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Illness perceptions, depression and coping in people with Multiple Sclerosis

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i. Abstract

Objectives: The study was designed to explore the relationship between the type of Multiple Sclerosis participants had, and their illness perceptions and coping style. Secondary objectives were to see how well the data supported the theoretical models upon which the questionnaires were based.

Method: The study was a cross-sectional between-participants design, and used General Linear Model Multivariate analysis. Confirmatory Principal Component Analysis was also carried out.

Results: Generally findings supported the notion that the type of Multiple Sclerosis people have has an effect on their illness perceptions. There was only one significant between- group comparison for coping. However, anxiety accounted for significant differences found on three coping styles. The model of illness perceptions the questionnaire was based on was largely supported, but the coping styles model was not.

Conclusions: Previous studies have tended to categorise people with Multiple Sclerosis as a single group, and to analyse data accordingly. Results from this study suggest that this may create problems, as there were some distinct differences between people with different types of Multiple Sclerosis on measures of illness perceptions. The illness perceptions model seems to be robust and relevant to an understanding

of Multiple Sclerosis. Coping seems to be affected by anxiety. This suggests that managing anxiety may be a core feature of healthy adaptation to MS.

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Illness perceptions, depression and coping in people with Multiple Sclerosis: A literature review

Introduction

Historically, the major cause of death was infectious disease. However, improved hygiene and diet during the 20th century led to a huge reduction in the number of deaths due to infectious diseases. This development (combined with improved medical technology) resulted in increases in lifespan (Maes, Leventhal, & de Ridder, 1996), the number of elderly people, and the cost of medical care. People are now much more likely to develop a chronic disease (an irreversible illness that must be lived with), and estimates suggest that chronic illnesses account for approximately 80% of deaths in western countries (Maes, et al., 1996). There is no universal medical definition of chronic illness, as there are huge differences in the cause, course, stability and consequence of chronic conditions (Maes, et al., 1996). However, chronic illnesses affect large numbers of individuals, are long lasting, have a major impact on the health care system, and often a high rate of mortality.

Interest in chronic illness has consequently recently grown significantly. Particular areas with a growing body of literature are coping and illness perceptions. It had been widely assumed in medical and research circles that all illnesses are stressful, and that more serious illness is more

stressful. However, it is important to separate the medical view of illness from the patient's view, as individual perceptions of illness may only be modestly related to symptoms, or illness severity (Maes, et al., 1996). For example, the level of distress and outcome experienced by individuals are also related to psychological factors (e.g. Moss-Morris, 1997).

Illness representations (the beliefs and feelings a person has about their illness) and coping strategies (how a person manages the problem and/or their feelings about the problem) are consequently being seen as major factors affecting how individuals regulate themselves and their environment. For example, illness representations are thought to be the main motivator for people's health behaviours, and combined with coping strategies, have been described as 'critical' for adaptation to illness (Leventhal, & Benyamini, 1997, p. 132). The supporting evidence is that illness perceptions are related to decisions to seek health care (Leventhal, Diefenbach, & Leventhal, 1992), compliance with medical advice (Leventhal, Meyer, & Nerenz, 1980), and return to work (Lacroix, Martin, Avendano, & Goldstein, 1991).

Systems models of illness propose that the use of specific coping strategies reflects a reciprocal relationship with illness perceptions (Leventhal, & Benyamini, 1997). This suggests that illness perceptions shape coping strategies, and coping strategies shape illness perceptions. For example, if an individual perceives that their

hypertension is caused by stress, they may cope by relaxing, and ignoring/reinterpreting stressors. If the relaxation reduces symptoms, the coping strategy reinforces the perception. These interactions between perceptions and coping strategies cause changes in both over the course of the illness. These changes reflect the reciprocal relationships between coping and perceptions, and the context within which they take place. Therefore, while it would be expected to find common factors in illness perceptions, there should also be significant differences between diseases, cultures and individuals (Leventhal, & Benyamini, 1997).

Multiple Sclerosis (MS) is considered a particularly interesting chronic disease to study with respect to illness representations and coping, because it has a variable and unpredictable course, and the cause is largely unknown (Moss-Morris, Weinman, Petrie, Horne, Cameron, et al., 2002). This literature review therefore focuses on MS, illness representations and coping, but has some limitations that need to be acknowledged. The coping literature was so vast (c.f. Aldwin, 1994) that a review of the coping literature was beyond the scope of this dissertation. Therefore only the literature specifically relevant to this study is included. Also, as is common with medical populations, many of the research studies discussed used small samples. However, this review is confined to the more reputable literature, and the more rigorously designed studies. It does therefore not include a lot of critical evaluation about the studies, except where this is relevant to the discussion. This is to allow a more thorough exploration and discussion

of the issues involved with MS, depression, coping and illness perceptions.

What is MS?

MS is a degenerative disease that effects the central nervous system. It is distinctive for its unpredictable, and often progressive pattern of remission and exacerbation of symptoms (McReynolds, Koch & Rumrill, 1999). MS is one of the most common neurological disorders in the world (Falvo, 1991), and in the UK (MacDonald, Cockerell, Sander, & Shorvon, 2000). MS is a difficult disease for people to cope with, and potentially has a damaging effect on people's psychological functioning as there is a large element of uncertainty about its progression (McReynolds et al., 1999).

Although there is limited support for an infectious mechanism of plaque formation (DeSousa, Albert, & Kalman, 2002), MS is widely thought to be an autoimmune disease (Robinson, Neilson & Rose, 2000). These hypotheses are not mutually exclusive, as it is possible that the infection triggers an autoimmune response, for example as occurs in rheumatoid arthritis. The immune system's job is to protect the body by destroying foreign tissue (Roberts, 1976). An autoimmune disease is one in which there is failure to distinguish between foreign and self-tissue, and the immune system attacks the body's own cells. Other autoimmune disorders include rheumatoid arthritis, pernicious anaemia, and diabetes

mellitus. In MS, the immune system only attacks the central nervous system (CNS; Robinson et al., 2000).

The CNS enables people to do things such as think, see, breathe and move (Roberts, 1976). It consists of the brain and the spinal cord, and is made up of billions of interconnected nerve cells (Roberts, 1976). Axons extend from nerve cells to create links with other nerve cells, and enable messages to be sent throughout the brain and body via the peripheral nervous system (Kapit & Elson, 1977). Messages travel along axons in much the same way that telephone signals travel along electrical wires (O'Connor, 1999). The axons are insulated by a fatty tissue called myelin so that the signal is not degraded during its travels (Falvo, 1991). In MS the myelin sheaths are damaged by the immune system, and may even be destroyed (McReynolds et al., 1999; Muller-Rohland, 1987). This damage slows down, or blocks the nerve messages, and this causes the symptoms of MS (Muller-Rohland, 1987).

Although it is now known what causes the symptoms of MS, it is still not possible to determine what course the illness will take (McReynolds et al., 1999). Which nerves are damaged, at what rate, and in what order varies greatly, and consequently the symptoms vary widely across individuals, and episodes. Also, tissue damage is gradually repaired, so there can be some recovery of functioning as inflammation at the damage site reduces (Robinson et al., 2000). However, damage may occur more quickly than it can be repaired, so there is usually an

ongoing decline over episodes, or time, as more and more damage accumulates (Robinson et al., 2000). The damage results in scar tissue called scleroses. As there are multiple sites of these scleroses, the disease is called multiple sclerosis.

Types of MS

The course of MS is highly varied and unpredictable (McReynolds et al., 1999).The clinical profile is different for everyone, and everyone has a different experience of MS (McReynolds et al., 1999). For example, some people experience a lot of symptoms that get worse very quickly, while some people experience hardly any symptoms for long periods of time. However, a progressive accumulation of debilitation characterises all forms of MS (DeSousa et al., 2002). Despite the variable nature of MS it is considered useful to recognise some general types (Gross, & Sinaki, 1987), and people within each of the 4 commonly recognised types will have at least some shared characteristics (McReynolds et al., 1999). As there are differences between these types of MS it could be hypothesised that there may be differences in illness perceptions as well.

Relapsing-Remitting

This is the most common form of MS (Gross, & Sinaki, 1987), and is especially common in younger people (Robinson et al., 2000). Exacerbations are usually several months apart, and may include any number of symptoms (McReynolds et al., 1999). Symptoms get worse

during an attack of MS, and may last for a few days before gradually improving over a few weeks (Robinson et al., 2000). Some attacks have few lasting effects with a complete, or almost complete, remission. This is more common in the early stages of the disease. Some attacks may result in permanent loss, or reduction of functioning. The period when symptoms are stable between attacks is called remission.

Progressive

There are two suggested forms of progressive MS: primary and secondary. Primary progressive MS affects approximately 20% of people, usually those who get the disease over the age of 40 (Robinson et al., 2000). The symptoms gradually get worse after the first attack; disability increases, and there is often a loss of body movement of some kind, or loss of sensory performance. Serious disability can occur in a few months, but in most cases MS progresses over many years with a slow steady rate of increase in disability (McReynolds et al., 1999). Remissions do not occur, and this type of MS is often associated with feelings of hopelessness, despair and perceived loss of control (McReynolds et al., 1999).

Two thirds of people with relapsing-remitting MS find that their disease becomes progressive as the remission between attacks become smaller, and the attacks last for longer (Mohr, & Goodkin, 1999). This is known as secondary progressive MS. However, it is possible that the distinction between primary and secondary progressive MS is less clear

than suggested by the literature. MS is so varied that people diagnosed with primary progressive MS may have had such mild symptoms initially that they passed unnoticed and no medical opinion was sought. There is some support for this notion as men are more likely to be diagnosed later and with primary progressive MS (Robinson et al., 2000), and there is corresponding evidence that men consult doctors less often than women (Briscoe, 1987). There is also some evidence that men use more avoidant coping, and women more vigilant coping (Krohne, Schumacher, & Egloff, 1992; Weidner, & Collins, 1993). These factors may be related to the diagnostic bias. The finding of histopathological features and multiple lesions in undiagnosed cases during autopsy (Herndon, & Rudick, 1983), and on magnetic resonance imaging scans (Miller, Ormerod, & du Boulay, 1987) lends some support to the notion of a delayed diagnosis, rather than a separate diagnosis for primary and secondary progressive MS.

Benign

For some people with MS the symptoms are relatively minor and/or the disease progresses so slowly that it is hardly perceptible, and/or there are very few attacks over a long period of time (Rumrill, 1996; Robinson et al., 2000). This is known as the benign form. People with this type of MS usually experience a full recovery from attacks (McReynolds et al., 1999). However, benign can be a misleading term, as it is not an indicator of how the MS will progress in the future. Many people who are

initially described as having benign MS have developed significant disabilities 25 years later (Robinson et al., 2000).

Fulminating

There is also an extremely rare form of MS called fulminating, or malignant MS. It has no relationship with cancer, but involves the rapid progression of MS symptoms that render the person incapacitated (Gross, & Sanaki, 1987). It is an aggressive, persistent form of MS (McReynolds et al., 1999), and can result in death within a few months (Robinson et al., 2000). Although MS is not considered a fatal disease, severe symptoms may result in problems with breathing, swallowing and kidney function. These can cause problems such as pneumonia, and blood or kidney infections, which may result in death (Antonak, & Livneh, 1995).

The Epidemiology of MS

Prevalence and Incidence

It is difficult to give an accurate figure of how many people in the UK have MS, as although identification has improved (Robertson, Deans, Fraser, & Compston, 1996), not everyone who has it may have been diagnosed (Robinson et al., 2000). Also, figures tend to be based on lots of small studies carried out in various locations, or on restricted populations (e.g. Ford, Gerry, Johnson, & Williams, 2002; Lockyer, 1991; Monks & Robinson, 1989; Roberts, Martin, McLellan, McIntosh-Michaelis, & Spackman, 1991; Robertson, et al., 1995; Shepherd, &

Summers, 1996; Williams, & McKeran, 1986), with few large-scale studies conducted (exceptions being Forbes, & Swingler, 1999; MacDonald et al., 2000; Swingler, & Compston, 1986). Nearest estimates are that 85,000 people in the UK had MS in 2000, with approximately 2500 new cases identified yearly (Robinson et al., 2000). This means that roughly 1 person in every 1000 people has MS in the UK.

A review of the literature suggests that there are regional variations, with Scotland having the highest prevalence, and the south of England the lowest (e.g. Swingler, & Compston, 1986). Recently it has been suggested that this latitude effect is declining, and that it may be a product of incorrect measurement (Robinson et al., 2000). As methods of ascertainment have not been standardised, better ascertainment in studies in the north of England could account for the regional variances (Forbes, Wilson, & Swingler, 1999). However, there is no evidence for this, as the one study designed to test this notion found differences in prevalence between northern and southern UK, despite ascertainment being similar across regions (Forbes, & Swingler, 1999). Other possible explanations for the decline in variance are increased migration and travel, cross-cultural marriages, and the convergence of lifestyles and affluence across regions and countries.

The finding of regional variations in the UK is in line with research in New Zealand, where regional variations have also been found (Skegg,

Corwin, Craven, Malloch, & Pollock, 1987). However, large numbers of Scottish immigrants settled the southern parts of the south island of New Zealand (MS Society of New Zealand, personal communication). It is therefore possible that the high incidents of MS in the South Island are related to Scottish ancestry, and not to regional variations. The study by Skegg et al. (1987) did not account for ancestry, and no large-scale studies have been carried out since 1987 (Chancellor, Addidle, & Dawson, 2003). However, a recent study has reported that levels of MS may be higher in the north island of New Zealand than previously thought (Chancellor et al., 2003), so it is possible that the latitude affect is declining in New Zealand as well.

Demographics

Age. People are usually diagnosed with MS between the ages of 20 and 40 (Falvo, 1991). Mean onset age has been variously quoted as 31.7 years (Robertson et al., 1995) and 34 years (Williams, & McKeran, 1986). The mean age of research participants in MS studies has been calculated as 49 years (Robertson et al., 1995).

Gender. More women are diagnosed with MS than men by an average of 2:1 (e.g. Mohr, & Cox, 2001). However, women tend to be diagnosed young, while men tend be diagnosed over 40. Men also tend to be diagnosed with primary progressive MS (McReynolds et al., 1999).

Life Expectancy. Although people with MS generally have a normal life expectancy (McReynolds et al., 1999), people in the advanced stages of MS may be more susceptible to general health dangers, such as infections and pneumonia (Antonak & Livneh, 1995)

Ethnicity. MS affects all the main racial groups, but is most frequent in white people (O'Connor, 1999). Cases are rare among people of Sami, Turkmen, Uzbek, Kazakh, Kyrgyzris, Siberian, north and south Native American, Chinese, Japanese, African and Maori origins (Rosati, 2001). However, it has been suggested to be geography, rather than racial group per se, that is related to higher incidence (Robinson et al., 2000).

Possible Causes of MS

Despite much research it is still not known what causes MS. However, there seems to be some genetic component, and genome analysis suggests that genes on at least two chromosomes make a person more likely to get MS (O'Connor, 1999). Alternative causes of MS such as viral infections, or sexually transmitted disease have also been suggested (DeSousa, et al., 2002; Robinson et al., 2000).

MS has historically been more common in cool temperate climates, and rare in tropical, or semi-tropical climates (Baum & Rothschild, 1981). This effect may be related to genetic similarities (e.g. common ancestors), lifestyle factors (e.g. diet, alcohol, refined foods, chemicals), affluence (e.g. air conditioning, sanitation, central heating, drugs),

environmental factors (e.g. temperature, humidity, sunshine, rain, altitude), or late exposure to viral infections (O'Connor, 1999). MS seems to affect more people from middle and upper socio-economic status groups, and to be more common in people who live in cities.

The Symptoms of MS

MS has multiple signs and symptoms (e.g. McReynolds et al., 1999). This is because the CNS is highly specialised, and different areas control different functions (Roberts, 1976). Common symptoms reported are: debilitating fatigue; depression; cognitive impairment; memory changes; pain; loss of vision; visual disturbances; motor impairment; unsteadiness; dizziness; weakness; shaking; loss of co-ordination; numbness; tingling; incontinence (bladder and bowel); emotional changes; and sexual problems (e.g. McReynolds et al., 1999; Mohr, & Dick, 1998).

Fatigue

Fatigue is probably the most common symptom, reported by approximately 77% of people (Schwatz, Coultland-Morris & Zeng, 1996). People generally report feeling tired within a few hours of getting up. The level of fatigue can be debilitating, and can interfere with work and/or home life. The cause of fatigue has not been discovered, although it may be related to factors such as depression, reduced muscle strength and endurance (O'Connor, 1999), hardening and scarring of the myelin sheath (McReynolds et al., 1999), or immune dysfunction (Robinson et

al., 2000). Because symptoms of fatigue are subjective, vague and hard to measure the problem often does not receive the validation that it deserves from others, or from the person with MS, and can be interpreted as laziness (McReynolds et al., 1999; O'Connor, 1999). This may be a factor in the depression often experienced by people with MS.

Depression

Depression is common in people with MS (Barak, Gabbay, Gilad, Sarova-Pinhas & Achiron, 1999). Research suggests that although people are no more likely to be depressed prior to getting MS than the general population (LaRocca, 2000), as many as 50% of people experience at least one episode of clinical depression after getting MS (Minden, & Schiffer, 1990; Sadovnick, Eisen, Ebers, & Paty, 1991). Between 14-57% of people with MS are thought to be clinically depressed at any one time, depending on the measure, criteria and population used (Schiffer, Caine, Bamford, & Levy, 1983; Schubert, & Foliart, 1993; Whitlock, & Siskind, 1980). This is higher than the 6% estimated to be the number of people in the general population who are depressed at any one time (Roth, & Fonagy, 1996).

The depression experienced by people with MS is classified as moderate in clinical severity, and tends to be accompanied by anger, irritability, anxiety and discouragement (Minden, Orav, & Reich, 1987). However, the assessment of depression in people with MS is complicated (Mohr, & Goodkin, 1999), as many of the symptoms used to

assess depression are also characteristic of MS (e.g. lack of concentration), or sequelae to MS symptoms (e.g. hypersomnia). Therefore standard measures following Diagnostic Statistical Manual IV (American Psychiatric Association, 1994) criteria may be inappropriate (Mohr & Goodkin, 1999). In support of this notion there is clinical evidence that depression is expressed differently in people with MS compared to people with psychiatric diagnoses. Symptoms such as anger, irritability, anxiety and hopelessness are common in MS (Minden, & Schiffer, 1991), rather than loss of appetite and insomnia.

Another complication in the study of depression in people with MS is the controversy about whether depression in MS is a reaction to a chronic illness, or organic (Barak et al., 1999; Lynch, Kroencke, & Denney, 2001). Most of the valid evidence shows a relationship between depression and disability (e.g. Aikens, Fischer, Namey, & Rudick., 1997; Pakenham, 1999), and this is often interpreted to mean that depression occurs in response to the pressures of the disease (Lynch et al., 2001). However, there is also evidence that depression in people with MS is affected by loss of social support (Barnwell, & Kavanagh, 1997; Pakenham, 1999), and inadequate coping (Aikens, et al., 1997; Pakenham, 1999). Depression in people with MS is also significantly reduced after psychological intervention (e.g. Mohr, & Goodkin, 1999; Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001). However, as Mohr & Cox (2001) point out, the reactive hypothesis does not explain

why rates of depression found in MS are higher than in other progressive diseases (e.g. Creed, 1990; Ron, & Logsdail, 1989).

Current views of depression in MS seem to be of a complex, multi-factor cause. Mohr and Cox (2001) suggest it may be caused by a combination of psychological reactions to illness, specific MS-related disease processes, and neurological damage. Alternatively, depression may be confused with the symptoms of MS, such as fatigue, sleep changes, and inability to concentrate (Mohr & Cox, 2001). This explanation would account for the high incidence of depression in MS compared to other chronic illnesses. Lynch et al. (2001) suggest that most likely both reactive and organic models of depression apply to MS. Meanwhile, researchers continue to look for links between depression and MS, and hope that improved magnetic resonance imaging techniques will help provide answers to organic processes (Barkof, 1999).

Cognitive Impairments

Cognitive impairments are a common symptom of MS, and are thought to affect 40 – 70% of MS people at any one time (Beaver, Grattan, Panitch & Johnson, 1995; DeSousa, et al., 2002; Rao, Leo, Bernardin & Unverzagt, 1991). Impairments vary from person to person, and can occur at any time during the disease (Ryan, Clark, Klonoff, Li, & Patty, 1996). Impairments are not linked to the presence of neurological symptoms, but to the total volume of brain matter damaged (Comi et al., 1995; Rovaris et al., 1998).

The most frequent cognitive difficulties fairly specific to MS are those involving sustained attention, memory, verbal associative fluency and visiospatial perception (e.g. Franklin, Nelson, Filley, & Heaton, 1989). These difficulties are most commonly caused by the diffuse spread of microscopic pathology in the brain (DeSousa et al., 2002). However, general intellectual ability is not normally affected (Brassington & Marsh, 1998; Peyser, Rao, LaRocca & Kaplan, 1990).

Motor Impairments

Motor disturbances are often the first symptoms of MS (McReynolds et al., 1999). Symptoms include spasticity, weakness, and difficulties with motor co-ordination and balance, and can result in poor mobility. Numbness, and tingling are also frequent symptoms (Rumrill, 1996).

Euphoria

Euphoria affects less than 10% of MS people, and is therefore not one of the most common features of MS (Minden, & Schiffer, 1991). It is largely considered to be associated with severe pathology, severe physical disability and dementia. However, as it is present in some people with MS who do not fit this profile, it has been suggested that it may also be an exaggerated expression of optimism in an effort to cope with the overwhelming negative emotions brought on by a diagnosis of MS (LaRocca, 2000). It is important to remember this when considering coping, depression, and illness representations.

Anxiety

There has been little research on anxiety in MS (Feinstein, O'Connor, Gray, & Feinstein, 1999; Mohr & Cox, 2001). However, rates of anxiety appear to be higher in people with MS than in the general population (Maurelli et al., 1992; Rumrill, 1996), with prevalence between 19-34% (Minden & Schiffer, 1991; Pepper, Krupp, Friedberg, Doscher, & Coyle, 1993; Stenager, Knudsen, & Jensen, 1994). A study by Feinstein et al. (1999) found anxiety to have a higher prevalence rate than depression, with 25% of participants rating symptoms for clinically significant anxiety, with or without concurrent depression. Although disease profiles were similar across gender, the ratio of anxious women to anxious men was 8:1. This is very different from anxiety rates in the general population. Data for Generalised Anxiety Disorder suggests a lifetime prevalence of between 3-8%; with a female to male ratio of 2:1 (American Psychiatric Association, 1994).

Problems associated with high levels of anxiety are increased levels of depression (Feinstein et al., 1999), and poor adherence to medication (Mohr, & Cox, 2001). People who are both anxious, and depressed have been found to be more debilitated. For example, people who are both anxious and depressed contemplate suicide more, are more somatically pre-occupied, and socially dysfunctional (Feinstein, et al., 1999). Anxiety has also been found to exacerbate MS symptoms,

although the relationship between stress and MS is insufficiently understood (Mohr, Goodkin, et al., 2000).

Other Factors

The symptoms of MS may result in an increased need for, and reliance on, help from family, friends and possibly government services. This can be a source of distress to people with MS and their families (McReynolds et al., 1999). The main provider may have to give up work due to the illness. Jobs and chores may have to be renegotiated (McReynolds et al., 1999). These changes in family dynamics are likely to precipitate emotional reactions such as anger, blaming, depression, resentment, guilt and anxiety with subsequent consequences (McReynolds et al., 1999).

Illness Perceptions

A range of problems arise with the onset of disease, and these vary greatly from person to person. In an effort to cope with these problems, people develop their own understanding of their illness (Leventhal, Nerenz, & Steele, 1984). This understanding has been variously labelled as the patient's cognitive model, or schema (Pennebaker, 1982), implicit models or beliefs (Baumann, Cameron, Zimmerman, & Leventhal, 1989), and common sense representations of illness/lay cognitive model (Meyer, Leventhal, & Gutmann, 1985). The common terms that will be used in this discussion are illness perceptions (Weinman, Petrie, Moss-Morris, & Horne, 1996), and illness representations (Leventhal et al.,

1984). Illness perceptions are important factors and guide coping (e.g. Lacroix et al., 1991), and influence medical, psychological and behavioural outcome (Scharloo, & Kapstein, 1997).

