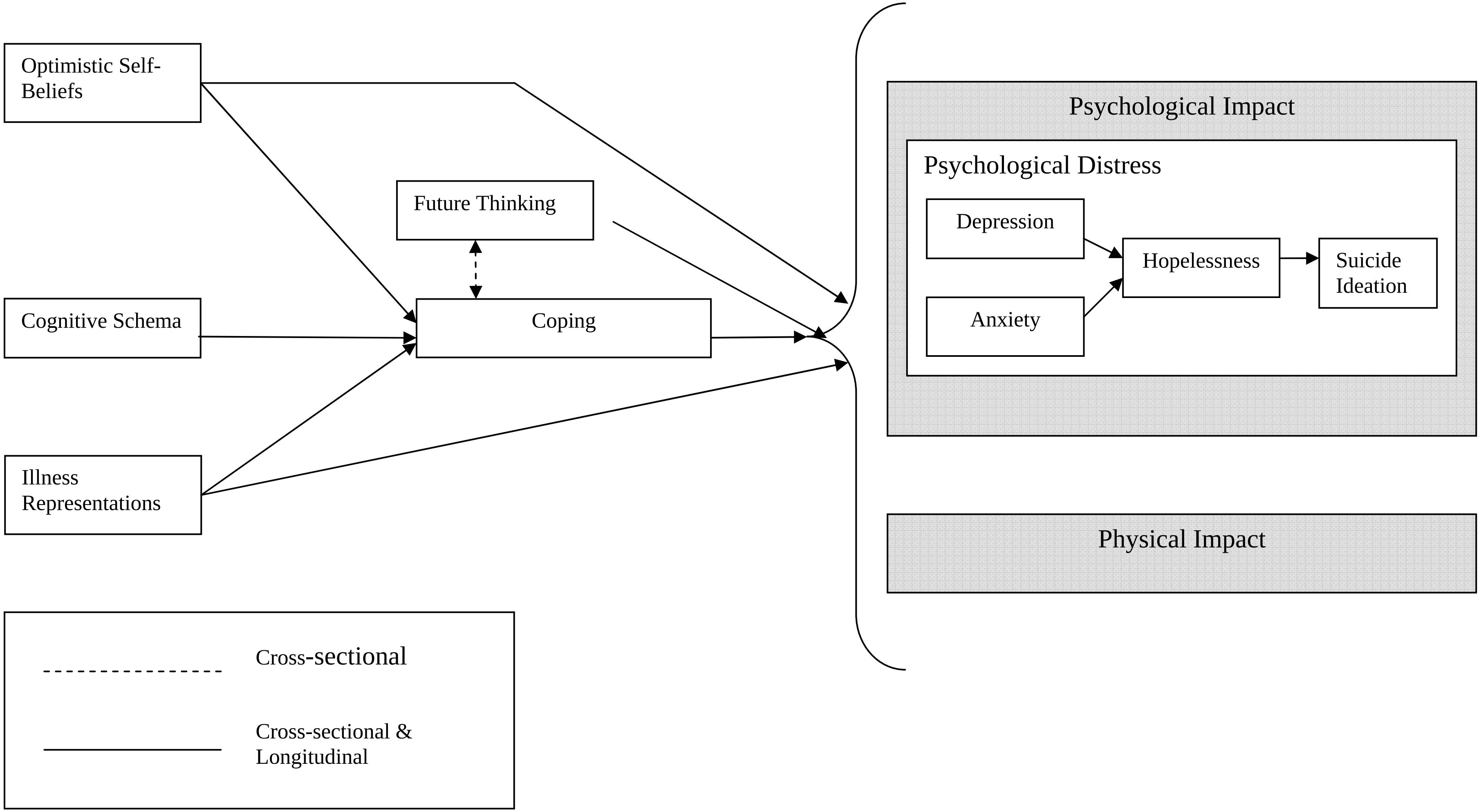
Consistent with previous research by Fournier et al (2002a), the current study found evidence that coping mediated the relationship between optimism and adjustment. Fournier and colleagues found that optimistic individuals were less likely to employ emotion-focused, more likely to employ problem-focused coping and consequently experienced lower levels of psychological distress over time. Although the results of the correlations found that optimism was associated with greater problem-solving coping, further analysis did not find evidence that this type of coping mediated the relationship between optimism and adjustment. The results did suggest however, that more optimistic individuals were more likely to accept their MS and as a result experienced better adjustment both concurrently and prospectively 4 and 8 months later. Since acceptance is a form of emotion-focused coping these findings are inconsistent with Fournier et al's (2002a) study. However, as discussed previously and as suggested by the results of the current research, some types of emotion-focused coping are beneficial for adjustment (Pakenham et al, 1999). This highlights the importance of examining the role of specific coping strategies instead of the categories emotion-focused and problem-focused.