Illness perceptions are thought to derive from personal experience with illness, social, religious and cultural messages, and information from the medical profession (Leventhal, & Benyamini, 1997; Schiaffino, Shawaryn, and Blum, 1998). They come into effect as soon as the person experiences their first symptoms, and typically change as the disease progresses, as symptoms change, and as treatment responses come into effect (Weinman, et al., 1996). Research into illness perceptions started with the development of a theoretical model describing the processes involved in the construction of illness perceptions (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984). The model is consistent with reported experiences of people with chronic illnesses (Schiaffino et al., 1998), and has been described as the most influential theoretical framework used in illness representation research today (Weinman et al., 1996).

The Five-Factor Model

The underlying assumptions of Leventhal's (1980, 1984) model are that people have a representation of the illness, and an emotional reaction to the illness. The model proposes that illness representations have distinct factors, which, in turn, help to determine coping. How each person sees their illness within this model is highly individual. Research has tended to

validate Leventhal's model, and has consistently found that illness perceptions are organised into five factors (e.g. Baumann, et al., 1989; Lau, Bernard, & Hartman, 1989; Lau, & Hartmann, 1983; Leventhal, & Diefenbach, 1991; Skelton, & Croyle, 1991). Each of these factors has been demonstrated to impact on the person's emotional response to illness (Easterling, & Leventhal, 1989), adherence to treatment (Leventhal, et al., 1992), and deciding to seek medical attention (Baumann, et al., 1989).

The factors identified in the model are disease identity, cause, consequence, timeline, and control/cure. Identity is conceptualised as ideas about the label and symptoms of the disease, and the links between these. For example, if a person has symptoms they will look for a diagnosis, and if they have a diagnosis they will look for symptoms (Baumann et al., 1989; Croyle, & Jemmott, 1991). People's perceptions of their symptoms and disease can be a powerful motivator, and can cause them to stop, or start treatment, irrespective of medical advice (Leventhal, & Benyamini, 1997). The cause dimension relates to the person's beliefs about the cause of the illness, either external (e.g. injury or germ), or internal (e.g. disposition). Timeline is the person's belief about the likely duration of their illness (i.e. whether it is acute, chronic or cyclical), which impacts on adherence to treatment. For example 58% of people with hypertension who perceived their illness as acute dropped out of treatment within 9 months, compared to 17% who saw hypertension as chronic (Meyer, et al., 1985). Consequence is the

person's understanding and expectations about the severity of the illness, and its probable impact on their somatic, social and economic functioning, and quality of life. Control is related to how controllable, or curable, the illness is believed to be. These five factors have been described as the building blocks of illness representations (Heijmans, & de Ridder, 1998), and as having important implications for people's conceptualisations of illness and development of coping strategies (Leventhal, et al., 1980, 1984).

However, although these factors are well validated, there are complex relationships between them. For example, although the components are distinct from each other, they are not necessarily independent of each other, and there may be direct links between the different factors (Weinman, et al., 1996). In support of this is the suggestion that timeline is implicit in all of the factors (Leventhal, & Nerenz, 1985). It has also been suggested that although there seems to be a consistent and valid underlying structure, all five illness perceptions may not be present in every person (Nerenz, & Leventhal, 1983). Additionally it has been suggested that the content of illness representations may very between people, and that a person may hold seemingly conflicting, or inconsistent perceptions of their illness (Heijmans, & de Ridder, 1998). This may be because some dimensions are less relevant to some illnesses, or some people, or two factors may merge together to create a four factor model, or a different factor altogether in a specific illness.

The model was recently updated by Leventhal et al., (1997) to include emotional representations. These are developed in parallel to the five cognitive representations, and lead to the person choosing problem-focused, or emotion focused coping strategies from their repertoire (Leventhal, Leventhal, & Cameron, 2001). It is considered important to consider emotional representations and how they might impact on adjustment (Moss-Morris et al., 2002), and new research in chronic illness and illness perceptions has attempted to address this.

Measuring Illness Perceptions

As interest in the area of illness representations has increased, so more ways of measuring them have been developed. Some researchers have used detailed, semi-structured interviews (e.g. Leventhal, & Nerenz, 1985; Leventhal et al., 1984). However, while these provide a richness of content and are clearly useful, they are also time-consuming, and do not control the quantity, or quality of data (Weinman et al., 1996). It is also difficult to use this method with large samples. Several self-report questionnaires have been developed, but these tend not to be theory based, and to only be validated with one type of illness (e.g. Lacroix, et al., 1991).

An exception to the above is the Illness Perceptions Questionnaire (IPQ; Weinman, et al., 1996). This was developed to facilitate understanding of the nature of coping with disease, and the development of interventions to aid self-management. The IPQ was theoretically derived, and

psychometrically validated. A particular strength was that it was also developed to be flexible enough to have items specifically relevant to particular disease groups included without losing psychometric validity. This enables it to be used with a range of illnesses (e.g. Cooper, Lloyd, Weinman, & Jackson, 1999; Fortune, Richards, Main, & Griffiths, 2000; Griva, Myers, & Newman, 2000; Heijmans, 1998; Moss-Morris, Petrie, & Weinman, 1996; Murphy, Dickens, Creed, & Bernstein, 1999; Scharloo, Kapstein, Weinman, Willems, & Rooijmans, 2000).

The IPQ has recently been revised (IPQ-R; Moss-Morris, et al., 2002). This has resulted in improved psychometric properties on two of the factors, and the inclusion of additional components (timeline cyclical, illness coherence, and emotional representations). These additions enable perceptions to be explored more fully. Using the IPQ-R it has been found that cognitive representations can be separated from emotional representations, and positive and negative affective traits (Moss-Morris, et al., 2002).

Illness Perceptions and Chronic Conditions

Research has consistently shown that people with chronic illnesses have beliefs about the identity, cause, consequences, duration, and controllability of their illness (e.g. Leventhal, et al., 1980; Lau, Bernard, Hartman, 1989). These perceptions of the illness mediate between the objective severity of the disease, and the outcome. Lau and Hartmann (1983) suggest that based on prior experience with minor illnesses,

illness representations of minor ailments are probably already well established before the person gets a chronic illness. They hypothesise that when people first feel ill with symptoms of the chronic illness, they try to fit these symptoms into their existing illness perceptions. For example, people may attribute chest pains to indigestion. According to Lau and Hartmann it is the lack of fit with existing illness perceptions that alerts people to the notion that they have a more serious disease, and this triggers the development of illness perceptions for that illness, largely based on pre-existing perceptions and treatment characteristics. For example, previous hospital admission, medical examinations, surgery, and medical treatment have all been found to affect people's illness perceptions of chronic illness (e.g. Johnston, Weinman, & Martineau, 1990)

Illness Perceptions in MS

It has been proposed that the variable and unpredictable nature of MS is likely to influence the illness perceptions that people have (Schiaffino et al., 1998). For example, people who have mild symptoms, or who quickly go into remission, may think of their MS as an acute illness. It may only be after repeated attacks, or increased symptom severity that is unresponsive to treatment, that the full impact of their illness becomes apparent. However, a literature search suggests there are very few studies concerning MS and illness perceptions. The handful that were identified were largely written in a foreign language, were a presentation or dissertation paper and not obtainable, or only explored one illness

perception factor. In the one study obtained (Moss-Morris et al., 2002), illness perceptions in the MS group accounted for 15% of the variance in adjustment and 27% of the variance in physical fatigue. Cognitive illness perceptions also accounted for 36% of the variance in emotional distress. However, it seems from the published paper that the type of MS was not differentiated in the final analysis. It is considered possible that mixing the types of MS may have acted as a confounding factor.

Illness Perceptions and Depression

Generally research suggests that illness perceptions and depression are related. For example, Murphy, et al. (1999) found an association between depression and illness perceptions in people with rheumatoid arthritis. The factors most strongly correlated with depression were consequence and control. People who viewed their illness as more serious and felt they had little control over it were more depressed, even when disability was controlled for. However, as the study was cross-sectional, the nature of the relationship (i.e. whether people view their illness more negatively because they are depressed, or whether they are more depressed because they view their illness negatively) is unclear.

Scharloo et al. (2000) found that higher identity score (i.e. a higher number of symptoms identified as related to their illness) in people with psoriasis was related to higher depression. Similarly, Moss-Morris et al. (1996) found the identity component was significantly associated with dysfunction and psychological adjustment in a study of Chronic Fatigue

Syndrome (CFS). Moss-Morris et al. considered the possibility that illness identity is merely a manifestation of illness pathology, and that it was the severity of symptoms rather than perception of illness that was responsible for the relationship. However, there is evidence against this hypothesis, as people with CFS have large discrepancies between their subjective reporting of symptoms, and objective laboratory measures of symptoms (e.g. Grafman et al., 1993).

Illness Perceptions Summary

Illness perceptions are the person's understanding of their illness. These beliefs are based on culture, social environments, treatment experiences and past experiences of illness. Illness perceptions are generally believed to be structured in a 5- factor model, and to be crucial for the understanding of coping and outcome in chronic illness. There is evidence to support the notion of a relationship between illness perceptions and depression, but the direction of the relationship is not known as most studies are cross-sectional. The most theoretically derived and well-validated measure of illness perceptions is the IPQ-R (Moss-Morris et al., 2002).

Coping

Coping research developed from studies on defensive behaviour in the 1960's (Parker, & Endler, 1996). Adaptive defence behaviour started to be differentiated from non-adaptive defensive behaviour, and was labelled 'coping' (Parker, & Endler, 1996). Initial work on adaptive

defensive behaviours evolved to include the study of conscious coping strategies (e.g. Cohen, & Lazarus, 1973). This early work tended to focus on coping with threatening or traumatic events. This led to the promotion of situational variables at the expense of dispositional (personality) variables, because threatening situations tend to have a limited number of available responses, irrespective of the habitually preferred strategies of the individual (Parker, & Endler, 1996). This bias led early theorists to propose that personality was not germane to coping behaviour (c.f. Parker, & Endler, 1996). This influenced researchers, who began to focus more on coping as a process that changed over time, and in accordance with situational contexts (Lazarus, 1993). However, recently it has again been proposed that coping styles are fairly consistent across situations (Carver, Scheier, & Weintraub, 1989; Krohne, 1996), and there has been some renewed interest in the study of personality (e.g. Endler, & Parker, 1992).

Current psychological views are that coping is an active and conscious process that interacts with other factors, such as personality and stress experiences, across time and across changing circumstances (Zeidner, & Saklofske, 1996). The most influential theory is Lazarus and Folkman's theory of stress and coping (e.g. Lazarus & Folkman, 1984a, 1984b). In this model, coping embodies strategies for managing external, or internal, stresses and threats that challenge, or exceed, personal resources (Lazarus, & Folkman, 1984b). It is generally

accepted that coping involves three concepts (e.g. Lazarus, & Folkman, 1984a; Moos, & Billings, 1982).

Cognitive Appraisal

The model of stress developed by Lazarus and colleagues (e.g. Lazarus, & Folkman, 1984a) proposes that stressors are appraised by individuals in two ways. Primary appraisal involves assessing potential threat. If the event is judged to be threatening it is subjected to secondary appraisal; the perceived ability to cope with that threat. In support of this model there seem to be some aspects of stressful events, such as 'controllability' and 'chronicity', which influence the choice of coping strategy (Pakenham, 1999). These seem to be similar to illness perceptions.

Coping Resources

Coping resources refer to assets that are available to the individual when choosing a coping strategy (Moos, & Billings, 1982). These are things like social support, time, money, and personality factors (e.g. Cohen, & Edwards, 1989; Ensel, & Lin, 1991; Moos, 1988). Extrinsic stressful life events have also been hypothesised to influence the coping process (Maes, et al., 1996).

Coping Style

This refers to how demands appraised as challenging are managed (e.g. Pakenham, 1999). Coping styles are often classified as either problem-

focused (aimed at altering the source of stress, e.g. confrontive coping), or emotion-focused (aimed at reducing the distress e.g. escape-avoidance) strategies (Lazarus, & Folkman, 1984a). A good fit between the situation and coping method is thought to be important, and generally problem-focused strategies seem to be more adaptive in situations appraised as changeable, while emotion-focused strategies seem more adaptive in unresolvable situations (Lazarus, & Folkman, 1984a). People tend to use both styles of coping when dealing with stressful events (Lazarus, & Folkman, 1984a).

From this perspective, one coping response is not inherently better than another, so long as it is appropriate to the individual's resources and the situation. However, there is a tendency for coping to be evaluated as either good or bad, with problem-focused approaches being considered more functional than emotion-focused coping (Ratsep, Kallasmaa, Pulver, & Gross-Paju, 2000). However, this evaluation confuses behaviour with outcome, and erroneously assumes that some styles of coping behaviour automatically lead to good outcomes, irrespective of circumstances and other factors (Weinman, Wright, & Johnston, 1995). It also assumes a one-way causal link between coping and outcome. Whether because of this view, or the as the cause of this view, coping questionnaires have tended to focus on a disparate group of emotion coping behaviours (e.g. venting, suppression, and denial) that are associated with worse adjustment (Nolen-Hoeksema, Parker, & Larson, 1994; Stanton, Danoff-Burg, Cameron, and Ellis, 1994). Not only do

these strategies have significant conceptual differences (Carver et al., 1989), but also some strategies labelled emotion-focused might be better considered as symptoms of distress (Stanton et al., 1994). These issues have possibly led to claims of a relationship between coping and distress that does not exist (Summerfeldt, & Endler, 1996).

Aside from emotion and problem-focused classifications, strategies have also been categorised as approach or avoidance according to the individual's attitude to the problem (e.g. Krohne, 1993). Approach strategies refer to the tendency to focus on the event, or its significance (e.g. planning, positive reinforcement, seeking social support, and positive reappraisal). Avoidance refers to the tendency to avoid, ignore, or deny the event, or its significance (e.g. denial, behavioural disengagement, focusing on emotions, alcoholism, and drugs). A review of the literature by Carver & Scheier (1994) suggests that avoidance coping tends to be unhelpful, although it can be effective in dealing with short-term stressors.

Measures of Coping

Coping measures can be broadly divided into two types (Parker, & Endler, 1996). The first type (situation scales) assess basic coping strategies used in specific circumstances (e.g. job loss, cancer). The second type (disposition scales) assesses several basic coping strategies used in a variety of situations. A problem with both types of measure is that they fail to tap positive aspects of emotion-focused

coping, such as emotional expressiveness and understanding (Stanton et al., 1994). Measures have focused on negative aspects of emotion-focused coping, and ignored the possibility that some emotion-focused strategies are approach focused, and potentially related to positive outcomes (Pakenham, 1999). This bias may have affected results, and be responsible for the findings that emotion–focused coping tends to be correlated with higher levels of distress (Aikens et al., 1997; Pakenham, Stewart, & Rogers, 1997). Another problem has been that the many coping measures in current use have focused on strategies, without looking at the meaning (i.e. illness perceptions) to the individual (Maes, et al., 1996). Also, although it seems agreed that coping is a process, most coping studies are cross-sectional, and it has yet to be evaluated if measures have sufficient sensitivity to measure changes in coping over time (Maes, et al., 1996).

Coping in Chronic Illness

The absence of a cure for the majority of chronic diseases means that people are coping and adjusting to chronic illness for the rest of their lives (Maes, et al., 1996). As well as coping with disease, the illness and the resulting disability can result in life stresses that have to be coped with (e.g. job loss, divorce, loss of independence and social life). Evidence from research of people with diabetes suggests that stressful life events unrelated to the illness can affect emotions and illness symptoms (Cox, & Gonder-Frederick, 1992). However, this area seems to be largely unexplored in the literature and models of coping.

Recently there has been an increase in psychological contributions to research and care for people with chronic illnesses (e.g. Scharloo, et al., 2000), and illness perceptions and coping have been shown to be a vitally important component in adaptation to chronic disease (Zeidner, & Saklofske, 1996). Research has demonstrated that the degree of disability associated with some chronic illnesses is related to psychological factors, as well as objective measures of disease/symptomatic severity (e.g. Graydon, & Ross, 1995; Ratsep, et al., 2000). However, chronic illnesses are unstable, and differences are common between illnesses, and between individuals with the same illness (Maes, et al., 1996). This means that it is difficult to draw general conclusions based on a single illness, or small group of individuals. Studies therefore need to consider each illness individually using large groups of individuals.

There is a growing body of evidence that some styles of coping (i.e. problem-focused) are associated with good outcome, and better physical or psychological health (e.g. Cohen, Reese, Kaplan, & Riggio, 1986; Ingledew, Hardy, Cooper, & Jemal, 1996). It is widely assumed that these differences between strategies are due to a number of different variables (e.g. timing and the nature of illness), and because different coping responses are appropriate for dealing with different aspects of situations (Moss-Morris, et al., 1996). This might seem to suggest that problem–focused strategies are better at dealing with chronic illness

than emotion-focused strategies. However, coping may be the cause, or the consequence of a physical or psychological state, and it is therefore important to consider the links and the causality between coping and other variables, such as mood (Weinman et al., 1995), or illness representations.

It may also depend on which emotion-focused strategies are measured, as not all are related to poor outcomes (Mohr & Cox, 2001). Although research has found that passive and/or avoidant emotion-focused strategies are related to worse adjustment and lower levels of quality of life in people with chronic illnesses (e.g. Aikens et al., 1997; Carver et al., 1993; Pakenham et al., 1997), more constructive emotion-focused strategies, such as emotional approach (Stanton et al., 1994), positive reinterpretation (Folkman, & Lazarus, 1980), and acceptance (Carver, et al., 1989), are related to positive outcomes. However, these constructive strategies are not included on the most common coping measures, despite evidence that they are potentially useful to people with MS (Pakenham, 1999) and possibly other chronic illnesses. When all the evidence is considered, it seems possible that a broader avoidance or approach perspective may be a more useful classification in understanding coping with chronic illness than a problem or emotion-focused perspective.

Coping in People with MS

The nature of MS with its debilitating symptoms, and the lack of a cure, means that MS is an extremely stressful disease to have, and adjustment difficulties are prevalent (Aikens, et al., 1997). Like other people who are chronically and terminally ill, people with MS are continually faced with multiple choices of coping strategies, with little evidence to help them decide which best suits their needs (Schwartz, 1999). However, clinical observations suggest some people with MS have severe disabilities, but cope better, and have better outcomes, than others with less severe disabilities (Sinnakaruppan, 2000). Coping therefore seems to be an important component in the management of MS.

Like other chronically ill people, people with MS have to deal with both ordinary stressors, and disease related stressors (Jean, Paul, & Beatty, 1999). The symptoms of MS are diverse, and potentially produce several different physical and psychological sub-stressors that affect non-MS-related stressors (Pakenham, 1999). It is therefore difficult to clearly discriminate between disease-related stressors and general stressors in MS. The dispositional approach to coping may therefore be appropriate for use with MS. The dispositional hypothesis suggests that the person's coping approach to any stressor will be indicative of their general coping style, which will reflect their approach to their illness (Pakenham, 1999). In support of this notion, coping in people with MS appears to be unaffected by severity of disability, duration of disease, or fatigue

severity (Beatty, et al., 1998). Neurological variables have also been found to have little influence on the coping strategies used by people with MS (Beatty, et al., 1998; Jean, et al., 1999).

Research has shown that people with MS use both emotion and problem-focused strategies, but that emotion-focused strategies tend to be emphasised during periods of psychological distress (Aikens et al., 1997; Jean et al., 1999). The meaning of this relationship is unclear. People who use emotion-focused coping may already be more depressed, or have tried more problem-focused strategies, and found them ineffective. It could be that emotion-focused strategies are found to be ineffective, and this increases psychological distress. Alternatively it is possible that people who are distressed make more negative appraisals of abilities, and effectiveness, in the same way that they make more negative appraisals about other aspects of stressful situations (Jean, et al., 1999). A study by Schwartz (1999) found that people with MS who were depressed responded better to a support group intervention, whereas those who were not depressed responded better to a coping skills group. This suggests emotion-focused coping is not less effective per se, but that people respond differently to different coping styles depending on whether they are depressed or not. This suggests that in MS research depression needs to be controlled for.

Coping and Illness Perceptions

According to Lazarus and Folkman (1984a) people continue to explore their ability to reduce threat throughout the course of the illness (i.e. they ask "what can I do about it?"). Therefore, changes in affect may depend on beliefs about abilities to control or alleviate symptoms. This suggests that the notion of illness perceptions is implicit in their model of coping, although it is now common to focus on illness perceptions separately from coping. The self-regulatory model of illness (Leventhal, & Cameron, 1987; Leventhal, et al., 1992), also suggests that coping responses are heavily influenced by illness perceptions. The theoretical notion of a link between coping and illness perceptions has been backed up by research findings (e.g. Heijmans, 1998; Moss-Morris, 1997; Moss-Morris et al., 1996; Scharloo et al., 2000). A link between illness representations and mood has also been found (Fortune et al., 2000; Murphy et al., 1999).

For example, in studies of people with CFS, coping and illness perceptions, and coping, illness perceptions, functioning and psychological adjustment were found to be related to each other ((Moss-Morris, 1997; Moss-Morris et al, 1996). Moss-Morris et al. (1996) found that illness perceptions were more strongly related to adjustment and psychological well being than coping. Perceptions expected to be related to greater distress, such as believing the illness will last a long time, and that the consequences will be serious, were related to more use of venting emotion, and disengaging from the stressor. The relationship between coping and illness perceptions appeared to be linear (Moss-

Morris et al., 1996), in that people who believed they had more control over their Chronic Fatigue Syndrome reported using significantly more positive coping strategies (e.g. planning and positive reframing).

Scharloo, et al. (2000), working with people with psoriasis, found a direct effect between coping and illness perceptions. Illness perceptions and coping strategies accounted for most of the variance in health outcomes one year later (Scharloo et al., 2000). However, it is possible that illness severity impacts on coping strategies and illness perceptions. Scharloo et al. suggest controlling for illness duration to try to reduce the effect of illness severity, although duration is not necessarily related to severity. They conclude that treatment aimed at reducing the number of symptoms perceived to be related to the illness could result in improved physical and psychological functioning. They suggest treatment should be aimed at increasing people' sense of control, encouraging active coping, restructuring negative thoughts about the consequences of disease, and encouraging people to express emotions, seek social support and distract themselves. They also suggest that these interventions should be conducted to test the hypothesis that coping and illness perceptions are instrumental in adaptation to illness, and psychological well being.

There have been few studies testing these hypotheses so far. However, one such intervention for the self-management of arthritis suggested that long-term self-management is dependent on three steps: acceptance of

arthritis as a lifelong illness; separating the disease from its symptoms; and learning to cope with and regulate the symptoms (Pimm, Byron, Curson, & Weinman, 1994). Observance of these steps led to the minimal disruption of an active lifestyle, but unfortunately this paper was not published after being presented at a conference.

Conclusions

MS is a complex disease to study. There are multiple factors involved (e.g. depression, and neurological disability), that result in each person's MS being different, although there are likely to be some common factors within the four recognised MS types. MS is considered a particularly interesting chronic disease with respect to illness representations and coping because of its variable and unpredictable course, and the cause being largely unknown (Moss-Morris, et al., 2002). Based on research so far with other chronic illnesses and with MS, the models of illness perceptions and coping have the potential to provide useful information about developing therapeutic interventions, and to be useful predictors of outcome. However, this area of study is in the early stages of development, and more work needs to be carried out on understanding illness perceptions in MS, and if there are differences between people with different types of MS, as seems possible.

More work also needs to be carried out on understanding coping strategies more fully, particularly with more adaptive emotion-focused strategies being included on questionnaires. In addition both situational

and dispositional questionnaires need to be used together to establish the relationship between types of problems (e.g. controllable vs. uncontrollable) and coping strategies. Therapeutic intervention studies need to be conducted as reduction in depression levels, or change in illness beliefs, would provide the opportunity to monitor the effects of a change in one variable on the other variables (Murphy et al., 1999). Other areas for future research are studies using longitudinal design, large groups of people, and single diseases, with depression, anxiety and disability controlled for. As far as possible (within the limits of time and resources) it was intended to address some of these issues in the empirical paper.

References

Aikens, J.E., Fischer, J.S., Namey, M., & Rudick, R.A. (1997). A replicated retrospective investigation of life stress, coping and depressive symptoms in multiple sclerosis. *Journal of Behavioural Medicine*, 20, 433-445

Aldwin, C. (1994). *Stress, coping, and development: an integrative perspective*. New York: Guilford.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders. 4th edition*. Washington DC: APA

Antonak, R.F., & Livneh, H. (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science Medicine*, 40, 1099-1108

Barak, Y., Gabbay, U., Gilad, R., Sarova-Pinhas, I., & Achiron, A. (1999). Neuropsychiatric assessment as a secondary outcome measure in a multiple sclerosis intravenous immunoglobulin (IVIg) trial. *International Journal of Psychiatry in Clinical Practice*, 3, 31-34

Barkof, F. (1999). MRI in multiple sclerosis: correlations with expanded disability status scale (EDSS). *Multiple Sclerosis*, 5, 283-286

Barnwell, A.M., & Kavanagh, D.J. (1997). Prediction of psychological adjustment to multiple sclerosis. *Social Science and Medicine*, 45, 411-418

Baum, H.M., & Rothschild, B.B. (1981). The incidence and prevalence of reported multiple sclerosis. *Annals of Neurology*, 10, 420-428

Baumann, L., Cameron, L., Zimmerman, R., & Leventhal, H. (1989). Illness representations and matching labels with symptoms. *Health Psychology*, 8, 449-469

Beatty, W.W., Hames, K.A., Blanco, C.R., Williamson, S.J., Wilbanks, S.L., Olson, K.A. (1998). Correlates of coping style in people with multiple sclerosis. *Multiple Sclerosis*, 4, 5, 440-3

Beaver, C.T., Grattan, L., Panitch, H.S., Johnson, K.P. (1995). The brief repeatable battery of neuro-psychological tests for multiple sclerosis: A preliminary serial study. *Multiple Sclerosis*, 1, 2, 165-169

Brassington, J.C., & Marsh, N.V. (1998). Neuropsychological aspects of multiple sclerosis. *Neuropsychological Review*, 8, 43-77

Briscoe, M.E. (1987). Why do people go to the doctor? Sex differences in the correlates of GP consultation. *Social Science Medicine*, 25, 5,

507-513

Carver, C., Pozo, C., Harris, S., Noriega, V., Scheier, M., Rodinson, D., Ketcham, A., Moffat, F., & Clark, K. (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65, 2, 375-390

Carver, C.S., Lawrence, J.W., & Scheier, M.F. (1996). A control-process perspective on the origins of affect. In L. Martin, & A. Tesser (Eds.). *Striving and feeling: Interactions among goals, affect, and self-regulation.* (pp. 11-52). Hillsdale, NJ: Lawrence Erlbaum Associates

Carver, C.S., Sheier, M.F. (1994). Situational coping and coping dispositions in a stressful transaction. *Journal of Personality and Social Psychology*, 66, 1, 184-195.

Carver, C.S., Sheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology*, 56, 2, 267-283

Chancellor, A., Addidle, M, & Dawson, K. (2003). Multiple sclerosis is more prevalent in northern New Zealand than previously reported. *Internal Medicine Journal*, 33, 79-83

Cohen, S., & Edwards, J.R. (1989). Personality characteristics as moderators of the relationship between stress and disorder. In R.W. Neufeld (Ed.). *Advances in the investigation of psychological stress* (pp. 235-283). New York: Wiley

Cohen, F., & Lazarus, R. (1973). Active coping processes, coping dispositions and recovery from surgery. *Psychosomatic Medicine*, 35, 375-389

Cohen, F., Reese, L.B., Kaplan, G.A., & Riggio, R.E. (1986). Coping with the stresses of arthritis. In R.W. Moskowitz, & M.R. Haug. (Eds.). *Arthritis and the elderly (p. 56-79).* New York: Springer

Comi, G., Filippi, M., Martinelli, V., Campi., Rodegher, M., Alberoni, M., et al. (1995). Brain MRI correlates of cognitive impairment in primary and secondary progressive multiple sclerosis. *Journal of the Neurological Sciences*, 132, 222-227

Cooper, A., Lloyd, G.S., Weinman, J., & Jackson, G. (1999). Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs. *Heart*, 82, 234-236

Cox, D., & Gonder-Frederick, L. (1992). Major developments in behavioural diabetes research. *Journal of Consulting and Clinical Psychology*, 60, 628-683

Crawford, J.D., & McIvor, G.P. (1987). Stress management for multiple sclerosis patients. *Psychology Report*, 61, 423-429

Creed, F.H. (1990). Psychological disorders in rheumatoid arthritis: a growing consensus? *Annals of Rheumatic Disorders*, 49, 808-812

Croyle, R., & Jemmott, J. (1991). Psychological reaction to risk factor testing. In J. Skelton, & R. Croyle (Eds.). *Mental representation in health and illness* pp. 85-107. New York: Springer-Verlag

DeSousa, E.A., Albert, R.H., & Kalman, B. (2002). Cognitive impairments in multiple sclerosis: a review. *American Journal of Alzheimer's Disease and Other Dementias*, 17, 1, 23-29

Easterling, D., & Leventhal, H. (1989). Contribution of concrete cognition to emotion: neutral symptom as elicitors of worry about cancer. *Journal of Applied Psychology*, 74, 78-796

Endler, N., & Parker, J. (1992). Interactionism revisited: the continuing crisis in the personality area. *European Journal of Personality*, 6, 177-198

Engle, G.L. (1977). The need for a new medical model: a challenge to biomedicine. *Science*, 196, 129-136

Ensel, W.M., & Lin, N. (1991). The life stress paradigm and psychological distress. *Journal of Health and Social Behaviour*, 32, 321-341

Falvo, D.R. (1991). *Medical and psychosocial aspects of chronic illness and disability.* Gaithersburg, MD: Aspen

Feinstein, A., O'Connor, P., Gray, T., & Feinstein, K. (1999). The effects of anxiety on psychiatric morbidity in patients with multiple sclerosis. *Multiple Sclerosis*, 5, 3, 323-326

Foley, F.W., Bedell, J.R., LaRocca, N.G., Scheinberg, L.C., & Reznikoff, M. (1987). Efficacy of stress inoculation training in coping with multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 55, 919-921

Folkman, S., & Lazarus, R.S. (1986). Stress processes and depressive symptomology. *Journal of Abnormal Psychology*, 95, 107-113

Folkman, S., & Lazarus, R.S. (1985). If it changes it must be a process. A study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, 48, 150-170

Folkman, S., & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour*, 21, 219-239

Forbes, R.B., & Swingler, R.J. (1999). Estimating the prevalence of multiple sclerosis in the United Kingdom by using the capture-recapture methodology. *American Journal of Epidemiology*, 149,11, 1016-1024

Forbes, R.B., Wilson, S.V., & Swingler, R.J. (1999). The prevalence of multiple sclerosis in Tayside, Scotland: Do latitudinal gradients really exist? *Journal of Neurology*, 246, 11, 1033-1040

Ford, H.L., Gerry, E., Johnson, M., & Williams, R. (2002). A prospective study of the incidence, prevalence and mortality of multiple sclerosis in Leeds. *Journal of Neurology*, 249, 3, 260 –265

Fortune, D., Richards, H., Main, C., & Griffiths, C. (2000). Pathological worrying, illness perceptions and disease severity in patients with psoriasis. *British Journal of Health Psychology*, 5, 1, 71-82.

Franklin, G.M., Nelson, L.M., Filley, C.J., & Heaton, R.K. (1989). Cognitive loss in multiple sclerosis: case reports and review of the literature. *Archives of Neurology*, 46, 162-167.

Grafman, J., Schartz, V., Dale, J., Scheffers, M., Houser, C., & Straus, S. (1993). Analysis of neuropsychological functioning in patients with chronic fatigue syndrome. *Journal of Neurology, Neurosurgery and Psychiatry*, 56, 684-689

Graydon J. E., & Ross, E. (1995). Influence of symptoms, lung function, mood, and social support on level of functioning of patients with COPD. *Research in Nursing and Health*, 18, 6, 525-533

Griva, K., Myers, L., & Newman, S. (2000). Illness perceptions and self-efficacy beliefs in adolescents and young adults with insulin dependant diabetes millitus. *Psychology and Health*, 15, 733-750

Gross, E.L., & Sinaki, M. (1987). Multiple sclerosis. In M. Sanaki. (Ed.). *Basic clinical rehabilitation medicine.* (pp.175-181). Philadelphia: B.C. Decker Inc.

Heijmans, M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *Journal of Psychosomatic Research*, 45, 1, 39-51

Heijmans, M., & de Ridder, D. (1998). Assessing illness representations of chronic illness: explorations of their disease specific nature. *Journal of Behavioral Medicine*, 21, 5, 485-503

Herndon, R.M., & Rudick, R.A. (1983). Multiple Sclerosis. The spectrum of severity. *Archives of Neurology*, 40, 531-532.

Ingledew, D.K., Hardy, L., Cooper, C.L., & Jemal, H. (1996). Health behaviours reported as coping strategies: A factor analytical study. *British Journal of Health Psychology*, 1, 3, 263-281

Jean, V.M., Paul, R.H., & Beatty, W.W. (1999). Psychological and neuropsychological predictors of coping patterns by patients with multiple sclerosis. *Journal of Clinical Psychology*, 55, 1, 21-26

Johnston, M., Weinman, J., & Martineau, T. (1990). Health psychology in hospital settings. In A. Kapstein, H. van der Ploeg, B. Garssen, P. Schreurs, & R. Beunderman (Eds.). *Behavioural Medicine* (pp. 13-32). New York: Wiley

Kapit, W. & Elson, L.M. (1977). *The anatomy colouring book.* New York: Harper Collins

Krohne, H. (1996). Individual differences in coping. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 410-433). New York: Wiley

Krohne, H. (1993). Attention and avoidance. Two central strategies in coping with aversiveness. In H. Krohne (Ed.). *Attention and avoidance:*

strategies in coping with aversiveness (pp. 3-15). Seattle: Hogrefe & Huber

Krohne, H., & Schumacher, A., & Egloff, B. (1992). The Mainz Coping Inventory. Cited in H. Krohne. (1996). Individual differences in coping. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 381-409). New York: Wiley

Lacroix, J., Martin, B., Avendano, M., & Goldstein, R. (1991). Symptoms schemata in chronic respiratory patients. *Health Psychology*, 10, 268-273

LaRocca, N.G. (2000). Cognitive and emotional disorders. In J.S. Burke, & K.P. Johnson (Eds.). *Multiple sclerosis: Diagnosis, medical management, and rehabilitation.* (pp. 405-421). New York: Demos.

Lau, R.R., Bernard, T.M., & Hartmann, K.A. (1989). Further exploration of common-sense representation of common illnesses. *Health Psychology*, 8, 195-219

Lau, R.R., & Hartmann, K.A. (1983). Common sense representations of common illnesses. *Health Psychology*, 2, 167-185

Lazarus, R.S. (1993). Coping theory and research: past, present, and future. *Psychosomatic Medicine*, 55, 234-247

Lazarus, R.S., & Folkman, S. (1984a). *Stress, appraisal and coping.* New York: Springer

Lazarus, R.S., & Folkman, S. (1984b).Coping and adaptation. In W.D. Gentry (Ed.). *The handbook of behavioural medicine* (pp. 282-325). New York: Guilford Press

Leventhal, H., Benyamini, Y. (1997). Lay beliefs about health and illness. In A. Baum (Ed.). *Cambridge handbook of psychological health and medicine.* Cambridge: Cambridge University Press

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., et al. (1997). Illness representations: Theoretical foundations. In K. Petrie, & J. Weinman (Eds.). *Perceptions of health and illness.* Amsterdam: Harwood Publishers

Leventhal, H., & Cameron, L. (1987). Behavioural therapies and the problems of compliance. *Patient Education and Counselling*, 10, 117-138

Leventhal, H., & Diefenbach, M. (1991). The active side of illness cognition. In J.A. Skelton, & R.T. Croyle (Eds.). *Mental representation in health and illness* (pp. 247-272). New York: Springer

Leventhal, H., & Diefenbach, M., & Leventhal, E. (1992). Illness cognition: using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16, 143-163

Leventhal, H., Leventhal, E., & Cameron, L. (2001). Representations, procedures and affect in illness self-regulation: a perceptual-cognitive model. In A. Baum, T. Revenson, & J. Singer (Eds.). *Handbook of health psychology* (pp. 19-48). New Jersey: Lawrence Erlbaum

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (Ed.). *Medical Psychology* Vol. 2 (pp. 7-30). New York: Pergamon

Leventhal, H, & Nerenz, D. (1985). The assessment of illness cognition. In P. Karoly (Ed.). *Measurement strategies in health psychology* (pp. 517-555). New York: Wiley

Leventhal, H., Nerenz, D., & Steele, D.J. (1984). Illness representations and coping with health threats. In A. Baum, S.E. Taylor, & J.E. Singer (Eds.). *Handbook of psychology and health. Vol. IV: Social psychological aspects of health* (pp. 219-252). Hillsdale, NJ: Erlbaum

Lockyer, M.J. (1991). Prevalence of multiple sclerosis in five rural Suffolk practices. *British Medical Journal*, 303, 6798, 347-348

Lynch, S., Kroencke, D., & Denney, D. (2001). The relationship between disability and depression in multiple sclerosis: the role of uncertainty, coping and hope. *Multiple Sclerosis*, 7, 4, 411-416

MacDonald, B.K., Cockerell, O.C., Sander, J.W., Shorvon, S.D. (2000). The incidence and lifetime prevalence of neurological disorders in a prospective community based study in the UK. *Brain*, 123, 4, 665-676

Maes, S., Leventhal, H., & de Ridder, T.D. (1996). Coping with chronic diseases. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 221-251). New York: Wiley

Maurelli, M., Marchioni, E., Cerretano, R., Bosone, D., Bergamaschi, R., Citterio, A., et al. (1992). Neuropsychological assessment in MS: Clinical neuropsychological and neuroradiological relationships. *Acta Neurologica Scandinavica*, 86, 124-128

McCracken, L.M., Semenchuk, E.M., Goetsch, V.L. (1995). Cross-sectional and longitudinal analyses of coping responses and health status in persons with systemic lupus erythematosus. *Behavioural Medicine*, 20, 179-187

McReynolds, C.J., Koch, L.C., & Rumrill, P.D. (1999). Psychosocial adjustment to multiple sclerosis: implications for rehabilitation professionals. *Journal of Vocational Rehabilitation*, 12, 83-91

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: the example of hypertension. *Health Psychology*, 4, 115-135

Miller, D. Ormerod, I., & du Boulay, G. (1987). A summary of the present contribution of magnetic resonance imaging to diagnosis and understanding of Multiple Sclerosis. In F. Rose, & R. Jones (Eds.). *Multiple Sclerosis. Immunological, diagnostic and therapeutic aspects* (pp. 121-127). London: J. Libbey.

Minden, S.L., Orav, J., & Reich, P. (1987). Depression in multiple sclerosis. *General Hospital Psychiatry*, 9, 426-434

Minden, S.L. & Schiffer, R.B. (1990). Affective disorders in multiple sclerosis: Review and recommendations for clinical research. *Archives of Neurology*, 47, 98-104

Mohr, D.C., Boudewyn, A., Goodkin, D., Bostrom, A., & Epstein, L. (2001). Comparative outcomes for individual cognitive behaviour therapy, supportive expressive group psychotherapy, and Sertraline for

the treatment of depression in multiple sclerosis. *Journal of Counselling and Clinical Psychology*, 69, 6, 942-949

Mohr, D.C., & Cox, D. (2001). Multiple sclerosis: empirical literature for the clinical health psychologist. *Journal of Clinical Psychology*, 57, 4, 479-499

Mohr, D.C., & Dick, L.P. (1998). Multiple sclerosis: In P.M. Camic & S. Knight. (Eds.). *Clinical handbook of health psychology: a practical guide to effective interventions* (pp, 313-348). Seattle, USA: Hogrefe & Huber

Mohr, D.C., & Goodkin, D.E. (1999). Treatment of depression in multiple sclerosis: review and meta-analysis. *Clinical Psychology: Science and Practice*, 6, 1-9

Mohr, D.C., Goodkin, D.E., Bacchetti, P., Boudewyn, A.C., Huang, L., Marrietta, P., et al. (2000). Psychological stress and the subsequent appearance of new brain MRI lesions in MS. *Neurology*, 55, 55-61

Mohr, D.C., Goodkin, D.E., Gatto, N., Van Der Wende, J. (1997). Depression, coping and level of neurological impairment in multiple sclerosis. *Multiple Sclerosis*, 3, 3, 254-258

Mohr, D.C., Goodkin, D.E., Likosky, W., Gatto, N., Baumann, K.A., & Rudick, R.A. (1997). Treatment of depression improves adherence to

interferon beta-1b therapy for multiple sclerosis. *Archives of Neurology*, 54, 531-533

Mohr, D.C., Likosky, W., Dick, L.P., Van Der Wende, J., Dwyer, P., Bertagnolli, A.C., et al. (2000). Telephone-administered cognitive-behavioural therapy for the treatment of depressive symptoms in multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 68, 356-361

Monks, J., & Robinson, I., (1989). The characteristics of a national register of people with multiple sclerosis: a comparison between the ARMS (Action for Research into Multiple Sclerosis) register and 10 British MS populations. *Journal of Epidemiological Community Health*, 43, 2, 179-186

Moos, R.H. (1993). *Coping Response Inventory: Professional Manual.* Florida: Psychological Assessment Resources, Inc.

Moos, R.H. (1988). Life stressors and coping resources influence health and wellbeing. *Psychological Assessment*, 4, 133-158

Moos, R.H., & Billings, A.G. (1982). Conceptualising and measuring coping resources and processes. In L. Goldberger, & S. Breznitz (Eds.). *Handbook of stress: theoretical and clinical aspects.* New York: Free Press

Moss-Morris, R. (1997). The role of illness cognitions and coping in the aetiology and maintenance of the chronic fatigue syndrome. In K. Petrie, & J. Weinman (Eds.). *Perceptions of health and illness*. Amsterdam: Harwood Publishers

Moss-Morris, R., Petrie, K., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 1, 15-25

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17, 1, 1-16

Muller-Rohland, J. (1987). The medical aspects of disabling conditions: an overview. In B. Caplan. (Ed.). *Rehabilitation psychology desk reference* (pp.473-499). Rockville, MD: Aspen

Multiple Sclerosis Society of New Zealand. March 2003 (personal communication).

Murphy, H., Dickens, C., Creed, F., & Bernstein, R. (1999). Depression, illness perception and coping in rheumatoid arthritis. *Journal of Psychosomatic Research*, 46, 2, 155-164

Nerenz, D., & Leventhal, H. (1983). Self-regulation theory in chronic illness. In B. Burish, & Bradley, I. (Eds.). *Coping with chronic disease.* New York: Academic Press

Nolen-Hoeksema, S., Parker, L.E., & Larson, J. (1994). Ruminative coping with depressed mood following loss. *Journal of Personality and Social Psychology*, 67, 1, 92-104.

O'Connor, P. (1999). *Multiple Sclerosis: the facts you need to know.* New York: Firefly Books

Pakenham, K.I. (1999). Adjustment to multiple sclerosis: application of a stress and coping model. *Health Psychology*, 18, 383-392

Pakenham, K.I., Stewart, C.A., & Rogers, A. (1997). The role of coping in adjustment to multiple sclerosis related adaptive demands. *Psychology, Health and Medicine*, 2, 197-211

Parker, J., & Endler, N. (1996). Coping and defence: a historical overview. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 3-23). New York: Wiley

Pennebaker, J.W. (1982). *The psychology of physical symptoms.* New York: Springer

Pepper, C.M., Krupp, L.B., Friedberg, F., Doscher, C., & Coyle, P.K. (1993). A comparison of neuropsychiatric characteristics in chronic fatigue syndrome, multiple sclerosis and major depression. *Journal of Neuropsychiatry and Clinical Neurosciences*, 5, 200-205

Petrie, K., & Weinman, J. (1997). *Perceptions of health and illness.* Amsterdam: Harwood Publishers

Petrie, K., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: a longitudinal study. *British Medical Journal*, 312, 1191-1194

Peyser, J.M., Rao, S.M., LaRocca, N.G., & Kaplan, E. (1990). Guidelines for neurological research in multiple sclerosis. *Archives of Neurology*, 47, 94-104

Pimm, T., Byron, M., Curson, B., & Weinman, J. (1994). *Personal illness models and the self-management of arthritis.* Paper presented at British Society of Health Psychology.

Rao, S.M., Leo, G.J., Bernardin, L., Unverzagt, F. (1991). Cognitive dysfunction in multiple sclerosis. I. Frequency, patterns and prediction. *Neurology*, 41, 685-691

Ratsep, T., Kallasmaa, T., Pulver, A., Gross-Paju, K. (2000). Personality as a predictor of coping efforts in patients with multiple sclerosis. *Multiple Sclerosis*, 6, 6, 397-402.

Roberts, M.B.V. (1976). *Biology: a functional approach. 2nd edition.* Walton on Thames, Surrey: Nelson

Roberts, M.H., Martin, J.P., McClellan, D.L., McIntosh-Michaelis, S.A., & Spackman, A.J. (1991). The prevalence of multiple sclerosis in the Southampton and South West Hampshire Health Authority. *Journal of Neurological and Neurosurgical Psychiatry,* 54, 1, 55-59

Robertson, N., Deans, J., Fraser, M., & Compston, D.A. (1995). Multiple sclerosis in the north Cambridgeshire districts of East Anglia. *Journal of Neurological and Neurosurgical Psychiatry*, 59, 1, 71-76

Robinson, I., Neilson, S., & Rose, F.C. (2000). *Multiple Sclerosis at your fingertips*. London: Class Publishing

Ron, M., & Logsdail, S. (1989). Psychiatric morbidity in multiple sclerosis: a clinical and MRI study. *Psychological Medicine*, 19, 887-895

Rosati, G. (2001). The prevalence of multiple sclerosis in the world: an update. *Neurological Science*, 22, 2, 117-139

Roth, A., & Fonagy, P. (1996). *What works for whom? A critical review of psychotherapy research*. London: Guilford press

Rovaris, M., Filippi, M., Falautano, M., Minicucci. L., Rocca, M., Martinelli, V., et al. (1998). Relation between MR abnormalities and patterns of cognitive impairment in multiple sclerosis. *Neurology*, 50, 1601-1608

Rumrill, P.D. (1996). *Employment issues and multiple sclerosis*. New York: Demos Vermande

Ryan, L., Clark, C.M., Klonoff, H., Li, D., & Paty, D.W. (1996). Patterns of cognitive impairment in relapsing-remitting multiple sclerosis and their relationship to neuropathology on magnetic resonance images. *Neuropsychology*, 10, 176-193

Sadovnick, A.D., Eisen, K., Ebers, G.C., & Paty, D.W. (1991). Cause of death in patients attending multiple sclerosis clinics. *Neurology*, 41, 1193-1196

Scharloo, M., & Kapstein, A. (1997). Measurement of illness perceptions in patients with chronic somatic illness: a review. In K. Petrie, & J. Weinman (Eds.). *Perceptions of health and illness*. Amsterdam: Harwood Publishers

Scharloo, M., Kapstein, A., Weinman, J.A., Willems, L., Rooijmans, H. (2000). Physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. *Journal of Asthma*, 37, 1, 17-29

Schiaffino, K., Shawaryn, M., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, 17, 3, 262-268

Schiffer, R.B., Caine, E.D., Bamford, K.A., & Levy, S. (1983). Depression episodes in patients with multiple sclerosis. *American Journal of Psychiatry*, 140, 1498-1500

Schubert, D.S., & Foliart, R.H. (1993). Increased depression in multiple sclerosis: a meta-anlysis. *Psychosomatics*, 34, 124-130

Schwartz, C. (1999). Teaching coping skills enhances quality of life more than peer support: results of a randomised trail with multiple sclerosis patients. *Health Psychology*, 18, 3, 211-220

Schwartz, C., Coultland-Morris, L., & Zeng, Q. (1996). Psychosocial correlates of fatigue in multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 77, 165-170

Shepherd, D.I., & Summers, A. (1996). Prevalence of multiple sclerosis in Rochdale. *Journal of Neurological and Neurosurgical Psychiatry*, 61, 4, 415-417

Sinnakaruppan, I. (2000). Development of a coping scale for use with chronic illnesses, especially multiple sclerosis – a pilot study. *International Journal of Rehabilitation Research*, 23, 155-161

Skegg, D.C., Corwin, P.A., Craven, R.S., Malloch, J.A., & Pollock, M. (1987). Occurrence of multiple sclerosis in the north and south of New Zealand. *Journal of Neurological and Neurosurgical Psychiatry,* 50, 2, 134- 139

Skelton, J.A., Croyle, R.T. (1991*). Mental representation in health and illness.* New York: Springer

Smith, C.A., & Wallston, K.A. (1992). Adaptation in patients with chronic rheumatoid arthritis: application of a general model. *Health Psychology*, 11, 151-162

Stanton, A.L., Danoff-Burg, S., Cameron, C.L., & Ellis, A.P. (1994). Coping through emotional approach: problems of conceptualisation and confounding. *Journal of Personality and Social Psychology,* 66, 350-362

Stenager, E., Knudsen, L., & Jensen, K. (1994). Multiple sclerosis: correlation of anxiety, physical impairment and cognitive dysfunction. *Italian Journal of Neurological Science*, 15, 99-103

Summerfeldt, L., & Endler, N. (1996). Coping with emotion and psychopathology. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 600-639). New York: Wiley

Swingler, R.J., & Compston, D. (1986). The distribution of multiple sclerosis in the united Kingdom. *Journal of Neurological and Neurosurgical Psychiatry,* 49, 10, 1115-1124

Vitaliano, P.P., Maiuro, R.D., Russo, J., Katon, W., DeWolfe, D., Hall, G. (1990). Coping profiles associated with psychiatric, physical health, work and family problems. *Health Psychology,* 9, 348-376

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health,* 1, 431-445

Weinman, J., Wright, S., & Johnston, M. (1995). *Measures in health psychology: A user's portfolio. Coping.* Windsor, UK: Nfer Nelson

Whitlock, F.A., & Siskind, M.M. (1980). Depression as a major symptoms of multiple sclerosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 43, 861-865

Williams, E.S., & McKeran, R.O. (1986). Prevalence of multiple sclerosis I a south London borough. *British Medical Journal (Clinical Research Edition)*, 293, 6541, 237-239

Zeidner, M., & Saklofske, D. (1996). Adaptive and maladaptive coping. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (p. 505-531). New York: Wiley

Empirical Paper

Illness perceptions, depression and coping in people with Multiple Sclerosis

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Illness perceptions and coping in people with Multiple Sclerosis: An empirical paper

1.0 Introduction

People are now more likely to develop a chronic illness (an irreversible disease that must be lived with), with estimates suggesting that chronic illnesses currently account for approximately 80% of deaths in western countries (Maes, Leventhal, de Ridder, 1996). Chronic illnesses affect large numbers of individuals, are long lasting, have a major impact on the health care system, have huge differences in their cause, course, stability and consequences, and often a high rate of mortality (Maes, et al., 1996). Interest in chronic illness has consequently recently grown significantly in recent times.