Overall the findings provide evidence for the role of optimism and coping in predicting adjustment to MS, as proposed by Chapter 4, Figure 4-1. Furthermore, they also suggest that optimism can directly impact adjustment. The model in Figure 9-1 has therefore been revised to indicate this.

9.1.8 Question 8 – Does hopelessness mediate the relationship between depression/anxiety and suicide ideation in MS?

Hopelessness is believed to mediate the relationship between depression and suicide ideation (O’Connor and Sheehy, 2000) (see Chapter 2 section 2.11). However, despite the high rates of suicide in MS (see Chapter 1, section 1.9.2.2), to date published research has investigated the relationship between hopelessness, anxiety, depression and suicide ideation in MS. The model proposed in Figure 8-1 postulated that hopelessness mediates the relationship between anxiety, depression and suicide ideation. The current research found support for this model. Consistent with this previous research hopelessness mediated the relationship between depression and suicide ideation. In addition, this variable was found to mediate the relationship between anxiety and suicide ideation. Overall the findings suggested that those MS patients who felt more depressed or anxious were more likely to feel hopelessness and consequently, experienced greater suicide ideation both cross-sectionally and over time. These findings suggest that by helping depressed and anxious MS patients to feel more hopeful they may be less likely to experience suicide ideation. This could therefore have considerable implications for health professional working with those experiencing psychological distress as a result of the MS.

Figure 9-1 A schematic representation of the relationships identified in the current research.



9.2 Methodological limitations and future research.

There were a number of methodological limitations that have emerged through the course of the current research. Many of these were reviewed individually following each of the studies. These are now revisited and summarised.

One of the main criticisms of the current research was the lack of significant change between time 1 and follow up, in both of the studies. Study 1 was designed to investigate the utility of the SRM in predicting adjustment to MS prospectively. To avoid contemporaneous contamination, participants were assessed at two time points. It was felt that by testing the model over two time points the likelihood of seeing change across a time-span, with minimum attrition, would be increased. However, due to the constraints of the PhD only a 2 month follow up was employed. Consequently, a limited number of relationships were identified in the longitudinal analysis, when time 1 was controlled for. It is likely that this is a result of the lack of significant change between time 1 and follow up, as the time frame was quite short. To address this limitation an 8 month follow up for Study 3 was employed. However, the results from the longitudinal analysis from this third study also suggested that there was still not enough of a difference between adjustment at time 1 and follow up to record a change (i.e. limited variance). One explanation for this may be that 8 months may not have been a long enough time to period to notice any change in such a chronic long term illness. In particular, with a condition like MS, which is associated with a wide array of fluctuating symptoms, it may take many years to notice any significant change in adjustment to the illness. Furthermore, the current research did not take into account whether patients were experiencing relapses. The majority of the sample in Study 3 (44.7%) consisted of those with relapsing-remitting MS. Consequently, although some individuals may have been adjusting better over time, they could have been experiencing a relapse during the time of the follow up interviews. This would inevitably influence the findings. These limitations highlight the need for future research to investigate these relationships over a number of years and control for patients' relapses.

There was some concern regarding the methods used to operationalise coping. The aim of the research was to use a measure of coping which was 1) MS- specific and 2) investigated how patients were coping with a disease-specific stressor. Therefore, the CMSS was used as it was developed to assess how individuals with MS cope with a specific disease-related stressor. However, it emerged that the internal reliabilities of some of the subscales were low. Furthermore, they were relatively sporadic and differed between the two studies. This is a relatively new measure and to date, only the study which developed this measure has provided evidence for its reliability in assessing coping (Pakenham, 2001). Some inconsistencies were identified between the results of this previous study and the current research. In particular, personal health control and emotional release, which Pakenham found to be beneficial for adjustment to MS, were found in Study 3 to be maladaptive. However, the internal reliability coefficient for personal health control was very low and in turn this low reliability may have influenced the findings.

There may also have been problems with the length of the question booklets used in the Studies 1 and 3. The possibility that responses were subject to boredom, lethargy and disinterest is always increased when interviews are long. Despite attempts to control for this by offering breaks and counterbalancing the order of presentation the possible effect of these factors should, nonetheless, be taken into account.

Reflexivity is another issue which should be taken into consideration in the present research. Due to the nature of the condition, interviews at time 1 were carried out in the participants' homes. Furthermore, the interviewer read out the questions from the questionnaire and participants were asked to provide a response from the response card provided. Undoubtedly the presence of the interviewer would have impacted upon the responses offered. As Breuer et al (2002) argues any ‘close range’ technique for gathering data or information is likely to be subject to possible influences.