Research has demonstrated that the degrees of disability and adaptation associated with chronic illness are related to psychosocial factors (e.g. Jopson, & Moss-Morris, 2003; Scharloo, Kapstein, Weinman, Willems, Rooijmans, 2000) as well as physical ones. For example, in Multiple Sclerosis (MS) clinical observations suggest some people have severe physical disabilities, but cope better and have better outcomes, than others with less severe disabilities (Sinnakaruppan, 2000). Consequently, Illness perceptions (the beliefs and feelings a person has about their illness) and coping strategies (how a person manages the problem and/or their feelings about the problem) are seen as major

factors affecting individuals. However, chronic illnesses are variable in symptom patterns and trajectories, and differences between illnesses and individuals are common (Maes, et al., 1996). This means that it is difficult to draw conclusions based on small or mixed illness groups. Studies therefore need to consider each illness individually using large groups of individuals.

MS is considered a particularly interesting disease to study with respect to illness perceptions and coping because it has a variable and unpredictable course (Moss-Morris, Weinman, Petrie, Horne, Cameron, et al., 2002), debilitating symptoms, and no cure. This means that MS is an extremely stressful disease to have, and adjustment difficulties are common (Aikens, Fischer, Namey, & Rudick, 1997). It has been proposed that the variable and unpredictable nature of MS is likely to influence the illness perceptions that people have (Schiaffino, Shawaryn, and Blum, 1998). For example, people who have mild symptoms, or who go into remission quickly may think of their MS as an acute illness. It may only be after repeated attacks, or increased symptom severity that is unresponsive to treatment that the full impact of their illness becomes apparent. As the profiles of the different MS types vary in respect to these characteristics, it could be expected that the different types would have distinct illness perceptions. This is in line with evidence that different chronic illnesses have different illness perception profiles (e.g. Heijmans and de Ridder, 1998).

1.1. Illness Perceptions

In an effort to cope with the highly individual problems that arise, people develop their own understanding of their illness (Leventhal, Nerenz, & Steele, 1984). These understandings are thought to derive from personal experience with illness, social, religious and cultural messages, and information from the medical profession (Leventhal, & Benyamini, 1997; Schiaffino et al., 1998). They come into effect as soon as people experience their first symptoms, and typically change as the disease progresses, as symptoms change, and as treatment responses come into effect (Weinman, Petrie, Moss-Morris, & Horne, 1996).

The most influential theoretical model of illness perceptions is that of Leventhal and colleagues, (1980, 1984), which was recently updated to include emotional representations (Leventhal, et al., 1997). The model proposes that illness perceptions have distinct factors, and each person sees their illness in highly individual ways. Research has tended to validate Leventhal's model (e.g. Lau, Bernard, & Hartman, 1989; Leventhal, & Diefenbach, 1991; Skelton, & Croyle, 1991). The factors identified in the model are disease identity, cause, consequence, timeline, control/cure, and emotions.

The identity factor is conceptualised as the ideas people have about the label and symptoms of the disease, and the links between these. The cause dimension relates to the person's beliefs about the cause of the

illness, either external (e.g. injury or germ), or internal (e.g. disposition). Timeline is the person's belief about the likely duration of their illness (i.e. whether it is acute, chronic or cyclical). The consequence factor is the person's understanding and expectations about the severity of the illness, and its probable impact on their somatic, social and economic functioning. The control factor is related to how controllable, or curable, the illness is believed to be. Emotional perceptions are developed in parallel to the five cognitive representations, and are thought to be related to whether the person chooses problem-focused, or emotion-focused coping strategies from their repertoire (Leventhal, Leventhal, & Cameron, 2001). These factors have been described as the building blocks of illness representations (Heijmans, & de Ridder, 1998), and as having important implications for people's conceptualisations of illness and development of coping strategies (Leventhal, et al., 1980, 1984).

Although these factors are well validated there are complex relationships between them. For example, although the components are distinct from each other, they are not necessarily independent, and there may be direct links between the different factors (Weinman, et al., 1996). It has also been suggested that although there seems to be a consistent and valid underlying structure, all illness perceptions may not be present in every person (Nerenz, & Leventhal, 1983). This may be because some factors are less relevant to some illnesses, or some people, or two factors may merge to create a different component.

1.2. Coping

Current psychological views are that coping is an active and conscious process that interacts with other factors, such as personality and stress experiences, across time and changing circumstances (Zeidner, & Saklofske, 1996). The most influential theory is Lazarus and Folkman's theory of stress and coping (e.g. Lazarus & Folkman, 1984), in which coping strategies manage external, or internal, stresses and threats that challenge, or exceed, personal resources. An assumption of this model is that coping strategies should not be prejudged as adaptive or non-adaptive.

Coping styles (how demands appraised as challenging are managed) have been variously classified. For example, Moos (1993) categorised strategies as approach (focusing on the event, or its significance; e.g. planning, seeking social support), or avoidance (avoiding the event, or its significance; e.g. denial, alcoholism, and drugs). Another common classification is problem-focused (aimed at altering the source of stress, e.g. planful problem solving), or emotion-focused (aimed at reducing the distress e.g. seeking social support) strategies (Lazarus, & Folkman, 1984). Generally problem-focused strategies are seen as more adaptive in situations appraised as changeable, while emotion-focused strategies seem more adaptive in unresolvable situations (Lazarus, & Folkman, 1984). However, people tend to use both styles of coping when dealing with stressful events (Lazarus, & Folkman, 1984).

1.3. Illness Perceptions and Coping

So far research has mainly focused on coping strategies without looking at illness perceptions (Maes, et al., 1996). However, systems models of illness propose that there is a reciprocal relationship between specific coping strategies and illness perceptions (Leventhal, & Benyamini, 1997). It is therefore important to consider both concepts in research. The notion of a reciprocal relationship suggests that illness perceptions shape coping strategies, and coping strategies shape illness perceptions, with interactions between them causing changes in both over the course of the illness (Leventhal, & Benyamini, 1997).

1.4. Hypotheses.

The hypothesis tested was that there would be differences in illness perceptions and coping strategies between people with different diagnostic classifications of MS.

2.0 Method

2.1 Design

The study used a cross-sectional between-subjects design. There was one independent variable (Type of MS) with 3 levels (Benign, Relapsing-Remitting and Progressive). There were two dependant variables (scores on the IPQ-R, and CRI) with eight levels each (IPQ-R: identity, timeline, timeline cyclical, consequences, personal control, treatment control, illness coherence, and emotional perceptions. CRI: logical

analysis, positive appraisal, support seeking, problem solving, cognitive avoidance, resignation, alternative rewards, emotional discharge).

The expected effect size of between-group differences was difficult to calculate, as there were no previous studies of MS to use. However, studies looking at other chronic illnesses have found differences between illnesses with different profiles. As the types of MS have different profiles, which could be expected to result in the formation of different illness perceptions, a medium effect was assumed. Choosing a medium effect size rather than large minimised the size of the error should the effect size turn out to be small. A medium effect size suggested a sample size of 64 participants in each group (Cohen, 1992), which was not obtained. As a consequence it is possible that the analysis was not powerful enough to detect more subtle differences between groups. Statistical specialists within the university Psychology Department were consulted and their advice was followed. There is a danger of a type 1 error when conducting several analyses with the same data. A statistical level of significance of .01 was therefore appropriate. Results with an alpha level of .05 were reported to allow for a more comprehensive view of the data, but these should be regarded with some caution.

Initially the data was screened as recommended by Tabachnik and Fidell (2001: Appendix C), and explored using descriptive statistics, frequencies and box plots. Then a confirmatory Principle Component

Analysis (PCA) was conducted on the IPQ-R and CRI to check the theoretical factors underpinning the questionnaires. Chi-square analyses were carried out to explore the possibility of differences between the groups in the distribution of age, gender, or problem type (i.e. the nature of the recent difficulty that people chose for the CRI). A one-way ANOVA was conducted to evaluate the possibility that people experiencing an absence of symptoms at the time of testing were a separate population. Subsequently, a between-subjects General Linear Model (GLM) Multivariate analysis was used to look for between group differences, with anxiety and depression scores entered as covariants.

2.2. Missing Data.

There were few data points missing. However, prior to making a decision to delete cases with missing data, recommendations by Tabachnik and Fidell (2001) were followed. The GLM analysis was conducted using the whole sample (with the mean score substituting for missing data), and compared to the managed data GLM analysis. The results were not different. T-tests were also conducted to check for significant differences between participants with and without missing data on complete variables (i.e. Age, Gender, How long had symptoms, How long been diagnosed, HADS Anxiety, HADS Depression [see Appendix D for results]). There were no significant differences.

As there were a reasonable number of participants for the purposes of this study, it was decided to exclude the 7 cases with missing data from

the analysis, leaving 158 participants. Deleting the participants with missing data avoided the potential problems of introducing error by the management of missing data by substituting means, or weakening the statistical analysis by including cases with missing data. It also avoided problems with test validity as guidelines in the CRI manual (Moos, 1993) suggest that the scale is invalid if less than 4 items within a scale are completed.

2.3. Participants

It is recommended that participants with MS be obtained via multiple sources because of difficulty with ascertainment, and low prevalence (Monks, & Robinson, 1989). Participants were therefore recruited from the MS Trust newsletter (80%), two MS Therapy Centres (Harrow and Milton Keynes; 11%), and the MS Society of New Zealand (8.5%). There were no differences in age, gender, or type of MS between the three groups.

The average age of participants was 48.60 years (S.D. 12.20), similar to the mean age of participants in MS research, calculated as 49.0 years (Robertson et al., 1995). The gender ratio was 3.9:1 women to men. Ethnicity was largely white (96.4%) with one or two people in each of the other categories (Asian 1.2%; black 0.6%; other 0.6%; prefer not to answer 1.2%). A neurologist had diagnosed 100% of the respondents with MS. Thirty-two percent of participants had relapsing-remitting MS, 42% had progressive MS (either secondary or primary), and 26% had

benign MS. Of the 94 participants with benign or relapsing-remitting MS, 79% provided information on the number of attacks or episodes that they experienced in the last year. The mean number of episodes was 1.80 (S.D. 1.57). The average time since diagnosis was 9.87 years (S.D. 9.62), and people retrospectively reported that they had symptoms that they attributed to MS for an average of 16.32 years (S.D. 11.75).

The level of response to the study is unknown, as it was not possible to calculate how many people may have become aware of the study by the methods used. The MS Trust sends its newsletter to 11,125 people internationally, but this includes sponsors, interested persons, and carers. The Trust no longer has figures on how many members have MS. The overall response rate to the number of questionnaires sent out was 63%, but this varied according to the method of recruitment. Seventy people from the MS Trust requested questionnaires by email, and the response rate was 92%. Seventy people from the MS Trust requested questionnaires by letter, and the response rate was 97%. One hundred questionnaires were sent to the MS Therapy Centres and the response rate was 18%. Twenty questionnaires were sent to New Zealand and 14 were returned, a response rate of 70%. As the response rates are not known it is difficult to be sure that the sample can be considered representative of the population it is drawn from. The sample was therefore compared to information available from other studies looking at MS.

The demographic profile of the participants in this study was consistent with findings from a recent study carried out on a New Zealand MS support group population (Moss-Morris et al., 2002), and a survey of MS Trust members (Monks, & Robinson, 1989). To check the representativeness of their sample, the Monks and Robinson (1989) study (n = 1481) compared their participants to 10 regional UK populations with MS. They concluded that the society members fell within the range of the regional populations on variables of geographic location, nationality, ethnicity, diagnostic status, age at diagnosis, and duration since diagnosis. The variables of gender, and age were close to within the ranges of the regional samples, but the society population was slightly younger and had a higher ratio of females. The Moss-Morris et al. (2002) study also had a higher ratio of women to men than findings from some other research studies (e.g. Ford, Gerry, Johnson, & Williams, 2002; Williams, & McKeran, 1986), as did this study. However, this was in line with evidence that members of support groups tend to be female, and younger than population based studies (Levy, 1982). It was therefore considered that this study sample was representative of MS support group members.

2.4. Measures and Apparatus

2.4.1. Demographic Questionnaire (Spinks, & Horn, 2003; Appendix E).

In addition to the published questionnaires, a demographic questionnaire was designed by the researchers to collect information such as age and

gender on each individual. After the questionnaire was sent out it was recognised that it would not be possible to differentiate between primary and secondary progressive participants. In future studies this should be considered earlier, and managed appropriately.

2.4.2. Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS was chosen as the Beck Depression Inventory has the potential to be contaminated by somatic symptoms in medical populations (e.g. Williams, & Richardson, 1993). The HADS is a 14-item self-report questionnaire. Items are rated on a four point Likert scale ranging from 0 to 3. Five of the items are reversed. Seven of the items are summed to provide a score of anxiety, and seven provide a score for depression. Scores range from 0 to 21, with higher scores indicating higher levels of anxiety and depression. It is suggested that total subscale scores of less than 7 indicate non-cases, scores of 8-10 indicate borderline cases, and subscale scores over 10 indicate definite cases (Zigmond & Snaith, 1983). The HADS was designed specifically for use with medically ill people (Feinstein, O'Connor, Gray, & Feinstein, 1999), and is reported to have good internal consistency with Cronbach alphas ranging from .80 to .90 for both the anxiety and depression subscales (e.g. Moorey et al., 1991). Compared to other questionnaires measuring depression the HADS is less reliant on physical symptoms, which is an important consideration with an MS population as fatigue is one of the main symptoms of MS.

2.4.3. Illness Perceptions Questionnaire-Revised (IPQ-R; Moss-Morris, et al., 2002; Spinks, & Horn, 2003). Spinks and Horn (2003) adapted the IPQ-R (Appendix F) for use with an MS population as suggested by Moss-Morris et al. (2002). The IPQ-R is a self-report questionnaire divided into three sections. The first section asks questions about the symptoms experienced, and whether people believe these to be related to MS. The symptoms included items typically found in MS, but also included space for up to 3 other symptoms to be specified.

The second section asks 38 questions about the consequences of the illness (Consequences), whether it is perceived as chronic or acute (Timeline), as cyclical or not (Timeline Cyclical), how well people believe they understand their illness (Illness Coherence), and how they feel about their illness (Emotional Perceptions). Items are rated on a five point Likert scale, ranging from strongly disagree to strongly agree. Ten items are scored reversed. The final section asks about 18 possible perceived causes of the illness. Items are rated on the same Likert scale as the identity items.

The IPQ-R is a simple and easy to use method of assessing illness perceptions. The validation study found it had good factor structure and good internal reliability, with Cronbach alpha's of between .79 to .89. It also demonstrated good discriminant, known group, and predictive validity across 8 different illness groups (Moss Morris et al., 2002). The

adapted version used in this study was tested for reliability (see results section).

2.4.4. Coping Response Inventory (CRI; Moos, 1993). The CRI (Appendix G) is a 48-item self-report or structured interview questionnaire, designed to assess multi-dimensional aspects of coping. Both forms of administration give similar results (Milne, 1992). The CRI assesses both the focus of coping (e.g. approach-focused or avoidance-focused) and the method of coping (e.g. cognitive or behavioural). The combination of these two concepts provides data in four domains, with two types of coping strategies in each. The domains of coping are cognitive approach (subscales of logical analysis, and positive reappraisal), behavioural approach (subscales of seeking guidance and support, and taking problem-solving action), cognitive avoidance (subscales of cognitive avoidance, and acceptance or resignation) and behavioural avoidance (subscales of seeking alternative rewards, and emotional discharge). The 6 items for each subscale are rated on a four-point scale, ranging from never to fairly often.

The CRI was chosen as it provides richer data, and enables more variance to be accounted for than other "more limited" measures (Milne, 1992, p. 4). The CRI is appropriate for use with medical populations. It can be administered to adults over 18 years old individually, or in groups. The CRI was originally constructed based on face and content validity. Subsequent validation showed that internal consistency

measured by Alpha coefficients was above .60 for all eight strategies (logical analysis .67; positive reappraisal .74; seeking guidance and support .61; problem solving .68; cognitive avoidance .72; acceptance or resignation .64; seeking alternative rewards .68; emotional discharge .62).

2.5. Procedure

The MS Trust and MS Therapy Centres were approached, and gave permission for their members/clients to be contacted. MS Trust members were contacted through an appeal for participants in the newsletter. People were able to email or write to the researcher at a FREEPOST address to request an information leaflet (Appendix H), consent form, and the questionnaires. It was explicit in the appeal and the information leaflet that a stamped addressed envelope would be provided for the return of the questionnaires.

The MS Society of New Zealand became aware of the study and contacted the researchers. The society was happy to provide a small New Zealand sample for the study, and approached members in the Auckland area to take part. MS Therapy Centre clients were contacted by information sheets on display at two of the largest centres in Harrow and Milton Keynes. Information sheets, questionnaires and envelopes were freely available at these two centres for people to take home.

The questionnaires were self-report and completed by the person with MS, or their carer where the person was unable to write. The instructions given for completion were those given on the published questionnaires. There were no additional instructions given about completing the questionnaires. The deadline for the return of questionnaires was set 3 months later. This deadline was extended by 6 weeks for the New Zealand sample.

The only problem identified with the use of the questionnaires was that in the CRI participants are asked to identify a stressful problem or situation experienced in the last 12 months, and answer the questionnaire relative to that event. As such it did not necessarily ask participants about their MS. It was not clear if this would be a significant problem for the study. It was decided that changing the questionnaire was not an option because of copyright. There was, however, the suggestion from test-retest data that coping strategies remain stable over time and across situations (Moos, 1993). It was therefore possible that data would be comparable, even when participants did not choose MS as their stressful event.

However, in order to try to explore the significance of the type of event chosen, answers were given a problem code according to whether the person chose their MS, an event that they related to their illness, or made no mention of their illness when describing the situation. Ratings were as follows. If the person provided their MS as the event it was coded as 'MS'. If they referred to their MS or MS symptoms it was coded

as 'MS Related'. Examples of MS related coding are "frustration over lack of communication from consultant about medication for pain management" and " tried to work in an attempt to feel normal – couldn't cope with the tiredness" and " giving up my job of 8 years due to MS". If MS was not mentioned anywhere in the problem description then the problem was coded as 'Not MS'. Examples of non-MS related coding are "death of father", "being diagnosed with breast cancer" and "incompetent builders".

3.0 Results

3.1 Analysis Strategy.

The main analyses were carried out using GLM Multivariate analysis, and Principle Components Analysis. Parametric statistics were used as generally the requirements for parametric analysis (homogeneity of variance in sample means; normal data distribution; a minimum of 20 possible scores on the scales; (quasi) interval or ratio data; sufficient sample size; sphericity; and independence of scores) were met, and parametric statistics are considered robust to violation of one of the assumptions (Tabachnik, & Fidell, 2001). Data tended to be in the form of whole numbers, but where this was not the case, it was rounded up to two decimal places. All significance levels over $p = .05$ are reported as ns (non-significant).

3.2. Participant Variables

There were various differences between participants, as the study included males and females, people from varied sources, from a wide age range (23-85 years), who had MS for varying amounts of time, and varying levels of anxiety (scores 0-20) and depression (scores 0-16). People also chose different types of problem against which to score the coping questionnaire. There were a small number of participants (18.2%) who reported times of being symptom free, and 10.9% of the participants were symptom free at the time of completing the questionnaires. It was considered possible that these factors might affect the results if they were not evenly distributed between the groups. The variables of Age, Gender, Problem Type, and being Symptom Free were therefore explored using a Chi-square to check for differences in distribution between the groups (see Table 1.).

Table 1. Here

The variables were generally fairly evenly distributed across the three groups. When considered separately, the older age group had lower anxiety and distress (i.e. emotional perception) scores, but were not

significantly different on other variables. They were therefore included in the main analysis. When all the participants were considered, there were visual differences in average age and anxiety scores between the groups, but these were not statistically significant. The total average length of time since symptom onset was 16.32 years, and since diagnosis was 9.87 years. This is consistent with other studies (e.g. Monks, & Robinson, 1989; Roberts, Martin, McClellan, McIntosh-Michealis, & Spackman, 1991). Only the Symptom Free (X_2=15.77, p< .01) and depression (X_2=58.16, p<.01) results were significant.

The significant result for depression was due to the benign group having fewer higher scoring participants than the remitting and progressive groups. As the depression and anxiety scores correlated with many of the questionnaire variables (see Appendix K), it was decided to include the HADS scores as covariants in the GLM Multivariate analysis. The significant result for the symptom free variable was because there were no symptom free participants in the progressive group, which is in accordance with the nature of this illness type. As there were differences in the distribution of people who were symptom free between the groups, a subset of analyses were conducted to see if there were differences between those who were symptom free and those who were not on the questionnaire variables. The results are shown in Table 2. below.

Table 2. Here

There were some differing characteristics between the groups. The symptom free group was younger, and had experienced symptoms and been diagnosed for shorter periods of time. The symptom free group also had significantly lower levels of depression, but anxiety levels were very similar between the groups. The direction of difference in the cyclical, consequence and control variables was in the expected direction (i.e. people who were symptom free considered their MS to be more cyclical, to have fewer consequences, and themselves to have more control). Although people who were symptom free were less depressed, they were more distressed about their illness (emotional perception scores). The two significantly different variables on the coping questionnaire showed that people who were symptom free used more emotional discharge and alternative reward seeking.

3.3. Reliability of Questionnaires

Before the GLM analysis was conducted, some data analysis was conducted to check the internal reliability of questionnaires, and to see if the data conformed to the underlying models the questionnaires were based on. Reliability is the consistency with which something can be measured. Where several items are used to provide information about a

single factor, the score is more likely to be reliable than a factor measured by a single item (Miller, 1984). The models of the 8 factor IPQ-R and CRI are based on the assumption that items within each factor are measuring the same thing. Cronbach alpha analysis was carried out to test this.

3.3.1. IPQ-R. All subscales, except Timeline Cyclical, demonstrated good internal reliability. Reliability coefficients ranged from .50 for Timeline Cyclical to .89 for Illness Coherence (see Table 3.).

3.3.2. CRI. All subscales demonstrated good internal reliability. Reliability coefficients were not as strong as for the IPQ-R, but were acceptable, and ranged from .61 for Seeking Support to .79 for Alternative Rewards (see Table 3.)

Table 3. here

3.4. Validity and internal reliability of the Identity subscale

Consistent with the Moss-Morris et al. (2002) study, the identity factor was tested in two ways. Firstly a paired samples t-test (t [157,1] = 8.42, p

<.01) was carried out, comparing the symptoms experienced with the symptoms rated as relating to the participant's MS. The results demonstrated that there were significant differences between the symptoms that people had, and those they identified as being related to their MS.

Secondly, frequencies were explored for each item on the identity scale. Every symptom was endorsed by a minimum of 15% of participants (see Table 4.). The most highly endorsed symptom was tiredness or fatigue (97%), followed by sensory loss (91%), and loss of strength and co-ordination problems (both 89%).

Table 4. Here

In addition, 66 people offered additional symptoms related to their MS. These were very varied, but a few had similar themes. Balance problems were reported and experienced by 12% of people, loss of function was cited by 7%; oesophageal or other neuralgia, and pins and needles were both cited by 3% of people. Other symptoms reported were cited by less than 2% of the participants. These included paralysis/numbness, sexual

dysfunction, tremors or spasticity, hearing loss, body temperature changes, cognitive problems and skin irritation/sensitivity.

3.5. Confirmatory Principle Components Analysis (PCA)

The goals of the PCA were to reduce a large number of items to a smaller number of factors/components, and test the theoretical models that the questionnaires were based on. PCA with Varimax rotation was used, as rotation makes the solution easier to interpret without changing fundamental mathematical properties (Tabachnik, & Fidell, 2001). Varimax rotation was chosen as it simplifies factors (Tabachnik, & Fidell, 2001), and was used in the original validation study for the IPQ-R.

3.5.1. IPQ-R. Four of the 7 factors were clearly defined, but there was some discrepancy from the original validation study on three of the factors. Item 18, which should have loaded on the Timeline factor, did not load onto any of the factors. The Timeline factor therefore consisted of items 1-5. The Control factors were also mixed, with items 12-17, plus items 19 and 21-23 all loaded onto one factor. Items 20-22 loaded mostly onto a separate factor that contained only those three factors (see table 5.).

Table 5. Here

Overall the 7 factors accounted for 60% of the variance. The Personal Control and Treatment Control items that loaded onto factor I accounted for 11% of the variance. Emotional perceptions accounted for 10%. Illness Coherence and Timeline (acute/chronic) factors accounted for 9% each. Consequences, Timeline Cyclical, and the Treatment Control items loading onto factor VII accounted for 8%, 7% and 6% respectively.

In line with recommendations (Moss-Morris et al., 2002) for participant numbers over 90, a factor analysis was carried out on the 18 items asking about the perceived causes of MS. The validation study identified 4 factors, which were labelled as psychological attributions, risk factors, immunity, and accident or chance. A confirmatory PCA (see Table 6.) was conducted, and this explained 51% of the variance.

Table 6. Here

As the confirmatory PCA was not a good fit for the Moss-Morris (2002) model, a non-confirmatory PCA was carried out to explore the data more openly. The results are shown in Table 7.

Table 7. Here

Overall the 6-factor model improved the model, and accounted for 67% of the variance. Psychological Attitude accounted for 18% of the variance. Risk accounted for 15% of the variance. The Mixed factor accounted for 12% of the variance, and Illness and Chance accounted or 9%. The Medical factor and Heredity both accounted for 7% of the variance.

3.5.2. CRI. The PCA of the CRI did not strongly confirm the coping model it was based on, and is placed in the Appendix (see Appendix I). The items were rearranged and factors relabelled to make the factors more interpretable (see Appendix J), but more work needs to be conducted to validate this structure. The GLM multivariate analysis did therefore not use the restructured grouping of the items, but the original grouping based on Moos (1993).

3.6. Correlations

A Pearson's partial correlation analysis was carried out to investigate the inter- relationships between factors with anxiety and depression

controlled for (see Appendix M). Higher identity scores were significantly positively correlated with people perceiving their MS to be cyclical, and to have more severe consequences. People who perceived their MS as chronic (denoted by higher scores on Timeline) perceived their MS to have more negative consequences, and to be less controllable, but to be more understandable to them (denoted by lower illness coherence scores). Perceiving MS as chronic was also related to using more cognitive avoidance, but less seeking alternative reward strategies. People who perceived their MS to be cyclical perceived that they had more personal and treatment control, and that MS had fewer consequences, but their MS made less sense to them. People who saw their MS as having more serious consequences believed they had less control. People who perceived that they had more personal control also perceived they had more treatment control, and this was associated with the use of more logical analysis and positive appraisal, and less resignation. The perception of having more treatment control was associated with the use of more support seeking and alternative reward finding, and less resignation. The perception that MS made less sense was associated with the use of more cognitive avoidance. Higher levels of emotional distress were associated with the use of more logical analysis, support seeking, problem solving, cognitive avoidance, resignation, alternative reward seeking and emotional discharge.

The coping factors were frequently positively correlated with each other. The use of logical analysis was associated with the use of positive

appraisal, support seeking, problem solving, alternative reward seeking, and emotional discharge. The use of positive appraisal was associated with using support seeking, problem solving, alternative reward seeking and cognitive avoidance. The use of support seeking was correlated with problem solving, alternative reward seeking and emotional discharge. Problem solving was associated with alternative reward seeking and emotional discharge. Cognitive avoidance was associated with resignation, alternative reward seeking and emotional discharge. Resignation and alternative reward seeking were both associated with emotional discharge.

The coping factors were frequently positively correlated with each other. People who reported using logical analysis were also likely to report using positive appraisal, support seeking, problem solving, alternative reward seeking, and emotional discharge. People who reported using positive appraisal were more likely to also report using support seeking, problem solving, alternative reward seeking and cognitive avoidance. People who used support seeking also used problem solving, alternative reward seeking and emotional discharge. Problem solving was associated with alternative reward seeking and emotional discharge. Cognitive avoidance was associated with resignation, alternative reward seeking and emotional discharge. Resignation and alternative reward seeking were both associated with emotional discharge.

3.7. GLM Multivariate Analysis

seeking and emotional discharge. Resignation and alternative reward seeking were both associated with emotional discharge.

3.7. GLM Multivariate Analysis

As there were significant differences between the symptom free and symptomatic groups, the GLM Multivariate analysis was carried out twice to check if including the symptom free participants affected the results. Some variables became non-significant when the symptom free group were excluded (see Appendix L for results of this analysis). A decision was made to include the symptom free participants in the analysis (see Table 9.), as being symptom free is a part of the natural process of MS in remitting-relapsing and benign forms. Symptom free participants may therefore make a significant contribution to finding difference between people with different types of MS. Excluding these participants may introduce a Type II error, where difference exists, but is discounted. The mean scores of the dependent variables were calculated prior to the main analysis (see Table 8.).

Table 8. Here

Table 9. Here

Pairwise comparisons showed the difference in the identity variable was between remitting and benign groups ($p<.01$), with the remitting group having a significantly higher illness identity score. In the Timeline and Cyclical variables the progressive group had significantly different scores to both the remitting ($p<.01$) and benign ($p<.01$) groups. The timeline scores were higher and the cyclical scores were lower. For the Consequences variable, the progressive group had significantly higher perceptions of adverse consequences than both the remitting ($p<.01$) and benign ($p<.01$) groups. The control variables had different patterns to each other, in that the progressive group had significantly lower perceptions of personal control compared to the benign group ($p<.01$), and lower perceptions of treatment control compared to the remitting group ($p<.01$). Illness coherence was not significant on the multivariate analysis. For emotional perceptions, the between group pairwise comparisons were not significant, but there was a significant effect of anxiety (F [1,157] =23.06, $p<.01$), and depression (F [1,157] =6.07, $p<.05$) as covariants.

The Logical Analysis factor on the CRI showed differences between remitting and progressive groups ($p<.05$) on pairwise comparisons, with the remitting group endorsing the use of logical analysis as a coping strategy more than the progressive group. There was no main effect of group for positive appraisal, problem solving, or alternative reward seeking. There was a main effect of group for support seeking, cognitive avoidance, resignation and emotional discharge, but pairwise comparisons were not significant. However, there was a significant effect of anxiety on the variables of Cognitive Avoidance (F [1,157] =10.94, $p<.01$). Resignation (F [1,157]=5.83, $p<.05$) and Emotional Discharge (F [1,157] =23.06, $p<.01$).

4.0 Discussion

4.1. Participant Differences

In general the results were as might be expected given the nature of the illness. Older adults were less anxious, and had fewer emotional perceptions of their MS than younger participants. This could be a result of necessary adaptation to chronic illness, or it could be that older people who participated had fewer worrying symptoms than younger participants. The difference in depression scores, with the benign group having fewer people scoring in the higher ranges on depression, could be considered in-line with the nature of the illness, whereby the benign group may have less distressing and severe symptoms, and periods of remission. Anxiety scores being similar across groups could be related to the unpredictability of MS, and supports other studies that have found

high prevalence of anxiety in people with MS (e.g. Feinstein, et al., 1999).

The symptom free group had several differences to the rest of the participants, which is to be expected. For example, there were no symptom free people in the progressive group, which is in-line with the nature of progressive MS, and supports the validity of the self-reported illness classification. The symptom free group was also younger, and had experienced symptoms and been diagnosed for shorter time periods. These results may signify a progressive change in MS over time. However, longitudinal analysis is needed to explore this possibility further.

The symptom free group was also less depressed. This may be related to having MS for less time, having less severe symptoms, and/or the absence of participants with progressive MS from this group. The direction of difference on IPQ-R scores was in the expected direction. People who were symptom free considered their MS to be more cyclical, to have fewer consequences, and saw themselves as having more control. However, they were also more distressed about their illness. This may be related to their being younger, and having less time to adjust to the illness, or to the unpredictability of the illness returning. This may be related to the finding that symptom free people used more emotional discharge and alternative reward seeking coping strategies.

may be related to the finding that symptom free people used more emotional discharge and alternative reward seeking coping strategies.

4.2. Validity of the Illness Identity Subscale of the IPQ-R

As the symptoms experienced were not all endorsed as related to MS, there is evidence that participants were able to differentiate their MS symptoms from other symptoms, as suggested by Moss-Morris et al. (2002). There is also evidence that the questionnaire covered the pertinent MS related symptoms, as the type of symptoms endorsed were in line with the literature (e.g. Mohr, & Dick, 1998), and few other symptoms were reported.

4.3. Principal Component Analysis

Analysis of the IPQ-R data generally supported the illness perception model, with small variations. Item 18 (My MS will improve in time), which should have loaded on the Timeline factor, did not load strongly on any factor, but was negatively correlated to treatment control. It is possible this notion is a direct link between several factors, as factors are not necessarily independent of each other (Weinman, et al., 1996). It is alternatively possible that, as the content of illness representations may vary across people, and illnesses (Heijmans, & de Ridder, 1998), this item does not make sense to people with MS.

The control items also did not quite fit the model. Moss- Morris et al. (2002) suggest that the distinction between personal and treatment

decision of how to best manage their symptoms. The boundary between the two would then be blurred, as found in this study. More research is needed to understand control perceptions more fully in MS. The cause factors found by Moss-Morris et al. (2002) were also not replicated. This may be related to participant differences, or the distribution of MS types. More research is needed to explore the views that people have of the cause of their MS.

The CRI factor structure was not strongly validated. This may be because different illnesses have different coping profiles, or because the model of coping is not robust. Certainly coping questionnaires have tended to focus on a disparate group of emotion-focused behaviours (e.g. venting, suppression, and denial) associated with worse adjustment (Nolen-Hoeksema, Parker, & Larson, 1994; Stanton, Danoff-Burg, Cameron, and Ellis, 1994). Not only do these strategies have significant conceptual differences (Carver, Sheier, & Weintraub, 1989), but Stanton et al. (1994) have argued that some strategies labelled emotion-focused might be better classified as symptoms of distress. This has perhaps led to claims of a relationship between coping style and distress that may not exist (Summerfeldt, & Endler, 1996). It is therefore possible that there are some conceptual problems inherent in the coping measures currently available. More research is needed to explore this idea.

4.4. Correlations

The finding that depression was related to illness perceptions was in line with evidence from other studies (e.g. Murphy, Dickens, Creed, & Bernstein, 1999; Scharloo et al., 2000). The main area of interest from the correlational analysis was in the area of relationships between perceptions and coping. For example, people who perceived their MS as chronic also perceived their MS to have more negative consequences, and to be less controllable, but to make more sense to them. They used more cognitive avoidance and less alternative reward strategies. People who saw their MS as controllable used more active coping strategies (e.g. logical analysis, support seeking and positive appraisal) and less resignation. This is similar to findings with people with chronic fatigue syndrome (CFS; Moss-Morris, Petrie, & Weinman, 1996), where perceptions expected to be related to greater distress, such as believing the illness will last a long time, and the consequences will be serious, were related to more use of venting emotion, and disengaging from the stressor. The relationship between coping and illness perceptions found in people with CFS appeared to be linear (Moss-Morris et al., 1996), in that people who believed they had more control over their CFS reported using significantly more positive coping strategies (e.g. planning and positive reframing).

This study also found that people who felt that their MS made less sense to them used cognitive avoidance more. Although it is not possible to comment on the direction of these relationships, it is conceivable it may

comment on the direction of these relationships, it is conceivable it may be important for people to understand and feel in control of their illness, in order to use coping strategies that have been related to better outcomes (e.g. Ingledew, Hardy, Cooper, & Jemal, 1996). This would be a useful area for future research to establish helpful support approaches for people with MS.

People who were more distressed (i.e. had more emotional perceptions about their illness), reported using a lot of different coping strategies, particularly emotional discharge. This may be related to a sense of distress motivating people to try anything they can think of. Alternatively, it maybe that trying a lot of different strategies can increase distress, possibly because of a lack of a sense of purpose and/or a lack of positive reinforcement from a successful experience with a coherent strategy. Either way it could be helpful to explore this relationship more fully, so that appropriate support or therapeutic interventions could be offered.

It might have been expected that the two control dimensions would have shown similar correlations, but in fact, although people who perceived that they had more personal control also perceived they had more treatment control, and used less resignation, there were differences. People with more personal control used more logical analysis and positive appraisal. People who perceived they had more treatment control used more support seeking and alternative reward finding.

However, as the control items did not factor exactly as predicted, these correlations may not be robust.

The coping factors were frequently positively correlated with each other. It seems that participants used several strategies for the same event, which is in line with previous research (e.g. Aikens et al., 1997). Research has shown that emotion-focused strategies tend to be emphasised during periods of psychological distress (Aikens et al., 1997; Jean, Paul, & Beatty, 1999). This might explain the 100% correlation between distress (emotional perceptions of MS) and emotional discharge when depression and anxiety were controlled for. Alternatively this relationship could be interpreted as support for the notion that some items classified as coping may in fact be symptoms of distress (Stanton et al., 1994).

4.5. GLM Multivariate Analysis

The decision to control for depression and anxiety as they were highly correlated with other variables is supported by evidence that illness perceptions and depression are related. For example, Murphy, et al. (1999) found an association between depression and illness perceptions in people with rheumatoid arthritis. However, as the study was cross-sectional, the nature of the relationship (i.e. whether people view their illness more negatively because they are depressed, or whether they are more depressed because they view their illness negatively) was unclear.

In the multivariate analysis, with affect controlled for, the remitting group had significantly higher perceptions of MS related symptoms than the benign group. The progressive group saw their MS as more chronic and less cyclical than both the remitting and benign groups. They also perceived the consequences of their MS to be more severe, and felt they had less control. There were no significant differences between the groups for illness coherence or emotional perceptions. However, there was a highly significant effect of anxiety on emotional perceptions as seems logical.

Coping strategies had one difference between the groups. The remitting group used logical analysis more often then the progressive group. There were no differences between groups for positive appraisal, problem solving, and alternative reward seeking. Although there was a main effect of group for seeking support, cognitive avoidance, resignation and emotional discharge, there were no pairwise comparison differences. However, there was an effect of anxiety on cognitive avoidance, resignation and emotional discharge. This suggests that when distress levels are high, people are less able to deal with issues around the illness. It also provides limited support for the argument that some items classified as coping strategies may be more usefully considered symptoms of distress (Stanton, et al., 1994), although as this was a cross-sectional study it is not possible to interpret cause and effect. However, if the finding is corroborated in future research it would provide strong support for the provision of interventions aimed at helping

people deal with distress, so they can then use adaptive coping strategies effectively. There is also the possibility that it might be possible to prevent more severe adverse psychological and physical effects of chronic stress developing by addressing affective disturbances/distress early, and as an issue in its own right.

4.6. Results Summary

The hypothesis was partly supported, with people with different diagnostic categories of MS showing differences in the measure of illness perceptions. There was some between group difference on the coping measure, but this was not consistent. Anxiety was found to be significantly related to how people coped with their illness.

Other findings were that there were differences on age, time since diagnosis, depression, and illness perceptions between people who were asymptomatic and people who had symptoms at the time of testing. The older adult group (over 65) was found not to be significantly different to the adult group. PCA analysis of the IPQ-R supported the model of illness perceptions, and suggested that it was an instrument relevant and suitable for use with an MS population. PCA analysis of the CRI did not support the coping model.

4.7. General Discussion

Many factors could have been considered in this study. However, the study confined itself to illness perceptions and coping due to time and

resource constraints. However, it is acknowledged that ideally it might usefully have included measures of stress, cognitive status, and disability. Disability in particular would have been helpful as people with mild problems might be expected to experience different challenges, threats and demands compared to a person in a wheel chair for example (Mohr, Goodkin, Gatto, & Van Der Wende, 1997). Other items that should perhaps have been considered, but were omitted, were whether people take medications (and if so what; e.g. interferon), and whether people have secondary progressive or primary progressive form.

There were several methodological limitations to this study. Unfortunately it was not possible to recruit groups of equal size, which is known to interfere with statistical analysis (Tabachnik, & Fidell, 2001). It is possible that recruiting matched groups would have aided the analysis and provided a clearer and more robust result. However, it might also have reduced the number of participants significantly. As it was, participant numbers were under the recommended number for detecting a medium sized effect. (Cohen, 1992). It was decided to accept the sample obtained to prevent error by excluding cases to make matched groups. However, in future this would be something to address prior to data collection.

A disadvantage of the CRI was that people chose their own stressful event. This may have meant the CRI data were not comparable (Beatty, Hames, Blanco, Williamson, Wilbanks, Olson, 1998). However, the

events that people chose were coded into one of three problem types, and these codes were fairly evenly distributed across the three MS types. Therefore, while an effect cannot be ruled out, it is not considered that this would have had a strongly misleading effect on the analysis conducted.

Participants were members of self-help groups, and willing to participate in a research study. It is possible that becoming a member of an organisation such as the MS Trust is a refection of a particular set of values. Also, it has been suggested that illness perceptions, degree of disability (Edwards, Suresh, Lynch, Clarkson, & Stanley, 2001), or coping style, depression or anxiety levels may influence whether people take part in research. This might mean the participants are different from the wider MS population, or that research populations are a distinct group of people.

Another problem is the validity of self-report data (Aikens et al., 1997). It is recommended that supplemental information is obtained from carers, spouses, or GP's, but this was not possible. However, there was evidence that people correctly reported at least some of the data. For example there were no people who were symptom free in the progressive MS group. Also, there is not much reason for people to lie as there are few, or no, social desirability issues involved.

Other methodological limitations were that the response rate may have influenced the findings, but as with all research of this type there is no way to compare responders with non-responders. Also, the study does not address causal relationships of illness perceptions, depression and coping as it is a cross-sectional study. The relationships could be linear, or reciprocal. A prospective, or longitudinal study, perhaps accessing previous medical histories, is needed to explore these issues, but this was beyond the scope of this study.

Despite these limitations, the results from the study suggest that illness perceptions and coping are a useful area of investigation for understanding psychological well being in MS. If these results are replicated in future studies, interventions designed to encourage a sense of control, and addressing distress and illness perceptions, could be an important part of helping people to manage their MS. Results also suggest that items currently thought of as coping strategies may be more helpfully construed as responses to distress. However, as MS has unique features (e.g. onset in early to mid adulthood; wide range of symptoms; unpredictability; high prevalence in women; cognitive impairments), which separate it from other chronic diseases (McReynolds, Koch, & Rumrill, 1999), it is not clear how generalisable these findings may be to any other chronic illness.

5.0 Conclusions

People with progressive and remitting-relapsing MS were more likely to be depressed than people with benign MS. Anxiety was more common (and scored higher) than depression, and occurred across all three types of MS. Participants used a variety of coping strategies to deal with stressors, and some of these were related to illness perceptions. There were between group differences in most illness perceptions, and in one coping strategy. Previously, studies have tended to categorise all people with MS together. These results suggest that this practice needs to be reconsidered and researched further.

There was a 100% correlation between emotional perceptions and emotional discharge with affect controlled for. There was also a highly significant effect of anxiety on the use of cognitive avoidance, resignation and emotional discharge. This may be interpreted as support for the notion that some items classified as coping may in fact be symptoms of distress. It could also be that people have difficulty using more active coping strategies if they are anxious. One way of testing this is by researching therapeutic interventions to help people manage their distress, and seeing if coping strategies (or symptoms of distress) change. There is some evidence to suggest that people with MS do respond well to therapeutic interventions aimed at alleviating distress.

Ideally, future research on coping should include more precise theoretical statements, continuous and longitudinal data collection, and

situational and personal variables including secondary stressors. Multiple assessment points, repeated measures, and various indices of outcome at regular intervals would help understand some of the complex interactions and effects. By exploring further how people cope with different problems it may be possible to clarify whether changing strategies based on situation requirements results in more effective coping than relying on the same strategies across problems (Zeidner, & Saklofske, 1996). Studies of this kind could provide evidence and guidance for therapeutic interventions.

6.0 References

Aikens, J.E., Fischer, J.S., Namey, M., & Rudick, R.A. (1997). A replicated retrospective investigation of life stress, coping and depressive symptoms in multiple sclerosis. *Journal of Behavioural Medicine*, 20, 433-445

Beatty, W.W., Hames, K.A., Blanco, C.R., Williamson, S.J., Wilbanks, S.L., Olson, K.A. (1998). Correlates of coping style in people with multiple sclerosis. *Multiple Sclerosis*, 4, 5, 440-3

Carver, C.S., Sheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology*, 56, 2, 267-283

Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 1, 155 - 159

Edwards, R. Suresh, R., Lynch, S., Clarkson, P., & Stanley, P. (2001). Illness perceptions and mood in chronic fatigue syndrome. *Journal of Psychosomatic Research*, 50, 65-68

Feinstein, A., O'Connor, P., Gray, T., & Feinstein, K. (1999). The effects of anxiety on psychiatric morbidity in people with multiple sclerosis. *Multiple Sclerosis*, 5, 3, 323-326

Ford, H.L., Gerry, E., Johnson, M., & Williams, R. (2002). A prospective study of the incidence, prevalence and mortality of multiple sclerosis in Leeds. *Journal of Neurology*, 249, 3, 260 –265

Heijmans, M., & de Ridder, D. (1998). Assessing illness representations of chronic illness: explorations of their disease specific nature. *Journal of Behavioral Medicine*, 21, 5, 485-503

Ingledew, D.K., Hardy, L., Cooper, C.L., & Jemal, H. (1996). Health behaviours reported as coping strategies: A factor analytical study. *British Journal of Health Psychology*, 1, 3, 263-281

Jean, V.M., Paul, R.H., & Beatty, W.W. (1999). Psychological and neuropsychological predictors of coping patterns by patients with multiple sclerosis. *Journal of Clinical Psychology*, 55, 1, 21-26

Jopson, N.M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to Multiple Sclerosis. *Journal of Psychosomatic Disorders*, 54, 503-511

Lau, R.R., Bernard, T.M., & Hartmann, K.A. (1989). Further exploration of common-sense representation of common illnesses. *Health Psychology*, 8, 195-219

Lazarus, R.S., & Folkman, S. (1984a). *Stress, appraisal and coping.* New York: Springer

Leventhal, H., & Benyamini, Y. (1997). Lay beliefs about health and illness. In A. Baum (Ed.). *Cambridge handbook of psychological health and medicine.* Cambridge: Cambridge University Press

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., et al. (1997). Illness representations: Theoretical foundations. In K. Petrie, & J. Weinman (Eds.). *Perceptions of health and illness.* Amsterdam: Harwood Publishers

Leventhal, H., & Diefenbach, M. (1991). The active side of illness cognition. In J.A. Skelton, & R.T. Croyle (Eds.). *Mental representation in health and illness* (pp. 247-272). New York: Springer

Leventhal, H., Leventhal, E., & Cameron, L. (2001). Representations, procedures and affect in illness self-regulation: a perceptual-cognitive model. In A. Baum, T. Revenson, & J. Singer (Eds.). *Handbook of health psychology* (pp. 19-48). New Jersey: Lawrence Erlbaum

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common-sense representation of illness danger. In S. Rachman (Ed.). *Medical Psychology* Vol. 2 (pp. 7-30). New York: Pergamon

Leventhal, H., Nerenz, D., & Steele, D.J. (1984). Illness representations and coping with health threats. In A. Baum, S.E. Taylor, & J.E. Singer (Eds.). *Handbook of psychology and health. Vol. IV: Social psychological aspects of health* (pp. 219-252). Hillsdale, NJ: Erlbaum

Levy, L. (1982). Mutual support groups in Great Britain: a survey. *Social Science Medicine*, 16, 1265-1275

Maes, S., Leventhal, H., & de Ridder, T.D. (1996). Coping with chronic diseases. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 221-251). New York: Wiley

McReynolds, C.J., Koch, L.C., & Rumrill, P.D. (1999). Psychosocial adjustment to multiple sclerosis: implications for rehabilitation professionals. *Journal of Vocational Rehabilitation*, 12, 83-91

Miller, S. (1984). *Experimental Design and statistics. 2nd Edition.* London: Routledge

Milne, D. (Ed.). (1992). *Assessment: A mental health portfolio. Stress, coping and social support.* Windsor, UK: Nfer Nelson

Minden, S.L. & Schiffer, R.B. (1990). Affective disorders in multiple sclerosis: Review and recommendations for clinical research. *Archives of Neurology*, 47, 98-104

Mohr, D.C., & Dick, L.P. (1998). Multiple sclerosis: In P.M. Camic & S. Knight. (Eds.). *Clinical handbook of health psychology: a practical guide to effective interventions* (pp, 313-348). Seattle, USA: Hogrefe & Huber

Mohr, D.C., Goodkin, D.E., Gatto, N., Van Der Wende, J. (1997). Depression, coping and level of neurological impairment in multiple sclerosis. *Multiple Sclerosis*, 3, 2, 254-258

Monks, J., & Robinson, I., (1989). The characteristics of a national register of people with multiple sclerosis: a comparison between the ARMS (Action for Research into Multiple Sclerosis) register and 10 British MS populations. *Journal of Epidemiological Community Health*, 43, 2, 179-186

Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., et al. (1991). The factor structure and factor stability for the Hospital Anxiety and Depression Scale in people with cancer. *British Journal of Psychiatry*, 158, 255-259.