A final limitation of the research was with the samples used. As a result of the recruitment procedure, it is possible that a selection bias operated on those participants who volunteered to take part in the research. All participants were screened for emotional difficulties prior to being invited to participate. Consequently, the sample may have been better adjusted to their condition than those who were not invited or who were not seen by these services. Therefore, it is difficult to ascertain whether the findings in the present study are representative of a particular stage of the adjustment process. The results of Studies 1 and 3 revealed that the majority of the samples were not suffering from depression (63.5% and 63.5% respectively). Although more people experienced anxiety these rates were still low with 49% in Study 1 and 54.7% in Study 2 found to have anxiety levels within normal range. Only 1 participant in each study was found to experience severe depression and 10 (Study 1) and 9 (Study 3) suffered from severe anxiety. Consequently, the sample may not be as representative of those suffering from more severe psychological distress. Furthermore, the result of Study 3 revealed that MS type was a key predictor in the development of psychological distress, with some types of MS leading to poorer adjustment compared to others. One further limitation in relation to the sample used was that the numbers of participants suffering from each of type of MS varied within the sample. Although this was representative of the rates with the MS population, it made interpretating the results difficult. Finally, there was no accurate information available regarding the treatment protocols participants were following. Consequently, these could not be controlled for during the analysis.

9.3 Clinical implications of the research

The findings of the current doctorate research have a number of implications for health professionals working with MS patients. A key finding was that individuals with MS who are vulnerable to psychological distress can be identified by their illness beliefs and coping strategies. The research found that those with a more negative view of their condition experienced higher levels of anxiety, depression, suicide ideation, hopelessness and physical disability. Interventions could, therefore, target the patient's illness beliefs in order to improve adjustment to MS.

The research found that a strong illness identity was associated with poorer adjustment to the illness. Health professionals should develop interventions aimed at changing patients' illness identity. MS is a condition characterised by a wide array of symptoms which not only fluctuate daily but can vary depending on the individual. It is therefore easy to understand how MS patients can misattribute everyday symptoms such as headaches to their MS, leading to a strong illness identity. Health professionals could therefore help patients to identify symptoms which are unrelated to their condition. The analysis from Study 2 suggested that participants experienced a loss of their former identity, as a result of no longer being physically active. Clinical interventions could also help them to define their sense of self based on other attributes, as opposed to their physical capabilities. If patients still saw themselves the way they did prior to MS, then they would not strongly identify with the condition. Another way health professionals could reduce the patient's illness identity would be to treat the condition as separate from the individual. This should be reflected in the language they use when discussing the illness. Referring to the disease as 'your MS', could have implications for adjustment, as it may result in patients defining their sense of self, based on the condition.

Interventions could also aim to increase the patient's sense of control over their

MS. Health professionals could help patients identify ways in which they can control different aspects of the condition. For example, specific symptoms can be controlled through treatment. The use of assistance aids would also help patients to exert greater control over their bodies. Many individuals with MS experience severe physical disability, which makes it difficult for them to live day-to-day without the use of physical aids or assistance. However, the findings of the current research suggest that this type of coping is associated with the feeling that the individuals no longer have control over their bodies. This feeling of a loss in personal control inevitably leads them to experience psychological distress. As a result, the findings highlight the need to target patients' perceptions of the strategies associated with this type of coping. Instead of relating assistance aids with a loss of control they should represent a way in which patients can exert greater control over their bodies. In the current research, mobility was identified by the majority of patients as the aspect of their MS that bothered them the most. This highlights the need for patients to be more accepting of aids designed to assist with mobility difficulties. Greater awareness and understanding within the wider community about disability may also facilitate this, by reducing some of the perceived stigma attached to using physical aids.

The results also found that those with dysfunctional attitudes experienced greater anxiety and depression. Individuals develop maladaptive cognitive schema or faulty thinking about themselves during childhood. According to Beck's theory these are then triggered during stressful events. This highlights the need for interventions to challenge patients' maladaptive beliefs in order to improve their sense of well-being.

Overall, the research highlighted how negative mind states can make MS patients vulnerable to psychological distress. It also highlights the importance of maintaining a positive outlook in order to experience a better quality of life. In addition to positive beliefs about the illness, the results suggest that positive future thinking and an optimistic outlook are essential for patients' well-being. Interventions should therefore focus on promoting positive thinking in order to protect individuals from psychological distress and greater physical disability.

Some illness beliefs or cognitions such as illness identity and control may be easier to change than others. For example, the belief that MS is time-cyclical is based on the physical characteristics of the illness and reflects the relapses and remission of symptoms. Furthermore, the condition does have a number of consequences for patient lives. It would, therefore, be difficult for health professionals to try and change these illness beliefs. However, the research suggests that the illness belief components were inter-related. Interventions aimed at reducing patients' illness identity and increasing their sense of control would also therefore affect their beliefs about the consequences of the condition. Health professionals would therefore be able to change the patient's perception of their condition by targeting beliefs or cognitions, which are more amenable to change.

Interventions could also target patients' coping strategies. The present research found that some coping strategies acted as mediators between illness beliefs and adjustment. Strategies used to improve coping would, therefore, reduce the likelihood that those with a more negative view of their condition experiencing psychological distress. In particular, the research highlighted the importance of acceptance in successful adjustment to the condition. Interventions designed to help individuals accept their MS would, therefore, have a considerable impact on patients overall quality of life. The types of strategies would include direct acceptance of the condition, humour (trying to see the funny side of their difficulties) or downward comparison (seeing themselves as lucky compared to those more debilitated by the illness).

Another coping strategy found to be beneficial for adjustment to MS was problem-solving coping. Interventions could teach patients to employ more problem-focused strategies. For example, these interventions could encourage them to think about how to solve problems they are faced with, plan ahead and try to find something positive out of situations. The research suggests that those individuals who believe they have more control over their illness feel more confident in using problem-solving coping. Therefore, by increasing the patient’s sense of control they may be more likely to employ active coping strategies.

In particular, interventions need to be developed to help patients suffering from secondary progressive MS. This type of the illness was found to be associated with greater levels of psychological distress when compared to the other MS types. In secondary-progressive MS, patients do not make a full recovery from symptoms after a relapse; they experience an unremitting loss of function and as a result their level of disability increases and becomes permanent over time. Patients with this type of the illness are, therefore, not only faced with the uncertainty of when they will next experience a relapse they are also aware that any exacerbation of symptoms can leave behind permanent damage. It is therefore unsurprising that this type of MS can lead to greater psychological distress.

Finally, the research highlights the need to increase people’s understanding of MS within the wider community. A better understanding of what it means for those living with the condition may help others to be more sensitive to the individual’s feelings. Furthermore, it is imperative to promote awareness of the patients needs amongst health professionals diagnosing and treating MS. The qualitative analysis suggested that some health providers were not taking patients well-being into consideration. A greater understanding and awareness of the patient’s needs is therefore required by those working and treating individuals with the condition.

9.4 Conclusion

To conclude, the findings of the current research only provide limited support for the SRM as a useful framework for predicting adjustment to MS, prospectively. There are two possible explanations for this. One possibility is that this reflects a limitation in the current research, the other is that it reflects a limitation in the Self-Regulation Model. What is now required is the replication of the present research over a longer time period with a larger sample size. This will help to determine whether the limited support for the SRM identified in the current study is a result of a limitation in the theoretical model or a limitation in the current research design.

Despite the limited support for the SRM, the findings do have a number of clinical implications for health professionals working with MS patients. In particular, the research highlights the importance of positive mind states and acceptance for MS patients' overall sense of well-being.

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Appendix 1: Mini-Mental State Exam

Orientation	**Score**	
What is the year, season, date, day and month (1 point for each).	5	
Where are we: town, district, country, which house number/name, and which floor (1 point for each).	5	
Registration		
I am going to name 3 objects (e.g., apple, table, penny) taking 1 second to say each one. **I would like you to repeat the names of all 3 objects.** Give 1 point for each correct answer. Repeat the object names until all 3 are learned (up to 6 trials). Record number of trials needed.	3	Score: No. of trials:
Attention and Calculation		
Spell "world" backwards. Give 1 point for each letter that is in the right place (e.g., DLROW = 5, DLORW = 3). Alternatively, do serial 7s. Ask the person to count backwards from 100 in blocks of 7 (i.e., 93, 86, 79, 72, 65). Stop after 5 subtractions. Give one point for each correct answer. If one answer is incorrect (e.g. 92) but the following answer is 7 less than the previous answer (i.e., 85), count the second answer as being correct. 1 point for each subtraction.	5	
Recall		
What are the 3 objects you were asked to repeat earlier ? (e.g., apple, table, penny). Give 1 point for each correct object.	3	
Language		
Point to a pencil and ask the person to name this object (1 point). Do the same thing with a wrist-watch (1 point).	2	
Ask the person to repeat the following: "No ifs, ands or buts" (1 point). Allow only one trial.	1	
Give the person a piece of blank white paper and ask them to follow a 3-stage command**: "Take a paper in your right hand, fold it in half and put it on the floor"** (1 point for each part that is correctly followed).	3	
Write "CLOSE YOUR EYES" in large letters and show it to the patient. Ask him or her to read the message and do what it says (give 1 point if they actually close their eyes).	1	
Ask the individual to write a sentence of their choice on a blank piece of paper. The sentence must contain a subject and a verb, and must make sense. Spelling, punctuation and grammar are not important (1 point).	1	
Show the person a drawing of 2 pentagons which intersect to form a quadrangle. Each side should be about 1.5 cm. Ask them to copy the design exactly as it is (1 point). All 10 angles need to be present and the two shapes must intersect to score 1 point. Tremor and rotation are ignored.	1	

Appendix 2: Illness Perception Questionnaire

I am going to read out a list of symptoms that you may or may not have experienced since the onset of your MS. Please indicate by saying *Yes* or *No*, whether you have experienced any of these symptoms since your MS, and whether you believe that these symptoms are related to your MS.