Moos, R.H. (1993). *Coping Response Inventory: Professional Manual.* Florida: Psychological Assessment Resources, Inc.

Moss-Morris, R., Petrie, K., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 1, 15-25

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17, 1, 1-16

Murphy, H., Dickens, C., Creed, F., & Bernstein, R. (1999). Depression, illness perception and coping in rheumatoid arthritis. *Journal of Psychosomatic Research*, 46, 2, 155-164

Nerenz, D., & Leventhal, H. (1983). Self-regulation theory in chronic illness. In B. Burish, & Bradley, I. (Eds.). *Coping with chronic disease.* New York: Academic Press

Nolen-Hoeksema, S., Parker, L.E., & Larson, J. (1994). Ruminative coping with depressed mood following loss. *Journal of Personality and Social Psychology*, 67, 1, 92-104.

Roberts, M.H., Martin, J.P., McClellan, D.L., McIntosh-Michaelis, S.A., & Spackman, A.J. (1991). The prevalence of multiple sclerosis in the Southampton and South West Hampshire Health Authority. *Journal of Neurological and Neurosurgical Psychiatry,* 54, 1, 55-59

Robertson, N., Deans, J., Fraser, M., & Compston, D.A. (1995). Multiple sclerosis in the north Cambridgeshire districts of East Anglia. *Journal of Neurological and Neurosurgical Psychiatry*, 59, 1, 71-76

Scharloo, M., Kapstein, A., Weinman, J.A., Willems, L., Rooijmans, H. (2000). Physical and psychological correlates of functioning in people with chronic obstructive pulmonary disease. *Journal of Asthma*, 37, 1, 17-29

Schiaffino, K., Shawaryn, M., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, 17, 3, 262-268

Sinnakaruppan, I. (2000). Development of a coping scale for use with chronic illnesses, especially multiple sclerosis – a pilot study. *International Journal of Rehabilitation Research*, 23, 155-161

Skelton, J.A., & Croyle, R.T. (1991*). Mental representation in health and illness.* New York: Springer

Spinks, H., & Horn, S. (2003). *Demographic questionnaire.* Unpublished questionnaire constructed as part of Doctoral thesis, Doctoral Programme in Clinical Psychology, University of Southampton

Spinks, H., & Horn, S. (2003). *Illness Perception Questionnaire- Revised (Multiple Sclerosis version).* Unpublished Multiple Sclerosis version of Illness Perception Questionnaire- Revised (Moss-Morris, et al., 2002),

constructed as part of Doctoral thesis, Doctoral Programme in Clinical Psychology, University of Southampton

Stanton, A.L., Danoff-Burg, S., Cameron, C.L., & Ellis, A.P. (1994). Coping through emotional approach: problems of conceptualisation and confounding. *Journal of Personality and Social Psychology*, 66, 350-362

Summerfeldt, L., & Endler, N. (1996). Coping with emotion and psychopathology. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (pp. 600-639). New York: Wiley

Tabachnik. B.G., & Fidell, L.S. (2001). *Using multivariate statistics. 4th edition.* London: Allyn and Bacon.

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health*, 1, 431-445

Williams, E.S., & McKeran, R.O. (1986). Prevalence of multiple sclerosis I a south London borough. *British Medical Journal (Clinical Research Edition)*, 293, 6541, 237-239

Williams, A.C., & Richardson, P.H. (1993). What does the BDI measure in chronic pain? *Pain*, 55, 259-266

Zeidner, M., & Saklofske, D. (1996). Adaptive and maladaptive coping. In M. Zeidner, & N. Endler (Eds.). *Handbook of coping: theory, research and applications* (p. 505-531). New York: Wiley

7.0 Tables and Figures

7.1. Table 1.

Table 1. Frequencies or Mean scores and Standard Deviations (S.D.) for variables by Type of MS

		Remitting n=53	Benign n=41	Progressive n=64	Total n=158
Age	< 65 (range 23-64)	48	34	59	141
	65 and over (range 65-85)	5	7	5	17
	Mean	M 46.45 (S.D. 12.32)	M 48.17 (S.D. 15.03)	M 50.62 (S.D. 9.74)	M 48.54 (S.D. 12.24)
Gender	Female	43	34	47	124
	Male	10	7	17	34
How long had symptoms		M 16.96 (S.D. 13.09)	M 15.76 (S.D. 12.24)	M 16.43 (S.D. 10.24)	M 16.32 (S.D. 11.75)
How long been diagnosed		M 12.09 (S.D. 12.34)	M 8.13 (S.D. 8.69)	M 9.64 (S.D. 7.35)	M 9.87 (S.D. 9.62)
Problem Type	MS	10	4	11	25
	MS Related	18	13	22	53
	Not MS	25	24	31	80
HADS	Anxiety < 7	27	17	22	66
	7-10	16	14	27	57
	> 10	10	10	15	35
	Mean Score	M 6.80 (S.D. 4.02)	M 7.76 (S.D. 4.40)	M 8.09 (S.D. 3.97)	M 7.59 (S.D. 4.16)
	Depression* < 7	33	36	32	101
	7-10	14	3	23	40
	>10	6	2	9	17
	Mean Score	M 5.44 (S.D. 3.47)	M 4.19 (S.D. 4.19)	M 6.84 (S.D. 2.98)	M 5.64 (S.D. 3.38)
Source	MS Trust email	23	13	28	64
	MS Trust letter	21	19	24	64
	MS Therapy Centre	4	3	9	16
	New Zealand	5	6	3	14
Symptom Free*		8	10	0	18

* = p <.05

7.2. Table 2.

Table 2. Currently Symptom Free Participants vs. All Others

Variable		F	Mean for Symptom Free Group (n=18)	Mean for Non Symptom Free Group (n=140)
AGE		14.50**	38.61 (S.D. 12.53)	49.83 (S.D. 11.58)
How long had symptoms		5.75*	10.17 (S.D. 6.37)	17.21 (S.D. 11.98)
How long since diagnosis		3.79	5.76 (S.D. 6.04)	10.59 (S.D. 9.89)
HADS	Anxiety	0.14	7.94 (S.D. 3.70)	7.52 (S.D. 4.17)
	Depression	9.53**	3.39 (S.D. 2.66)	5.99 (S.D. 3.39)
IPQ-R	Illness Identity	2.77	10.33 (S.D. 9.78)	11.83 (S.D. 3.43)
	Timeline	3.44	24.94 (S.D. 3.89)	26.67 (S.D. 3.78)
	Cyclical	5.03*	14.33 (S.D. 3.79)	12.07 (S.D. 4.02)
	Consequences	21.27**	19.44 (S.D. 5.35)	24.42 (S.D. 4.17)
	Personal Control	3.92*	21.66 (S.D. 4.38)	19.11 (S.D. 5.16)
	Treatment Control	8.69**	16.66 (S.D. 3.11)	13.80 (S.D. 3.91)
	Illness Coherence	0.01	12.33 (S.D. 4.92)	12.47 (S.D. 4.88)
	Emotional Perceptions	9.10**	7.06 (S.D. 4.56)	4.50 (S.D. 3.30)
CRI	Logical analysis	0.03	9.61 (S.D. 2.48)	9.80 (S.D. 4.38)
	Positive appraisal	3.44	11.33 (S.D. 3.31)	9.12 (S.D. 4.83)
	Support seeking	0.06	9.17 (S.D. 4.46)	8.95 (S.D. 4.03)
	Problem solving	0.81	9.06 (S.D. 4.81)	10.09 (S.D. 4.50)
	Cognitive avoidance	3.38	8.00 (S.D. 5.23)	6.15 (S.D. 3.80)
	Resignation	1.63	8.17 (S.D. 4.54)	6.80 (S.D. 4.20)
	Alternative rewards	8.92**	8.33 (S.D. 5.28)	4.89 (S.D. 4.44)
	Emotional discharge	8.92**	7.06 (S.D. 4.56)	4.52 (S.D. 3.30)

* p<.05 **p<.01

7.3. Table 3.

Table 3. Internal Reliability

Questionnaire	Sub Scale	Cronbach alpha
IPQ-R	Timeline	.80
	Timeline Cyclical	.50
	Consequences	.81
	Personal Control	.82
	Treatment Control	.74
	Illness Coherence	.89
	Emotional Perceptions	.88
CRI	Logical analysis	.70
	Positive apparel	.77
	Support seeking	.61
	Problem solving	.73
	Cognitive avoidance	.72
	Resignation	.67
	Alternative rewards	.79
	Venting emotions	.62

7.4. Table 4.

Table 4. Endorsement of symptom ratings

Symptom	Percentage of endorsement	Percentage of endorsement related to MS*
Tiredness or Fatigue	97	96
Loss of sensation	91	91
Loss of strength	89	87
Co-ordination problems	89	87
Continence problems	81	80
Stiff joints	80	69
Muscle aches	80	75
Pain	78	70
Eye problems	74	70
Sleep problems	71	59
Unusual forgetfulness	64	60
Dizzy	64	60
Headache	57	32
Nausea	48	25
Speech problems	46	45
Sore eyes	45	37
Upset stomach	43	21
Sore throat	41	6
Breathlessness	33	16
Weight loss	29	13
Wheezy	15	7

* Percentage of total sample

7.5. Table 5.

Table 5. PCA of IPQ-R

Item*	I	II	III	IV	V	VI	VII
Timeline acute/chronic (alpha = .80)							
1. My illness will last a short time (r)	-.15	-.01	-.01	**.47**	.24	-.01	-.17
2. My illness is likely to be permanent	-.01	.01	-.01	**.77**	-.01	.12	-.01
3. My illness will last for a long time	-.01	.01	.01	**.91**	.14	-.01	-.01
4. This illness will pass quickly (r)	-.01	-.01	-.01	**.78**	.15	-.01	-.15
5. I expect to have this illness for the rest of my life	-.01	.01	-.11	**.75**	.23	-.01	-.01
18. My illness will improve in time (r)	-.16	.01	-.15	.23	.24	-.29	-.50
Timeline Cyclical (alpha = .50)							
29. My symptoms change a great deal	.10	.01	.01	.01	.20	**.55**	.01
30. My symptoms come and go in cycles	.17	-.01	.01	-.01	-.26	**.79**	.01
31. My illness is very unpredictable	.01	.11	.18	.01	.01	**.71**	-.01
32. My illness gets better or worse in cycles	.01	.01	.01	-.01	-.13	**.82**	.17
Consequences (alpha = .81)							
6. My illness is a serious condition	.01	.19	-.01	.30	**.59**	-.01	-.21
7. My illness has major consequences	.12	.20	.01	.30	**.69**	.01	-.27
8. My illness does not effect my life much (r)	-.01	.01	.01	.16	**.66**	-.01	-.31
9. My illness affects the way others see me	.23	.17	.10	-.01	**.67**	-.18	.16
10. My illness has serious financial consequences	-.16	.11	.01	.11	**.65**	.01	-.01
11. My MS causes difficulties for those close to me	-.19	.18	.01	.14	**.68**	-.01	.01
Personal Control (alpha = .82)							
12. There is a lot I can do to control my symptoms	**.68**	-.18	-.01	-.01	-.01	.01	.27
13. What I do determines if I get better or worse	**.74**	.01	.01	-.01	-.01	-.01	.30
14. The course of my illness depends on me	**.63**	-.11	.12	-.27	-.18	.01	.14
15. Nothing I do will affect my illness (r)	**.54**	-.11	-.01	.01	-.15	.20	-.16
16. I have the power to influence my illness	**.70**	-.01	-.01	-.13	-.14	-.01	.01
17. My actions will not effect the outcome (r)	**.75**	-.12	.01	-.01	-.01	.18	-.20
Treatment Control (alpha = .74)							
19. Little can be done to improve my illness (r)	**.54**	-.01	-.15	.01	-.01	.01	.29
20. Treatment will be effective in curing my illness	.16	.01	.11	-.20	-.22	.01	**.66**
21. Treatment prevents negative effects of my illness	**.46**	-.01	.01	-.01	.01	.01	**.67**
22. My treatment can control my illness	**.53**	-.01	-.01	.01	-.01	.01	**.47**
23. Nothing can help my condition (r)	**.54**	-.14	-.17	-.01	-.01	.18	.19
Illness Coherence (alpha = .89)							
24. The symptoms of my condition are puzzling (r)	.01	.14	**.83**	-.01	.01	.01	.01
25. My illness is a mystery to me (r)	-.01	.10	**.90**	-.01	.01	.01	.01
26. I don't understand my illness (r)	.01	-.01	**.85**	.01	.01	.01	.01
27. My illness doesn't make any sense to me (r)	-.01	.01	**.85**	.01	.01	.01	.01
28. I have a clear understanding of my condition	-.01	.18	**.64**	-.13	-.01	.20	.01
Emotional Perceptions (alpha = .88)							
33. I get depressed when I think about my illness	-.11	**.82**	.01	-.01	.15	-.01	.01
34. When I think about my illness I get upset	-.20	**.83**	.01	-.01	.15	-.01	.01
35. My illness makes me angry	-.20	**.66**	.01	-.01	.17	.14	.12
36. My illness does not worry me (r)	-.01	**.74**	.01	.01	.10	.01	.01
37. Having this illness makes me anxious	-.01	**.75**	.10	.01	.15	-.01	-.20
38. My illness makes me feel afraid	-.01	**.79**	.13	-.01	.01	.01	-.24

* Items are not presented in full for space saving. See Appendix F for full wording
(r) = Scoring is reversed

7.6. Table 6.

Table 6. Confirmatory PCA of the IPQ-R 'cause' items

Items	I	II	III	IV
Psychological attributions (alpha = .84)				
Stress or worry	.82	.01	.13	-.01
My mental attitude	.48	.35	.42	.01
Family problems	.80	.20	.01	.01
Overwork	.71	.17	.24	.16
My emotional state	.74	.29	.20	.01
My personality	.41	.37	.40	.01
Risk Factors (alpha = .75)				
Heredity	-.16	.36	.18	.01
Diet	.11	.11	.84	.01
Poor medical care	.16	.33	.31	-.01
My own behaviour	.40	.28	.69	.01
Ageing	.27	.69	.24	.01
Smoking	.29	.81	.01	.19
Alcohol	.24	.84	.01.	.19
Immunity (alpha = .47)				
A germ or virus	-.01	-.01	-.01	.75
Pollution in the environment	.01	.18	.69	.22
Altered immunity	.19	-.01	.14	.73
Accident or Chance (alpha = -.06)				
Chance or bad luck	.01	.18	-.01	.50
Accident or injury	.15	.59	.18	-.23

7.7. Table 7.

Table 7. PCA of the IPQ-R 'cause' items

Items	I	II	III	IV	V	VI
Psychological attributions (alpha = .84)						
Stress or worry	.82	.01	.01	-.01	-.01	-.01
My mental attitude	.54	.28	.35	-.01	.01	.33
Family problems	.76	.24	-.01	.01	.18	-.19
Overwork	.72	.17	.18	.17	.12	.01
My emotional state	.76	.29	.15	.01	.01	.15
My personality	.44	.28	.33	.01	.25	.20
Risk Factors (alpha = .77)						
Ageing	.26	.64	.21	.01	.25	.15
Smoking	.25	.88	.13	.11	.01	.01
Alcohol	.21	.89	.13	.10	.01	.12
Accident or injury	.11	.50	.15	-.20	.48	-.01
Mixed (alpha = .74)						
Diet	.16	.01	.84	-.01	.01	.01
Pollution in the environment	.01	.25	.74	.23	.12	-.18
My own behaviour	.46	.22	.64	.01	.01	.28
Illness and Chance (alpha = .44)						
A germ or virus	-.01	.10	.01	.72	-.25	-.01
Chance or bad luck	.01	.01	-.14	.54	.31	.31
Altered immunity	.18	.01	.10	.76	.01	-.01
Medical						
Poor medical care	.14	.01	.16	.01	.86	.01
Accident or injury	.11	.50	.15	-.20	.48	-.01
Heredity						
Heredity	-.01	.13	.01	.01	.01	.84

7.8. Table 8.

Table 8. Mean scores on dependant variables by group

	Variables	Remitting n=53	Benign n=41	Progressive n=64	Total n=158
IPQ-R	Identity	12.60 (S.D. 3.48)	10.46 (S.D. 4.07)	11.72 (S.D. 3.08)	11.69 (S.D. 3.56)
	Timeline	25.53 (S.D. 4.14)	25.73 (S.D. 3.46)	27.86 (S.D. 2.95)	26.52 (S.D. 3.66)
	Timeline Cyclical	13.77 (S.D. 2.99)	13.66 (S.D. 3.14)	10.31 (S.D. 4.59)	12.34 (S.D. 4.09)
	Consequences	22.74 (S.D. 4.66)	21.00 (S.D. 4.41)	26.34 (S.D. 3.08)	23.74 (S.D. 4.59)
	Personal Control	19.94 (S.D. 5.14)	21.34 (S.D. 4.39)	17.73 (S.D. 5.22)	19.41 (S.D. 5.17)
	Treatment Control	14.91 (S.D. 3.30)	14.90 (S.D. 3.95)	12.87 (S.D. 4.26)	14.08 (S.D. 3.98)
	Illness Coherence	11.92 (S.D. 5.33)	12.66 (S.D. 4.67)	12.58 (S.D. 4.47)	12.37 (S.D. 4.00)
	Emotional perceptions	5.04 (S.D. 3.33)	4.87 (S.D. 3.91)	4.61 (S.D. 3.55)	4.82 (S.D. 3.56)
CRI	Logical Analysis	10.87 (S.D. 3.75)	9.78 (S.D. 4.37)	9.17 (S.D. 4.26)	9.89 (S.D. 4.18)
	Positive Appraisal	10.70 (S.D. 4.35)	9.19 (S.D. 5.08)	8.67 (S.D. 4.50)	9.49 (S.D. 4.87)
	Support Seeking	9.68 (S.D. 3.88)	8.97 (S.D. 4,01)	8.62 (S.D. 4.12)	9.06 (S.D. 4.01)
	Problem Solving	10.66 (S.D. 4.13)	9.61 (S.D. 4.91)	9.98 (S.D. 4.48)	10.11 (S.D. 4.47)
	Cognitive Avoidance	6.62 (S.D. 3.92)	5.92 (S.D. 3.86)	6.29 (S.D. 4.30)	6.31 (S.D. 4.04)
	Resignation	7.15 (S.D. 3.90)	7.60 (S.D. 4.51)	6.37 (S.D. 4.33)	6.95 (S.D. 4.25)
	Alternative Rewards	6.13 (S.D. 4.75)	5.29 (S.D. 4.46)	4.60 (S.D. 4.70)	5.29 (S.D. 4.67)
	Emotional Discharge	5.04 (S.D. 3.33)	4.88 (S.D. 3.91)	4.61 (S.D. 3.55)	4.82 (S.D. 3.56)

7.9. Table 9.

Table 9. GLM Multivariate Analysis Results

	Variable	F	Observed Power
IPQ-R	Identity	9.97**	1.0
	Timeline	3.99**	.90
	Timeline Cyclical	11.00**	1.0
	Consequences	19.32**	1.0
	Personal Control	4.55**	.93
	Treatment Control	3.17*	.82
	Illness Coherence	2.15*	.63
	Emotional Perceptions	15.42**	1.0
CRI	Logical Analysis	3.04*	.79
	Positive Appraisal	2.14	.62
	Seek Support	2.59*	.72
	Problem Solve	1.10	.32
	Cognitive Avoidance	6.01**	.98
	Resignation	5.90**	.98
	Alternative Rewards	1.37	.42
	Emotional Discharge	15.43**	1.0

* = p< .05 ** = p<.01

8.0 Appendices

8.1 Appendix A. Instructions to authors

NOTES FOR CONTRIBUTORS

1. The aim of the *British Journal of Health Psychology* is to provide a forum for high quality research relating to health and illness. The scope of the Journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

(a) Papers reporting original empirical investigations

(b) Theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations

(c) Review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology

(d) Methodological papers dealing with methodological issues of particular relevance to health psychology.

2. The Journal is international in its authors and readers. Contributors should bear the international readership in mind, particularly when referring to specific health services.

3. Pressure on Journal space is considerable and brevity is requested. Papers should normally be no more than 5000 words.

4. Supplementary data too extensive for publication may also be deposited with the British Library Document Supply Centre. Such material should be submitted to the Editors together with the article for simultaneous refereeing. Further details of the scheme are given in the *Bulletin of the British Psychological Society*, 1977, **30**, February, p. 58.

5. This Journal operates a policy of blind peer review. Papers will normally be scrutinized and commented on by at least two independent expert referees as well as by an editor or associate editor. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page (and the text should be free of such clues as identifiable self-citations ('In our earlier work…').) The paper's title should be repeated on the first page of text.

6. The editors will reject papers which evidence discriminatory, unethical or unprofessional practices.

7. Submission of a paper implies that it has neither been published elsewhere nor is under consideration by another journal.

8. In preparing material for submission authors should follow these guidelines:

(*a*) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. Sheets must be numbered. Four good copies of the manuscript should be submitted and a copy should be retained by the author.

(*b*) Tables should be typed in double spacing, each on a separate sheet of paper. Each should have a self-explanatory title and be comprehensible without reference to the text.

(*c*) Figures are usually produced direct from authors' originals and should be presented as good black and white images preferably on high contrast glossy paper, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns or lines and shading should be avoided. Captions should be listed on a separate sheet.

(*d*) The Editors propose to adopt structured abstracts and all articles should be preceded by a structured abstract of between 100 and 250 words (less in the case of a short paper), giving a concise statement of the intention and results or conclusions of the article. Authors requiring further details on structured abstracts should contact the Journals Department (details on inside front cover).

(*e*) Bibliographic references in the text should quote the author's name and the date of publication thus: Hunt (1995). Multiple citations should be given alphabetically rather than chronologically: (Blackburn, 1996; Fortheringhame, 1994; Norman, 1995). If a work has two authors, cite both names in the text throughout: Choi and Salmon (1995). In the case of reference to five authors, use all the names on the first mention and *et al.* thereafter except in the reference list. For six or more, use *et al.* throughout.