	You have experienced this symptom *since the onset of your MS*			This symptom is *related to your MS*	
Pain	Yes	No	________________	Yes	No
Sore Throat	Yes	No	________________	Yes	No
Nausea	Yes	No	________________	Yes	No
Breathlessness	Yes	No	________________	Yes	No
Weight Loss	Yes	No	________________	Yes	No
Fatigue	Yes	No	________________	Yes	No
Stiff Joints	Yes	No	________________	Yes	No
Sore Eyes	Yes	No	________________	Yes	No
Wheeziness	Yes	No	________________	Yes	No
Headaches	Yes	No	________________	Yes	No
Upset Stomach	Yes	No	________________	Yes	No
Sleep Difficulties	Yes	No	________________	Yes	No
Dizziness	Yes	No	________________	Yes	No
Loss of Strength	Yes	No	________________	Yes	No

We are interested in your own personal views of how you now see your current MS. I will now read out a list of statement. Please indicate how much you agree or disagree with the following statements about your MS using the responses provided on the response sheet.

		Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
IP1	Your MS will last a short time					
IP2	Your MS is likely to be permanent rather than temporary					
IP3	Your MS will last for a long time					
IP4	Your MS will pass quickly					
IP5	You expect to have MS for the rest of your life					
IP6	Your MS is a serious condition					
IP7	You MS has major consequences on your life					
IP8	Your MS does not have much effect on your life					
IP9	Your MS strongly affects the way others see you.					
IP10	Your MS has serious financial consequences					
IP11	Your MS causes difficulties for those who are close to you.					
IP12	There is a lot which you can do to control my symptoms					

		Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
IP13	What you do can determine whether your MS gets better or worse					
IP14	The course of your MS depends on you					
IP15	Nothing your do will affect your MS					
IP16	You have the power to influence your MS					
IP17	Your actions will have no affect on the outcome of your MS					
IP18	Your MS will improve in time					
IP19	There is very little that can be done to improve your MS					
IP20	Your treatment will be effective in curing your MS					
IP21	The negative effects of your MS can be prevented (avoided) by your treatment					
IP22	Your treatment can control your MS					
IP23	There is nothing which can help your condition					
IP24	The symptoms of your condition are puzzling to you					
IP25	Your MS is a mystery to you					
IP26	You don' t understand your MS					
IP27	Your MS doesn't make any sense to you					
IP28	You have a clear picture or understanding of your condition					
IP29	The symptoms of your MS change a great deal from day to day					
IP30	Your symptoms come and go in cycles					
IP31	Your MS is very unpredictable					
IP32	You go through cycles in which your MS gets better and worse.					
IP33	I get depressed when I think about my CFS					
IP34	When you think about your MS you get upset					
IP35	Your MS makes you feel angry					
IP36	Your MS does not worry you					
IP37	Having MS makes you feel anxious					
IP38	Your MS makes you feel afraid					

Causes of MS

We are interested in what you consider may have been the cause of your MS. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your MS rather than what others including doctors or family may have suggested to you. I am going to read out a list of factors, which individuals believe may cause a range of illnesses. Please indicate using the responses on the response card provided how much you agree or disagree that the factor caused your MS.

POSSIBLE CAUSES

		Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
C1	Stress or worry					
C2	Hereditary – it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behavior					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

Please list in rank-order the three most important factors that you now believe caused YOUR MS. You may use any of the items mentioned previously, or you may have additional ideas of your own.

The most important causes are:
1. ____
2. ____
3. ____

Appendix 3: The Illness Perception Questionnaire-Brief

For the following questions, indicate the number that best corresponds to you.

1. How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10

not at all severely affects my life

2. How long do you think your illness will continue?

0 1 2 3 4 5 6 7 8 9 10

a very short time forever

3. How much control do you feel you have over your illness?

0 1 2 3 4 5 6 7 8 9 10

absolutely no control extreme amount of control

4. How much do you think your treatment can help your illness?

0 1 2 3 4 5 6 7 8 9 10

not at all extremely helpful

5. How much do you experience symptoms of your illness?

0 1 2 3 4 5 6 7 8 9 10

no symptoms at all many severe symptoms

6. How concerned are you about your illness?

0 1 2 3 4 5 6 7 8 9 10

Not at all concerned extremely concerned

7. How much do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10

don't understand at all understand very clearly

8. How much does your illness affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?

0	1	2	3	4	5	6	7	8	9	10

not at all affected emotionally extremely affected emotionally

Please list in rank-order the three most important factors that you now believe caused <u>YOUR MS</u>.

The most important causes are:

1. ____
2. ____
3. ____

Appendix 4: Dysfunctional Attitude Scale

I am going to read out a list of statements. Using the response card please answer each statement according to the way you think most of the time.

Attitudes	Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
It is difficult to be happy unless one is good looking, intelligent, rich and creative.							
Happiness is more a matter of my attitude towards myself than the way other people feel about me.							
People will probably think less of me if I make a mistake.							
If I do not do well all the time, people will not respect me.							
Taking even a small risk is foolish because the loss is likely to be a disaster							
It is possible to gain another person's respect without being especially talented at anything.							
I cannot be happy unless most people I know admire me.							
If a person asks for help , it is a sign of weakness							
If I do not do as well as other people it means I am an inferior human being.							
If I fail at my work , then I am a failure as a person							
If you cannot do something well, there is little point in doing it at all.							
Making mistakes is fine because I can learn from them.							
If someone disagrees with me, it probably indicates he does not like me.							
If I fail partly, it is as bad as being a complete failure.							
If people know what you are really like they will probably think less of you							
I am nothing if the person I love doesn't love me.							
One can get pleasure from an activity regardless of the end result.							
People should have a reasonable likelihood of success before undertaking anything.							
My value as a person depends greatly on what others think of me.							

Attitudes	Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
If I don't set the highest standards for myself , I am likely to end up a second rate person.							
If I am to be a worthwhile person, I must be truly outstanding in at least one major respect.							
People who have good ideas are more worthy than those who do not.							
I should be upset if I made a mistake							
My opinions of myself are more important than other opinions of me.							
To be good, moral and worthwhile person, I must help everyone who needs it.							
If I ask a question, it makes me look inferior.							
It is awful to be disapproved of by people, important to you.							
If you don't have other people to lean on, you are bound to be sad.							
I can reach important goals without slave driving myself.							
It is possible for a person to be scolded and not get upset.							
I cannot trust other people to be scolded and not get upset.							
I cannot trust other people because they might be cruel to me.							
If others dislike you, you cannot be happy.							
It is best to give up your own interests in order to please other people.							
My happiness depends more on other people than it does on me.							
I do not need the approval of other people than it does on me.							
I do not need the approval of other people to be happy.							
If a person avoids problems, the problems tend to go away.							
I can be happy even if I miss out on many of the good things in life.							
What other people think about me is very important							
Being isolated form others is bound to lead to unhappiness							
I can find happiness without being loved by another person.							

Appendix 5: Life Orientation Test-Revised

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

	Agree a lot	Agree a little	Neither agree nor disagree	Disagree a little	Disagree a lot
1. In uncertain times, I usually expect the best.					
[2. It's easy for me to relax.]					
3. If something can go wrong for me, it will.					
4. I'm always optimistic about my future.					
[5. I enjoy my friends a lot.]					
[6. It's important for me to keep busy.]					
7. I hardly ever expect things to go my way.					
[8. I don't get upset too easily.]					
9. I rarely count on good things happening to me.					
10. Overall, I expect more good things to happen to me than bad.					

Appendix 6: Coping with Multiple Sclerosis Scale (CMSS; Pakenham, 2001)

Most people with Multiple Sclerosis (MS) say that MS affects many areas of their lives and produces a variety of problems. For example, MS may cause financial problems, strain relationships, create emotional distress such as depression and, of course, physical problems such as limited mobility and the loss of control of some body functions. What is it about you MS that has bothered you the most in the last month?

Rate how stressful this problem has been for you in the past month

Not at all Stressful			Somewhat Stressful			Extremely Stressful
1	2	3	**4**	5	6	**7**

Individuals with MS have developed a number of ways to cope, or deal with the problems caused by MS. Sometimes our attempts are successful in helping us solve a problem or feel better, and other times they are not. I am going to read out a list of things that people have reported they may do when confronted with problems related to MS. **Please indicate how often you have tried each of the coping strategies in dealing with your main MS-related problem (you identified above) in the past month**. If you were unable to identify a "main problem" please indicate using the responses provided on the response card how often you have tried each of the coping strategies in dealing with your MS in general. There are no 'right' or "wrong" answers.