(*f*) References cited in the text must appear in the list at the end of the article. The list should be typed double spaced in the following format:

Hunter, M. (1994). *Counselling in obstetrics and gynaecology*. Leicester: The British Psychological Society.

Pruitt, S.D., & Elliott, C.H. (1989). Paediatric procedures. In M. Johnstone & L. Wallace (Eds.), *Stress and medical procedures* (pp. 157–174). Oxford: Oxford University Press.

Ray, C., Phillips, L., & Weir, W.R.C. (1993). Quality of attention in chronic fatigue syndrome: Subjective reports of everyday attention and cognitive difficulty, and performance on tasks of focused attention. *British Journal of Clinical Psychology*, *32*, 357–364.

Note that journal titles are cited without abbrevation.

(*h*) Measurements should be in units of the International System.

(*i*) If the title of the article is longer than 80 characters, a short title should be provided for use as a running head.

(*j*) Footnotes are expensive to set and should be avoided.

(9) Proofs are sent to the corresponding author for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the corresponding author, but further copies may be ordered on a form supplied with the proofs.

(10) Authors should consult the Journal editor concerning prior publication in any form or in any language of all or part of their article.

(11) To protect authors and journals against unauthorized reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to the Journal, authors will be requested to sign an appropriate assignment of copyright form.

8.2. Appendix B. Ethical approval letter

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31 July 2002

Helen Spinks
Clinical Psychology
University of Southampton
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Dear Helen,

Re: Illness perceptions and coping in people with MS

The above titled application - which was recently submitted to the departmental ethics committee, has now been given approval.

Should you require any further information, please do not hesitate in contacting me on 023 8059 3995. Please quote reference CLIN/2002/24.

Yours sincerely,

KMSmith

Kathryn Smith
Ethical Secretary

cc. Janet Turner

8.3. *Appendix C. Data screening checklist (Tabachnik, & Fidell, 2001)*

1. Inspect univariate descriptive statistics for accuracy of input
   a. out of range values
   b. plausible means and standard deviations
   c. univariate outliers

2. Evaluate amount and distribution of missing data. Deal with problem

3. Check pairwise plots for nonlinearity and heteroscedasticity

4. Identify and deal with nonnormal variables
   a. check skewness and kurtosis, probability plots
   b. transform variables if desirable
   c. check results of transformation

5. identify and deal with multivariate outliers
   a. variables causing multivariate outliers
   b. description of multivariate outliers

6. Evaluate variables for multicollinearity and singularity

8.4. *Appendix D. T-test for group with and group without missing data.*

Independent Samples Test

		Levene's Test for Equality of Variances F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
AGE	Equal variances assumed	.451	.503	-.285	163	.776	-1.44654	5.07356
	Equal variances not assumed			-.289	5.397	.783	-1.44654	5.00036
how long since symptoms	Equal variances assumed	.010	.922	-.281	163	.779	-1.3718	4.8766
	Equal variances not assumed			-.294	5.433	.779	-1.3718	4.6597
how long since diagnosis	Equal variances assumed	.087	.769	-.668	163	.505	-2.6837	4.0190
	Equal variances not assumed			-.626	5.340	.557	-2.6837	4.2876
HADSANX	Equal variances assumed	1.086	.299	.099	163	.922	.1849	1.8740
	Equal variances not assumed			.135	4.507	.898	.1849	1.3669
HADSDEP	Equal variances assumed	.076	.784	-1.810	163	.072	-2.7836	1.5377
	Equal variances not assumed			-1.953	4.301	.118	-2.7836	1.4256

8.5. Appendix E. Demographic Questionnaire (Spinks, & Horn, 2003)

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Demographic Questionnaire Sheet (October 2002)

Illness perceptions and coping in people with MS.

N.B. Please write, circle or mark the answer you wish to give

1. How old are you? _____

2. Are you male or female? M / F

3. Ethnic Origin:
   a. Asian
   b. Black/African American
   c. Hispanic
   d. White/Caucasian
   e. Other
   f. Prefer not to answer

4. Do you have Multiple Sclerosis (MS) YES / NO

5. Has a neurologist diagnosed you with MS? YES / NO

6.a. How long have you had MS? _____

6.b. How long have you been diagnosed with MS? _____

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Measure of Symptoms

7. Which of the following statements most nearly describes your MS?

a. Symptoms get worse during an attack, stay bad for several days or more and then gradually improve. Some attacks result in permanent loss of ability.

b. Symptoms got worse after the first attack. Loss of abilities continues over time. There are no times of being symptom free.

c. Symptoms are relatively minor, the disease progresses so slowly that it seems to stay the same, or there are relatively few attacks for long periods of time. Recovery from attacks seems almost complete.

d. Symptoms started suddenly and quickly became very bad.

8. Do you get periods of time when you are free of symptoms? YES / NO

9. Are you symptom free now? YES / NO

10. If you have MS in episodes how many episodes of MS have you had in the last year? _____

11. How would you rate yourself compared to other people of a similar age who also have MS?

Better Worse The Same

8.6. Appendix F. IPQ-R (MS Version; Spinks, & Horn, 2003. Adapted from Moss-Morris, et al., 2002)

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

By Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002

(MS Version developed by Spinks & Horn, 2002)

Name..... *Date*.....

1. YOUR VIEWS ABOUT YOUR MS

Listed below are a number of symptoms that you may or may not have experienced since your MS. Please indicate by circling *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.

	I have experienced this symptom *since my MS*			This symptom is *related to my 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
Unusual Forgetfulness or Disorientation	Yes	No	_____	Yes	No
Tiredness or Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Continence problems	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
Eyesight Problems	Yes	No	_____	Yes	No
Loss of Sensation	Yes	No	_____	Yes	No
Muscle Aches	Yes	No	_____	Yes	No
Poor Co-ordination	Yes	No	_____	Yes	No
Speech and/or Eating Problems	Yes	No	_____	Yes	No
Other (Please Specify)					
.....	Yes	No	_____	Yes	No
.....	Yes	No	_____	Yes	No

IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my MS change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My MS is very unpredictable					
IP32	I go through cycles in which my MS gets better and worse.					
IP33	I get depressed when I think about my MS					
IP34	When I think about my MS I get upset					
IP35	My MS makes me feel angry					
IP36*	My MS does not worry me					
IP37	Having MS makes me feel anxious					
IP38	My MS makes me feel afraid					

3. CAUSES OF MY MS

We are interested in what <u>you</u> 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. Below is a list of possible causes for your MS. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	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 behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my MS					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					

2. We are interested in your own personal views of how you now see your MS.

Please indicate how much you agree or disagree with the following statements about your MS by ticking the appropriate box.

	VIEWS ABOUT YOUR MS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1*	My MS will last a short time					
IP2	My MS is likely to be permanent rather than temporary					
IP3	My MS will last for a long time					
IP4*	The MS will pass quickly					
IP5	I expect to have MS for the rest of my life					
IP6	My MS is a serious condition					
IP7	My MS has major consequences on my life					
IP8*	My MS does not have much effect on my life					
IP9	My MS strongly affects the way others see me					
IP10	My MS has serious financial consequences					
IP11	My MS causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my MS gets better or worse					
IP14	The course of my MS depends on me					
IP15*	Nothing I do will affect my MS					
IP16	I have the power to influence my MS					
IP17*	My actions will have no affect on the outcome of my MS					
IP18*	My MS will improve in time					
IP19*	There is very little that can be done to improve my MS					
IP20	My treatment will be effective in curing my MS					
IP21	The negative effects of my MS can be prevented (avoided) by my treatment					
IP22	My treatment can control my MS					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My MS is a mystery to me					
IP26	I don't understand my MS					
IP27	My MS doesn't make any sense to me					

C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity (ability to fight germs and viruses)					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR MS. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____

2. _____

3. _____

8.7. Appendix G. CRI (Moos, 1993)

NFER-NELSON
Health & Social Care
INFORMING YOUR DECISIONS

Coping Responses Inventory

This is your copy of the **Coping Responses Inventory**. *It contains questions about how you manage important problems that come up in your life.*

Please answer each question as accurately as you can. All your answers are strictly confidential. If you do not wish to answer a question, please circle the number of that question so that we know you have intentionally skipped it. If a question does not apply to you, please write 'N/A' (Not Applicable) in the margin next to the question.

We appreciate your cooperation.

What is your name? .....

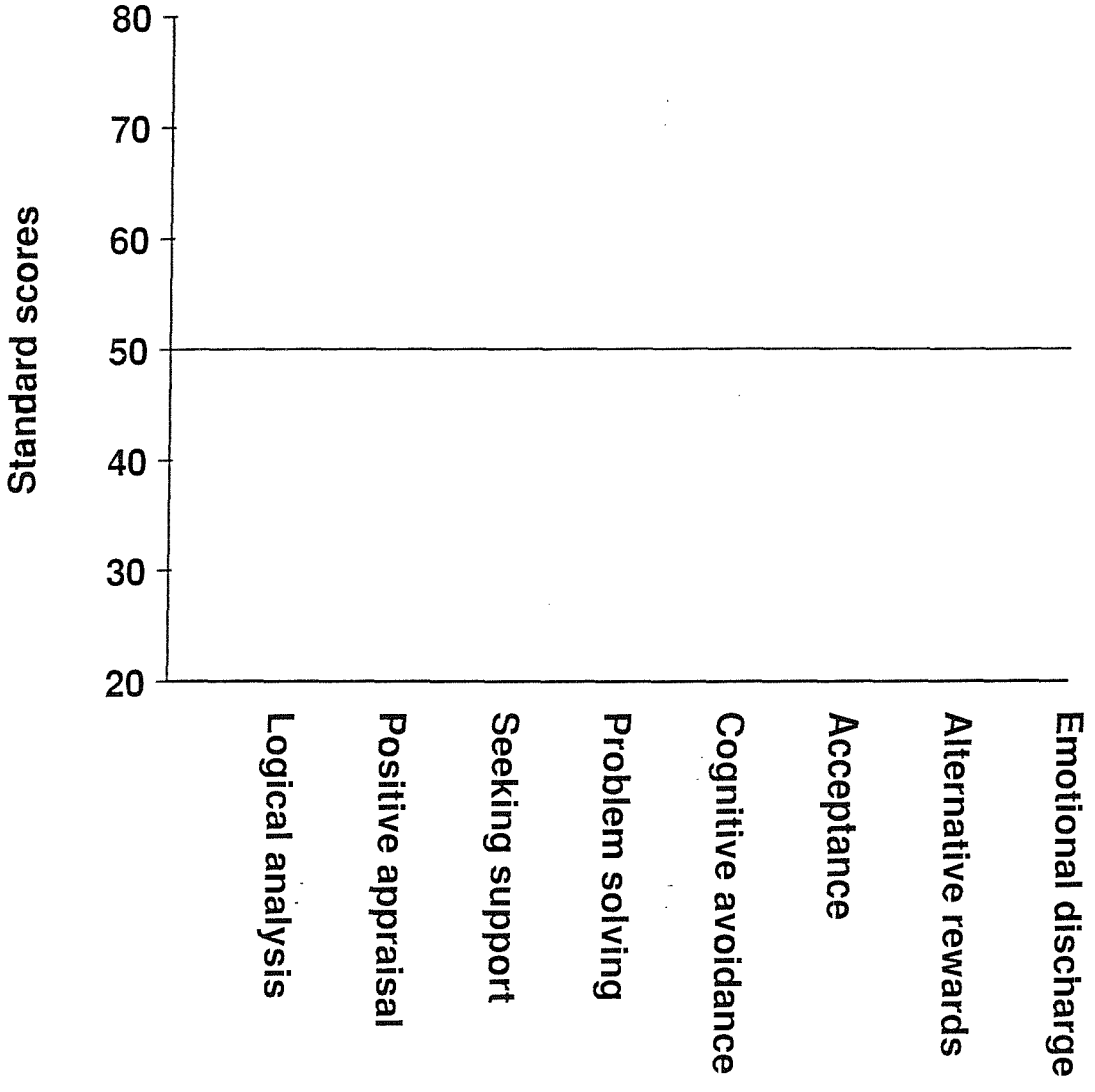
What is today's date? .....

NFER-NELSON
Health & Social Care
INFORMING YOUR DECISIONS

Coping Responses Inventory

Coping Profile Sheet

Name . . . . . Date . . . . . .



This measure is part of *Assessment: A Mental Health Portfolio*, edited by Derek Milne. Once the invoice has been paid, it may be photocopied for use **within the purchasing institution only**. Published by The NFER-NELSON Publishing Company Ltd, Darville House, 2 Oxford Road East, Windsor, Berkshire SL4 1DF, UK. Code 4900 08 4

Dealing with a problem or situation

Please think about the most important problem or stressful situation you have experienced *DURING THE LAST 12 MONTHS* (for example, having troubles with a relative or friend, experiencing the illness or death of a relative or friend, having an accident or illness, having financial or work problems). Describe the problem in the space provided below. If you have not experienced a major problem, then list a minor problem that you have had to deal with.

Describe the problem or situation . . . . . .

. . . . . .

. . . . . .

Part I

Please answer the following questions about the problem you have listed.
Place an 'X' in the appropriate box.

	Definitely No 0	Mainly No 1	Mainly Yes 2	Definitely Yes 3
1. Have you ever faced a problem like this before?	☐	☐	☐	☐
2. Did you know this problem was going to occur?	☐	☐	☐	☐
3. Did you have enough time to get ready to handle this problem?	☐	☐	☐	☐
4. When this problem occurred, did you think of it as a threat?	☐	☐	☐	☐
5. When this problem occurred, did you think of it as a challenge?	☐	☐	☐	☐
6. Was this problem caused by something you did?	☐	☐	☐	☐
7. Was this problem caused by something someone else did? . .	☐	☐	☐	☐
8. Did any thing good come out of dealing with this problem? . .	☐	☐	☐	☐
9. Has this problem or situation been resolved?	☐	☐	☐	☐
10. If the problem has been worked out, did it turn out all right for you?	☐	☐	☐	☐

Part II

Please think again about the problem you described at the beginning of this Inventory; indicate which of the following you did in connection with that situation.

Did you:	NO 0	YES, once or twice 1	YES, some-times 2	YES, fairly often 3
1. Think of different ways to deal with the problem?	☐	☐	☐	☐
2. Tell yourself things to make yourself feel better?	☐	☐	☐	☐
3. Talk with your partner or other relative about the problem?	☐	☐	☐	☐
4. Make a plan of action and follow it?	☐	☐	☐	☐
5. Try to forget the whole thing?	☐	☐	☐	☐
6. Feel that time would make a difference – the only thing to do was wait?	☐	☐	☐	☐
7. Try to help others deal with a similar problem?	☐	☐	☐	☐
8. Take it out on other people when you felt angry or depressed?	☐	☐	☐	☐
9. Try to step back from the situation and be more objective?	☐	☐	☐	☐
10. Remind yourself how much worse things could be?	☐	☐	☐	☐
11. Talk with a friend about the problem?	☐	☐	☐	☐
12. Know what had to be done and try hard to make things work?	☐	☐	☐	☐
13. Try not to think about the problem?	☐	☐	☐	☐
14. Realize that you had no control over the problem?	☐	☐	☐	☐
15. Get involved in new activities?	☐	☐	☐	☐
16. Take a chance and do something risky?	☐	☐	☐	☐
17. Go over in your mind what you would say or do?	☐	☐	☐	☐
18. Try to see the good side of the situation?	☐	☐	☐	☐
19. Talk with a professional person (e.g. doctor, lawyer, clergy)?	☐	☐	☐	☐
20. Decide what you wanted and try hard to get it?	☐	☐	☐	☐

Questions about how you handled the problem you described at the beginning of this Inventory (continued)

Did you:	NO 0	YES, once or twice 1	YES, some-times 2	YES, fairly often 3
21. Daydream or imagine a better time or place than the one you were in?	☐	☐	☐	☐
22. Think that the outcome would be decided by fate?	☐	☐	☐	☐
23. Try to make new friends?	☐	☐	☐	☐
24. Keep away from people in general?	☐	☐	☐	☐
25. Try to anticipate how things would turn out?	☐	☐	☐	☐
26. Think about how you were much better off than other people with similar problems?	☐	☐	☐	☐
27. Seek help from persons or groups with the same type of problem?	☐	☐	☐	☐
28. Try at least two different ways to solve the problem?	☐	☐	☐	☐
29. Try to put off thinking about the situation, even though you knew you would have to at some point?	☐	☐	☐	☐
30. Accept it; nothing could be done?	☐	☐	☐	☐
31. Read more often as a source of enjoyment?	☐	☐	☐	☐
32. Yell or shout to let off steam?	☐	☐	☐	☐
33. Try to find some personal meaning in the situation?	☐	☐	☐	☐
34. Try to tell yourself that things would get better?	☐	☐	☐	☐
35. Try to find out more about the situation?	☐	☐	☐	☐
36. Try to learn to do more things on your own?	☐	☐	☐	☐
37. Wish the problem would go away or somehow be over with?	☐	☐	☐	☐
38. Expect the worst possible outcome?	☐	☐	☐	☐
39. Spend more time in recreational activities?	☐	☐	☐	☐
40. Cry to let your feelings out?	☐	☐	☐	☐
41. Try to anticipate the new demands that would be placed on you?	☐	☐	☐	☐

Questions about how you handled the problem you described at the beginning of this Inventory (continued)

Did you:	NO 0	YES, once or twice 1	YES, some-times 2	YES, fairly often 3
42. Think about how this event could change your *life in a positive way?*	☐	☐	☐	☐
43. Pray for guidance and/or strength?	☐	☐	☐	☐
44. Take things a day at a time, one step at a time?	☐	☐	☐	☐
45. Try to deny how serious the problem really was?	☐	☐	☐	☐
46. Lose hope that things would ever be the same?	☐	☐	☐	☐
47. *Turn to work or other activities to help you manage things?*	☐	☐	☐	☐
48. Do something that you didn't think would work, but at *least you were doing something?*	☐	☐	☐	☐

This completes the Inventory. Thank you very much for your help.

8.8. Appendix H. Information Sheet and Consent Forms

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

Participant Information Sheet (October 2002)

Illness perceptions and coping in people with MS.

My name is Helen Spinks and I am in my final year of training to be a clinical psychologist. As part of the academic requirement of the Doctoral Programme in Clinical Psychology at the University of Southampton, I am required to conduct a research project. I have chosen to study how people with MS understand their disease and how this might affect how they manage their disease. I hope that this study will help professionals working with people with MS understand more about what is likely to be the most helpful support to offer.

I am therefore asking if you would be willing to take part in my research study. Before deciding whether to take part it is important for you to understand what the research is about and what you will need to do. Please take time to read the following information and do not hesitate to ask me if you have any questions regarding the research.

Thank you for your time and attention. Your help is much appreciated.

What is the study about?

The study is designed to provide information about what people with MS think about their illness and how they cope with it. Currently this seems to be an under-researched area.

Why have I been chosen?

For the study to be meaningful as many people over 18 as possible are being contacted. People will hear of the study either through the MS Therapy Centres or the MS Trust. People who agree to participate will complete the questionnaires.

Do I have to take part?

No, it is up to you to decide whether to take part. Deciding not to take part will not affect any treatment.

What will happen if I take part?

You will need to complete 3 anonymous questionnaires (1 each about coping, depression and beliefs about illness) and a brief questionnaire about yourself. These should take around 35 minutes to complete in total. A FREEPOST envelope that does not need a stamp will be provided for the questionnaires to be returned by post. If you are filling them out using the internet then they can be sent electronically using the website.

Completing and returning the questionnaire will be taken as evidence of your giving informed consent for your questionnaire answers to be used for the purposes of this study. This is so that you do not need to give your name.

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
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SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

Consent Form (October 2002)

Illness perceptions and coping in people with MS.

By completing and returning the attached questionnaires I give my consent for this information to be used in the above named study.

I have read the Participant Information Sheet YES / NO

I understand that participation/non-participation will not affect my care YES / NO

As it is intended that my data will be collected anonymously, the feedback will be a summary of the results available on the website, in the MS Trust newsletter, or at the MS therapy centres after October 2003.

If you have any questions regarding this study please contact:

Helen Spinks
Department of Clinical Psychology
University of Southampton
Highfield
Southampton
SO17 1BJ.

Telephone: 02380 595320

envelope that does not need a stamp will be provided for the questionnaires to be returned by post..

Completing and returning the questionnaire will be taken as evidence of your giving informed consent for your questionnaire answers to be used for the purposes of this study. This is so that you do not need to give your name. The study does not include any questionnaires that are designed to be distressing. However, it is possible that some people may find answering questions about their illness upsetting. If you feel upset after completing the questionnaires then please contact your usual sources of support to help you deal with this.

Will the information I provide be kept confidential?
All information will be collected anonymously and kept strictly confidential. The data will be stored anonymously on a non-networked, password protected computer. Paper questionnaires will be kept in a locked cabinet. Answers will be analysed as group data and individual participants will not be identifiable.

What will happen to the results of the study?
A dissertation using the data will be written and submitted to the university. An academic paper may be submitted for publication in a professional journal. A summary of the results will be available on the website **www.soton.ac.uk/hes500~,** via the MS Trust newsletter and the MS Therapy Centres after September 2003.

Who is organising and funding the research?
I am a trainee clinical psychologist at the University of Southampton Doctoral Programme in Clinical Psychology. This research is conducted as part of my training and is supervised by a qualified psychologist employed by the university.

Who has reviewed the study to protect the participants?
The Department of Psychology Research Ethics Committee at the University of Southampton has approved the study as being ethical.

If you would like to take part in this study and need questionnaires (or if you have questions about taking part) then please contact:

By post: Clinical Psychology (HSp),
FREEPOST SO286
University of Southampton
Southampton SO17 1YN

By email: spinksmsresearch@aol.com

Questionnaires will be sent to you on request with an addressed freepost envelope for return by 15 January 2003.

If you have any questions about your rights as a participant in this research, or you feel that you have been placed at risk, you can contact: The Chair of the Ethics Committee, Department of Psychology, University of Southampton, Highfield, Southampton SO17 1BJ. Tel: 02380 593995

8.9. Appendix I. Confirmatory Principle Component Analysis of CRI using original factor labels and items.

Item*	I	II	III	IV	V	VI	VII	VIII
Logical Analysis (alpha = .69)								
Think of different ways to cope	**.61**	.00	-.13	.21	.13	.00	.15	.00
Step back and be objective	**.59**	.26	-.38	.00	.19	.00	.00	.00
Go over what to say or do	**.57**	-.10	.00	.17	.00	.00	.15	.21
Try to anticipate end result	**.60**	.00	.17	.00	.25	-.12	.11	.18
Look for personal meaning	**.58**	.25	.11	.00	.00	.26	.00	.00
Anticipate new demands	**.52**	.00	.17	.00	.00	.00	.22	.00
Positive Appraisal (alpha = .77)								
Make yourself feel better	**.50**	.13	.00	.00	.00	.16	.00	**.61**
Things could be worse	**.32**	.20	.00	.11	**.64**	.00	.00	.00
See good side	**.59**	.29	-.23	-.16	.31	.00	.00	.00
You are better off than others	**.35**	.16	.00	.00	**.54**	.00	.00	.00
Things will get better	.27	.00	.13	.00	**.69**	.00	.00	.00
Change could be positive	**.67**	.21	.00	-.11	.12	.00	-.11	.00
Seek Support (alpha = .61)								
Talk to partner or relative	.14	.00	.00	.00	.00	.16	.00	**.61**
Talk to a friend	.22	.22	.11	-.13	.00	.00	.21	**.58**
Talk with a professional person	.10	.00	**.35**	.00	.00	-.19	**.38**	**.36**
Use people or groups with same problem	.24	**.46**	.15	.19	.00	-.24	.13	.27
Try to find out more	**.38**	.00	.27	.00	.22	-.14	.41	.00
Pray for guidance	.00	.00	.00	.00	.00	.16	**.66**	.16
Problem Solve (alpha = .73)								
Make a plan of action	**.64**	.16	-.15	-.21	.22	.00	.00	.21
Try hard to make things work	**.52**	.11	-.16	-.23	.19	.12	.24	.00
Try to get what you want	**.57**	.20	.15	-.14	.00	-.28	.19	-.18
Try two different solutions	**.49**	.28	.15	.00	.00	-.28	.17	-.27
Learn to do more things alone	**.40**	**.32**	**.30**	.14	.16	-.21	.21	-.28
Take things a day at a time	.29	.00	.00	.00	.00	.22	**.53**	.00
Cognitive Avoidance (alpha = .71)								
Try to forget whole thing	.00	.00	.00	**.70**	.00	.00	.00	.00
Try not to think about it	.00	.10	-.16	**.71**	.00	.00	.00	.00
Daydream	.14	.00	**.33**	.22	**.50**	.20	.00	.12
Put off thinking about it	.00	.00	.26	**.70**	.00	.00	.00	.00
Wish it would go away	.00	.13	**.36**	**.41**	.00	.00	.25	.00
Deny seriousness	.00	.00	.18	**.53**	.00	.10	.00	-.11
Resignation (Alpha = .67)								
Time will make a difference	-.13	.00	.00	.12	**.34**	**.50**	**.33**	-.21
Have no control over problem	-.28	.00	.15	.19	.18	**.54**	**.38**	.00
Fate will decide	.23	.00	.21	.14	.00	**.70**	.11	.00
Accept it	.00	.00	.00	.00	.00	**.69**	.00	.14
Expect the worst	.00	-.17	**.39**	.27	-.40	**.34**	.00	.11
Loose hope	.00	.00	**.32**	**.36**	-.36	**.35**	.00	-.10
Alternative Rewards (alpha = .78)								
Try to help others	.18	.21	-.18	.00	.00	-.12	**.49**	.00
Start new activities	.00	**.81**	.00	.00	.00	.00	.00	-.18
Make new friends	.00	**.75**	.00	.00	.18	.00	.00	.00
Read more for pleasure	.12	**.55**	.00	.24	.24	.00	.00	.11
Spend more time in recreation	.12	**.77**	.00	.00	.11	.00	.00	.00
Turn to work	.28	**.67**	-.11	.10	-.18	.00	.13	.11
Emotional Discharge (alpha = .61)								
Take it out on other people	.00	.00	**.77**	.10	.10	.00	.00	.00
Take a chance	.28	.27	.22	-.21	-.11	.15	.00	-.41
Keep away from people	.00	.00	**.33**	**.36**	.00	.00	.00	.11
Yell to let off steam	.00	.12	**.75**	.00	.00	.00	.00	.00
Cry	.00	.00	**.47**	.22	-.11	.27	.21	**.32**
Do something that you don't think will work	.23	**.45**	.25	.27	-.15	.16	.00	-.14

* Items not given in full. See Appendix G for full description.