		Does not Apply/ never	Rarely	Some times	Often	Very often
1	I use exercise programs such as hydrotherapy, physio exercises, gym program	0	1	2	3	4
2	I try to find comfort in my religion/faith.	0	1	2	3	4
3	I go on as if nothing has happened	0	1	2	3	4
4	I take medication, for example, prescribed medication, pain killers, vitamins or minerals	0	1	2	3	4
5	I try to get information about the problem	0	1	2	3	4
6	I avoid situations that may aggravate the problem	0	1	2	3	4
7	I have a rest	0	1	2	3	4
8	I attend a support group	0	1	2	3	4
9	I eat, drink or smoke more	0	1	2	3	4
10	I ask for physical assistance	0	1	2	3	4
11	I conserve my energy, for example, by pacing myself or prioritising activities	0	1	2	3	4
12	I go on a diet or limit my fluid intake	0	1	2	3	4
13	I modify my living environments to meet my needs, for example, make home modifications, install air conditioners.	0	1	2	3	4
14	I keep pushing myself to get things done	0	1	2	3	4
15	I let my feelings out.	0	1	2	3	4
16	I concentrate my efforts on things I can do	0	1	2	3	4
17	I focus on the here and now	0	1	2	3	4
18	I think about how I might best solve the problem	0	1	2	3	4
19	I talk to someone about how I feel.	0	1	2	3	
20	I seek alternative therapies such as acupuncture, chiropractics, osteopathy.	0	1	2	3	4
21	I keep others from knowing my problems.	0	1	2	3	4

		Does not Apply/ never	Rarely	Some times	Often	Very often
22	I use relaxation techniques such as meditation, visualisation, yoga, massage.	0	1	2	3	4
23	I laugh and try to find humour in my situation.	0	1	2	3	4
24	I think of others worse off than me.	0	1	2	3	4
25	I accept the fact that it happened.	0	1	2	3	4
26	I control my emotions.	0	1	2	3	4
27	I turn to work or other substitute activities Such as gardening, hobbies or sport to take my mind off things	0	1	2	3	4
28	I try to get something positive out of it	0	1	2	3	4
29	I plan ahead what I need to do.	0	1	2	3	4
30	I ask people who have had similar experiences, what they did.	0	1	2	3	4
31	I put it to the back of my mind and try not to think about it.	0	1	2	3	4
32	I blame MS	0	1	2	3	4
33	I use assistive equipment such as a wheelchair, computer, crutches or incontinence aids.	0	1	2	3	4
34	I use respite services	0	1	2	3	4
35	I ask for financial or other material assistance.	0	1	2	3	4
36	I wish that I could change what had happened.	0	1	2	3	4
37	I talk to someone to find out more about the problem	0	1	2	3	4
38	I learn to live with it	0	1	2	3	4
39	I express the feelings I am having	0	1	2	3	4
40	I talk to someone who could help with the problem	0	1	2	3	4
41	I try to understand my feelings	0	1	2	3	4
42	I make sure that I don’t overdo things	0	1	2	3	4
43	I explore my emotions	0	1	2	3	4

Appendix 7: Hospital Anxiety and Depression Scale

Emotions play an important part in most illnesses. This questionnaire is designed to investigate how you feel. I will read out a list of statements and using the responses on the response card indication which answer comes closest to how you have been feeling over the past week. Don’t take too long with you replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

A **I feel tense or wound up:**
3 Most of the time
2 A lot of the time
1 From time to time, occasionally
0 Not at all

D **I still enjoy the things I used to enjoy:**
0 Definitely as much
1 Not quite as much
2 Only a little
3 Hardly at all

A **I get sort of frightened feeling as if something awful is about to happen:**
3 Very definitely and quite badly
2 Yes, but not too badly
1 A little, but it doesn’t worry me
0 Not at all

D **I can laugh and see the funny side of things**
0 As much as I always could
1 Not quite so much now
2 Definitely not so much now
3 Not at all

A **Worrying thoughts go through my mind**
3 A great deal of the time
2 A lot of the time
1 From time to time but not too often
0 Only occasionally

D **I feel cheerful:**
3 Not at all
2 Not often
1 Sometimes
0 Most of the time

A **I can sit at ease and feel relaxed:**
0 Definitely
1 Usually
2 Not often
3 Not at all

D **I feel as if I am slowed down.**
3 Nearly all the time
2 Very often
1 Sometimes
0 Not at all

A **I get sort of frightened feeling like 'butterflies' in my stomach:**
0 Not at all
1 Occasionally
2 Quite often
3 Very often.

D **I have lost interest in my appearance:**
3 Definitely
2 I don't take as much care as I should
1 I may not take quite as much care
0 I take as much care as ever

A **I feel restless as if I have to be in the move:**
3 Very much indeed
2 Quite a lot
1 Not very much
0 Not at all

D **I look forward with enjoyment to things:**
0 As much as ever I did
1 Rather less than I used to
2 Definitely less than I used to
3 Hardly at all

A **I get sudden feelings of panic**
3 Very often indeed
2 Quite often
1 Not very often
0 Not at all

D **I can enjoy a good book or radio or TV programme:**
0 Often
1 Sometimes
2 Not often
3 Very seldom

Appendix 8: Multiple Sclerosis Impact Scale

The following questions ask you for your views about the impact of MS on your day to day life during the past two weeks. For each statement I read out please indicate using the response card which of the responses best describes your situation.

In the past two weeks, how much has your MS limited your ability to	**Not at all**	**A little**	**Moderately**	**Quite a bit**	**Extremely**
1. Do physically demanding tasks?	1	2	3	4	5
2. Grip things tightly?	1	2	3	4	5
3. Carry things?	1	2	3	4	5
In the past two weeks, how much have you been bothered by………	**Not at all**	**A little**	**Moderately**	**Quite a bit**	**Extremely**
4. Problems with your balance?	1	2	3	4	5
5. Difficulties moving indoors?	1	2	3	4	5
6. Being clumsy?	1	2	3	4	5
7. Stiffness?	1	2	3	4	5
8. Heavy arms and/or legs?	1	2	3	4	5
9. Tremor of your arms or legs?	1	2	3	4	5
10. Spasms in your limbs?	1	2	3	4	5
11. Your body not doing what you want it to do?	1	2	3	4	5
12. Having to depend on others to do things for you?	1	2	3	4	5
13. Limitations in your social and leisure activities at home?	1	2	3	4	5
14. Being stuck at home more than you would like to be?	1	2	3	4	5
15. Difficulties using you hands in everyday tasks?	1	2	3	4	5
16. Having to cut down the amount of time you spent on work and other daily activities?	1	2	3	4	5
17. Problems using transport (e.g. car, bus, train, taxi etc?)?	1	2	3	4	5
18. Taking longer to do things?	1	2	3	4	5
19. Difficulty doing things spontaneously?	1	2	3	4	5
20. Needing to go to the toilet urgently?	1	2	3	4	5
21. Feeling unwell?	1	2	3	4	5
22. Problems sleeping?	1	2	3	4	5
23. Feeling mentally fatigued?	1	2	3	4	5
24 Worries related to your MS?	1	2	3	4	5
25. Feeling anxious or tense?	1	2	3	4	5
26. Feeling irritable, inpatient, or short tempered?	1	2	3	4	5
27. Problems concentrating?	1	2	3	4	5
28. Lack of confidence?	1	2	3	4	5
29. Feeling depressed?	1	2	3	4	5

Appendix 9: Beck Hopelessness Scale

I am going to a list of statements one by one. If the statement describes your attitude for the past week including today, please respond by saying the word true. If the statement does not describe your attitude, please respond by saying the word false.

	True	False
I look forward to the future with hope and enthusiasm.		
I might as well give up because there is nothing I can do about making things better for myself.		
When times are going badly, knowing that they cannot stay that way forever helps me.		
I can’t imagine what my life would be like in ten years.		
I have had enough time to accomplish the things I want to do.		
In the future, I expect to succeed in what concerns me most		
My future seems dark to me		
I happen to be particularly lucky, and I expect to get more if the good things in life than the average person.		
I just can’t get the breaks, and there’s no reason I will in the future.		
My past experiences have prepared me well for the future.		
All I can see ahead of me is unpleasantness rather than pleasantness.		
I don’t expect to get what I really want		
When I look ahead to the future, I expect that I will be happier than i am now.		
Things just won’t work out the way I want them to.		
I have great faith in the future		
I never get what I want, so it’s foolish to want anything.		
It’s very unlikely that I will get any real satisfaction in the future.		
The future seems vague and uncertain to me.		
I can look forward to more good times than bad times.		
There’s no use in really trying to get anything I want because I probably won’t get it.		

Appendix 10: Suicide Ideation Subscale of the Suicide Probability Scale

Please indicate how often you have felt or thought a certain way.

	None or a little of the time	Some of the time	Good part of the time	Most or all of the time
I think of things to bad to share with other people.				
In order to punish others I think of suicide.				
I feel the need to punish myself for things I have done or thought.				
I feel the world is not worth continuing to live in.				
I feel people would be better off if I was dead.				
I feel it would be less painful to die can keep living the way things are.				
I have thought about how to do myself in.				
I think of suicide.				

Appendix 11: Semi-Structured Interview Schedule

I am interested in findings out about your beliefs about MS. Although to date we don’t know what causes this illness many people have there own ideas about what they believed caused their MS. Could you please tell me some of you ideas about your MS?

How much control do you feel you have over your MS?

What do you do to cope with your MS?

How do you feel you cope with your MS?

How do you feel your MS affects your overall quality of life?