8.10. Appendix J. Principal Component Analysis of CRI using new factor labels.

Item*	I	II	III	IV	V	VI	VII	VIII
Practical Approaches (alpha .86)								
Think of different ways to cope	**.61**	.00	-.13	.21	.13	.00	.15	.00
Step back and be objective	**.59**	.26	-.38	.00	.19	.00	.00	.00
Go over what to say or do	**.57**	-.10	.00	.17	.00	.00	.15	.21
Try to anticipate end result	**.60**	.00	.17	.00	.25	-.12	.11	.18
Look for personal meaning	**.58**	.25	.11	.00	.00	.26	.00	.00
Anticipate new demands	**.52**	.00	.17	.00	.00	.00	.22	.00
See good side	**.59**	.29	-.23	-.16	.31	.00	.00	.00
Change could be positive	**.67**	.21	.00	-.11	.12	.00	-.11	.00
Try to find out more	**.38**	.00	.27	.00	.22	-.14	.41	.00
Make a plan of action	**.64**	.16	-.15	-.21	.22	.00	.00	.21
Try hard to make things work	**.52**	.11	-.16	-.23	.19	.12	.24	.00
Try to get what you want	**.57**	.20	.15	-.14	.00	-.28	.19	-.18
Try two different solutions	**.49**	.28	.15	.00	.00	-.28	.17	-.27
Learn to do more things alone	**.40**	**.32**	**.30**	.14	.16	-.21	.21	-.28
Social Approaches (alpha .81)								
Use people or groups with same problem	.24	**.46**	.15	.19	.00	-.24	.13	.27
Start new activities	.00	**.81**	.00	.00	.00	.00	.00	-.18
Make new friends	.00	**.75**	.00	.00	.18	.00	.00	.00
Read more for pleasure	.12	**.55**	.00	.24	.24	.00	.00	.11
Spend more time in recreation	.12	**.77**	.00	.00	.11	.00	.00	.00
Turn to work	.28	**.67**	-.11	.10	-.18	.00	.13	.11
Do something that you don't think will work	.23	**.45**	.25	.27	-.15	.16	.00	-.14
Emotional Discharge (alpha .65 excluding *)								
Yell to let off steam	.00	.12	**.75**	.00	.00	.00	.00	.00
Cry	.00	.00	**.47**	.22	-.11	.27	.21	**.32**
Take it out on other people	.00	.00	**.77**	.10	.10	.00	.00	.00
Expect the worst*	.00	-.17	**.39**	.27	-.40	**.34**	.00	.11
Avoidance (alpha = .71 excluding *)								
Try to forget whole thing	.00	.00	.00	**.70**	.00	.00	.00	.00
Try not to think about it	.00	.10	-.16	**.71**	.00	.00	.00	.00
Put off thinking about it	.00	.00	.26	**.70**	.00	.00	.00	.00
Wish it would go away	.00	.13	**.36**	**.41**	.00	.00	.25	.00
Deny seriousness	.00	.00	.18	**.53**	.00	.10	.00	-.11
Loose hope *	.00	.00	**.32**	**.36**	-.36	**.35**	.00	-.10
Keep away from people	.00	.00	**.33**	**.36**	.00	.00	.00	.11
Wishful Thinking (alpha = .68)								
Daydream	.14	.00	**.33**	.22	**.50**	.20	.00	.12
You are better off than others	**.35**	.16	.00	.00	**.54**	.00	.00	.00
Things will get better	.27	.00	.13	.00	**.69**	.00	.00	.00
Things could be worse	**.32**	.20	.00	.11	**.64**	.00	.00	.00
Fatalism (alpha =.66)								
Time will make a difference	-.13	.00	.00	.12	**.34**	**.50**	**.33**	-.21
Have no control over problem	-.28	.00	.15	.19	.18	**.54**	**.38**	.00
Fate will decide	.23	.00	.21	.14	.00	**.70**	.11	.00
Accept it	.00	.00	.00	.00	.00	**.69**	.00	.14
Good Samaritan (alpha = .50)								
Try to help others	.18	.21	-.18	.00	.00	-.12	**.49**	.00
Take things a day at a time	.29	.00	.00	.00	.00	.22	**.53**	.00
Pray for guidance	.00	.00	.00	.00	.00	.16	**.66**	.16
Talk with a professional person	.10	.00	**.35**	.00	.00	-.19	**.38**	**.36**
Social Support (alpha = .44)								
Talk to partner or relative	.14	.00	.00	.00	.00	.16	.00	**.61**
Talk to a friend	.22	.22	.11	-.13	.00	.00	.21	**.58**

• Items not given in full. See Appendix G for full description.

8.11. Appendix K.

Correlations[a]

		AGE	HADSANX	HADSDEP	identity	MISTIME
AGE	Pearson Correlation	1.000	-.104	-.006	-.100	.102
	Sig. (2-tailed)	.	.194	.939	.211	.200
HADSANX	Pearson Correlation	-.104	1.000	.539**	.369**	.095
	Sig. (2-tailed)	.194	.	.000	.000	.235
HADSDEP	Pearson Correlation	-.006	.539**	1.000	.284**	.106
	Sig. (2-tailed)	.939	.000	.	.000	.184
identity	Pearson Correlation	-.100	.369**	.284**	1.000	.176*
	Sig. (2-tailed)	.211	.000	.000	.	.026
MISTIME	Pearson Correlation	.102	.095	.106	.176*	1.000
	Sig. (2-tailed)	.200	.235	.184	.026	.
MISCYCLE	Pearson Correlation	-.198*	.133	-.128	.204**	-.164*
	Sig. (2-tailed)	.012	.095	.108	.010	.039
MISCONSE	Pearson Correlation	.105	.250**	.446**	.326**	.462**
	Sig. (2-tailed)	.189	.002	.000	.000	.000
MISPERS	Pearson Correlation	-.210**	-.099	-.239**	-.059	-.300**
	Sig. (2-tailed)	.008	.214	.002	.464	.000
MISTREAT	Pearson Correlation	-.240**	-.111	-.184*	-.013	-.286**
	Sig. (2-tailed)	.002	.165	.020	.870	.000
MISILLCO	Pearson Correlation	.031	.203*	.186*	.153	-.172*
	Sig. (2-tailed)	.695	.010	.019	.053	.030
MISEMOTI	Pearson Correlation	-.303**	.491**	.383**	.215**	.066
	Sig. (2-tailed)	.000	.000	.000	.007	.407
MISLOGAN	Pearson Correlation	-.048	.178*	.060	.165*	.072
	Sig. (2-tailed)	.551	.025	.451	.038	.368
MISPOSAP	Pearson Correlation	-.198*	.025	-.097	.133	-.018
	Sig. (2-tailed)	.012	.752	.226	.094	.820
MISSUPPO	Pearson Correlation	.061	.195*	.154	.199*	-.078
	Sig. (2-tailed)	.441	.014	.053	.012	.329
MISPROB	Pearson Correlation	.027	.129	.086	.189*	.014
	Sig. (2-tailed)	.736	.104	.282	.017	.858
MISCOGAV	Pearson Correlation	-.217**	.343**	.259**	.271**	-.137
	Sig. (2-tailed)	.006	.000	.001	.001	.085
MISRESIG	Pearson Correlation	-.112	.298**	.235**	.141	-.087
	Sig. (2-tailed)	.158	.000	.003	.075	.276
MISALTRE	Pearson Correlation	-.081	.023	-.090	.005	-.178*
	Sig. (2-tailed)	.310	.775	.262	.953	.024
MISEMOT	Pearson Correlation	-.303**	.491**	.383**	.215**	.066
	Sig. (2-tailed)	.000	.000	.000	.007	.407

Correlations[a]

		MISCYCLE	MISCONSE	MISPERS	MISTREAT	MISILLCO
AGE	Pearson Correlation	-.198*	.105	-.210**	-.240**	.031
	Sig. (2-tailed)	.012	.189	.008	.002	.695
HADSANX	Pearson Correlation	.133	.250**	-.099	-.111	.203*
	Sig. (2-tailed)	.095	.002	.214	.165	.010
HADSDEP	Pearson Correlation	-.128	.446**	-.239**	-.184*	.186*
	Sig. (2-tailed)	.108	.000	.002	.020	.019
identity	Pearson Correlation	.204**	.326**	-.059	-.013	.153
	Sig. (2-tailed)	.010	.000	.464	.870	.053
MISTIME	Pearson Correlation	-.164*	.462**	-.300**	-.286**	-.172*
	Sig. (2-tailed)	.039	.000	.000	.000	.030
MISCYCLE	Pearson Correlation	1.000	-.142	.240**	.219**	.178*
	Sig. (2-tailed)	.	.074	.002	.005	.025
MISCONSE	Pearson Correlation	-.142	1.000	-.339**	-.348**	.143
	Sig. (2-tailed)	.074	.	.000	.000	.072
MISPERS	Pearson Correlation	.240**	-.339**	1.000	.616**	.000
	Sig. (2-tailed)	.002	.000	.	.000	.997
MISTREAT	Pearson Correlation	.219**	-.348**	.616**	1.000	-.025
	Sig. (2-tailed)	.005	.000	.000	.	.755
MISILLCO	Pearson Correlation	.178*	.143	.000	-.025	1.000
	Sig. (2-tailed)	.025	.072	.997	.755	.
MISEMOTI	Pearson Correlation	.086	.124	-.033	.002	.173*
	Sig. (2-tailed)	.282	.121	.684	.980	.030
MISLOGAN	Pearson Correlation	.091	.052	.151	.054	-.092
	Sig. (2-tailed)	.256	.515	.057	.502	.251
MISPOSAP	Pearson Correlation	.173*	-.073	.268**	.150	-.032
	Sig. (2-tailed)	.030	.357	.001	.058	.686
MISSUPPO	Pearson Correlation	.089	.034	.093	.097	.031
	Sig. (2-tailed)	.263	.673	.243	.224	.694
MISPROB	Pearson Correlation	.032	.148	.098	.092	-.026
	Sig. (2-tailed)	.685	.063	.219	.249	.743
MISCOGAV	Pearson Correlation	.169*	.011	.092	.072	.237**
	Sig. (2-tailed)	.033	.888	.247	.368	.003
MISRESIG	Pearson Correlation	.090	.068	-.211**	-.179*	.123
	Sig. (2-tailed)	.257	.394	.008	.024	.124
MISALTRE	Pearson Correlation	.057	-.076	.174*	.183*	-.014
	Sig. (2-tailed)	.476	.340	.028	.021	.859
MISEMOT	Pearson Correlation	.086	.124	-.033	.002	.173*
	Sig. (2-tailed)	.282	.121	.684	.980	.030

Correlations[a]

		MISEMOTI	MISLOGAN	MISPOSAP	MISSUPPO	MISPROB
AGE	Pearson Correlation	-.303**	-.048	-.198*	.061	.027
	Sig. (2-tailed)	.000	.551	.012	.441	.736
HADSANX	Pearson Correlation	.491**	.178*	.025	.195*	.129
	Sig. (2-tailed)	.000	.025	.752	.014	.104
HADSDEP	Pearson Correlation	.383**	.060	-.097	.154	.086
	Sig. (2-tailed)	.000	.451	.226	.053	.282
identity	Pearson Correlation	.215**	.165*	.133	.199*	.189*
	Sig. (2-tailed)	.007	.038	.094	.012	.017
MISTIME	Pearson Correlation	.066	.072	-.018	-.078	.014
	Sig. (2-tailed)	.407	.368	.820	.329	.858
MISCYCLE	Pearson Correlation	.086	.091	.173*	.089	.032
	Sig. (2-tailed)	.282	.256	.030	.263	.685
MISCONSE	Pearson Correlation	.124	.052	-.073	.034	.148
	Sig. (2-tailed)	.121	.515	.357	.673	.063
MISPERS	Pearson Correlation	-.033	.151	.268**	.093	.098
	Sig. (2-tailed)	.684	.057	.001	.243	.219
MISTREAT	Pearson Correlation	.002	.054	.150	.097	.092
	Sig. (2-tailed)	.980	.502	.058	.224	.249
MISILLCO	Pearson Correlation	.173*	-.092	-.032	.031	-.026
	Sig. (2-tailed)	.030	.251	.686	.694	.743
MISEMOTI	Pearson Correlation	1.000	.220**	.078	.319**	.187*
	Sig. (2-tailed)	.	.005	.326	.000	.018
MISLOGAN	Pearson Correlation	.220**	1.000	.612**	.445**	.652**
	Sig. (2-tailed)	.005	.	.000	.000	.000
MISPOSAP	Pearson Correlation	.078	.612**	1.000	.331**	.605**
	Sig. (2-tailed)	.326	.000	.	.000	.000
MISSUPPO	Pearson Correlation	.319**	.445**	.331**	1.000	.466**
	Sig. (2-tailed)	.000	.000	.000	.	.000
MISPROB	Pearson Correlation	.187*	.652**	.605**	.466**	1.000
	Sig. (2-tailed)	.018	.000	.000	.000	.
MISCOGAV	Pearson Correlation	.374**	.142	.208**	.157*	.132
	Sig. (2-tailed)	.000	.074	.009	.048	.097
MISRESIG	Pearson Correlation	.365**	.064	-.003	.163*	-.017
	Sig. (2-tailed)	.000	.421	.967	.040	.836
MISALTRE	Pearson Correlation	.283**	.388**	.453**	.356**	.493**
	Sig. (2-tailed)	.000	.000	.000	.000	.000
MISEMOT	Pearson Correlation	1.000**	.220**	.078	.319**	.187*
	Sig. (2-tailed)	.000	.005	.326	.000	.018

Correlations[a]

		MISCOGAV	MISRESIG	MISALTRE	MISEMOT
AGE	Pearson Correlation	-.217**	-.112	-.081	-.303**
	Sig. (2-tailed)	.006	.158	.310	.000
HADSANX	Pearson Correlation	.343**	.298**	.023	.491**
	Sig. (2-tailed)	.000	.000	.775	.000
HADSDEP	Pearson Correlation	.259**	.235**	-.090	.383**
	Sig. (2-tailed)	.001	.003	.262	.000
identity	Pearson Correlation	.271**	.141	.005	.215**
	Sig. (2-tailed)	.001	.075	.953	.007
MISTIME	Pearson Correlation	-.137	-.087	-.178*	.066
	Sig. (2-tailed)	.085	.276	.024	.407
MISCYCLE	Pearson Correlation	.169*	.090	.057	.086
	Sig. (2-tailed)	.033	.257	.476	.282
MISCONSE	Pearson Correlation	.011	.068	-.076	.124
	Sig. (2-tailed)	.888	.394	.340	.121
MISPERS	Pearson Correlation	.092	-.211**	.174*	-.033
	Sig. (2-tailed)	.247	.008	.028	.684
MISTREAT	Pearson Correlation	.072	-.179*	.183*	.002
	Sig. (2-tailed)	.368	.024	.021	.980
MISILLCO	Pearson Correlation	.237**	.123	-.014	.173*
	Sig. (2-tailed)	.003	.124	.859	.030
MISEMOTI	Pearson Correlation	.374**	.365**	.283**	1.000**
	Sig. (2-tailed)	.000	.000	.000	.000
MISLOGAN	Pearson Correlation	.142	.064	.388**	.220**
	Sig. (2-tailed)	.074	.421	.000	.005
MISPOSAP	Pearson Correlation	.208**	-.003	.453**	.078
	Sig. (2-tailed)	.009	.967	.000	.326
MISSUPPO	Pearson Correlation	.157*	.163*	.356**	.319**
	Sig. (2-tailed)	.048	.040	.000	.000
MISPROB	Pearson Correlation	.132	-.017	.493**	.187*
	Sig. (2-tailed)	.097	.836	.000	.018
MISCOGAV	Pearson Correlation	1.000	.383**	.237**	.374**
	Sig. (2-tailed)	.	.000	.003	.000
MISRESIG	Pearson Correlation	.383**	1.000	-.004	.365**
	Sig. (2-tailed)	.000	.	.958	.000
MISALTRE	Pearson Correlation	.237**	-.004	1.000	.283**
	Sig. (2-tailed)	.003	.958	.	.000
MISEMOT	Pearson Correlation	.374**	.365**	.283**	1.000
	Sig. (2-tailed)	.000	.000	.000	.

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

8.12. *Appendix L. GLM Multivariate analysis results with symptom free participants excluded (n=140)*

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	identity	266.692	4	66.673	6.893	.000
	MISTIME	162.657	4	40.664	3.341	.012
	MISCYCLE	502.839	4	125.710	9.407	.000
	MISCONSE	669.847	4	167.462	12.733	.000
	MISPERS	336.484	4	84.121	3.297	.013
	MISTREAT	105.252	4	26.313	1.697	.154
	MISILLCO	164.570	4	41.143	1.821	.128
	MISEMOTI	453.933	4	113.483	14.174	.000
	TREATMEN	756.079	4	189.020	2.953	.022
	MISLOGAN	218.418	4	54.605	3.046	.019
	MISPOSAP	160.986	4	40.247	1.806	.131
	MISSUPPO	106.723	4	26.681	1.728	.147
	MISPROB	46.674	4	11.668	.587	.673
	MISCOGAV	293.109	4	73.277	5.644	.000
	MISRESIG	305.057	4	76.264	4.786	.001
	MISALTRE	46.997	4	11.749	.583	.676
	MISEMOT	453.933	4	113.483	14.174	.000
Intercept	identity	2506.329	1	2506.329	259.131	.000
	MISTIME	18674.836	1	18674.836	1534.425	.000
	MISCYCLE	3730.761	1	3730.761	279.166	.000
	MISCONSE	12928.553	1	12928.553	982.992	.000
	MISPERS	11432.971	1	11432.971	448.098	.000
	MISTREAT	5764.374	1	5764.374	371.807	.000
	MISILLCO	2872.303	1	2872.303	127.110	.000
	MISEMOTI	22.804	1	22.804	2.848	.094
	TREATMEN	33433.591	1	33433.591	522.303	.000
	MISLOGAN	2000.417	1	2000.417	111.593	.000
	MISPOSAP	2509.546	1	2509.546	112.638	.000
	MISSUPPO	1567.861	1	1567.861	101.525	.000
	MISPROB	2514.457	1	2514.457	126.492	.000
	MISCOGAV	282.145	1	282.145	21.732	.000
	MISRESIG	447.780	1	447.780	28.099	.000
	MISALTRE	727.406	1	727.406	36.066	.000
	MISEMOT	22.804	1	22.804	2.848	.094
HADSANX	identity	123.211	1	123.211	12.739	.000
	MISTIME	11.700	1	11.700	.961	.329
	MISCYCLE	121.570	1	121.570	9.097	.003
	MISCONSE	1.920	1	1.920	.146	.703
	MISPERS	2.018	1	2.018	.079	.779
	MISTREAT	1.683	1	1.683	.109	.742
	MISILLCO	13.297	1	13.297	.588	.444

	MISEMOTI	103.313	1	103.313	12.904	.000
	TREATMEN	1.518E-02	1	1.518E-02	.000	.988
	MISLOGAN	109.608	1	109.608	6.114	.015
	MISPOSAP	34.115	1	34.115	1.531	.218
	MISSUPPO	24.542	1	24.542	1.589	.210
	MISPROB	31.422	1	31.422	1.581	.211
	MISCOGAV	93.608	1	93.608	7.210	.008
	MISRESIG	39.018	1	39.018	2.448	.120
	MISALTRE	10.580	1	10.580	.525	.470
	MISEMOT	103.313	1	103.313	12.904	.000
HADSDEP	identity	.544	1	.544	.056	.813
	MISTIME	3.736	1	3.736	.307	.580
	MISCYCLE	52.049	1	52.049	3.895	.050
	MISCONSE	92.006	1	92.006	6.995	.009
	MISPERS	45.441	1	45.441	1.781	.184
	MISTREAT	4.471	1	4.471	.288	.592
	MISILLCO	62.069	1	62.069	2.747	.100
	MISEMOTI	93.761	1	93.761	11.711	.001
	TREATMEN	78.420	1	78.420	1.225	.270
	MISLOGAN	6.735	1	6.735	.376	.541
	MISPOSAP	60.949	1	60.949	2.736	.100
	MISSUPPO	12.983	1	12.983	.841	.361
	MISPROB	4.199	1	4.199	.211	.647
	MISCOGAV	29.379	1	29.379	2.263	.135
	MISRESIG	88.135	1	88.135	5.531	.020
	MISALTRE	22.270	1	22.270	1.104	.295
	MISEMOT	93.761	1	93.761	11.711	.001
TYPE	identity	102.959	2	51.480	5.323	.006
	MISTIME	141.577	2	70.789	5.816	.004
	MISCYCLE	375.813	2	187.906	14.061	.000
	MISCONSE	346.697	2	173.349	13.180	.000
	MISPERS	197.925	2	98.963	3.879	.023
	MISTREAT	72.598	2	36.299	2.341	.100
	MISILLCO	5.105	2	2.552	.113	.893
	MISEMOTI	15.416	2	7.708	.963	.384
	TREATMEN	468.744	2	234.372	3.661	.028
	MISLOGAN	127.663	2	63.832	3.561	.031
	MISPOSAP	112.427	2	56.213	2.523	.084
	MISSUPPO	41.881	2	20.941	1.356	.261
	MISPROB	20.909	2	10.455	.526	.592
	MISCOGAV	24.957	2	12.479	.961	.385
	MISRESIG	68.899	2	34.449	2.162	.119
	MISALTRE	28.330	2	14.165	.702	.497
	MISEMOT	15.416	2	7.708	.963	.384
Error	identity	1305.729	135	9.672		
	MISTIME	1643.028	135	12.171		
	MISCYCLE	1804.133	135	13.364		
	MISCONSE	1775.553	135	13.152		
	MISPERS	3444.451	135	25.514		
	MISTREAT	2092.998	135	15.504		

		MISILLCO	3050.601135	22.597
		MISEMOTI	1080.888135	8.007
		TREATMEN	8641.607135	64.012
		MISLOGAN	2420.003135	17.926
		MISPOSAP	3007.757135	22.280
		MISSUPPO	2084.820135	15.443
		MISPROB	2683.576135	19.878
		MISCOGAV	1752.684135	12.983
		MISRESIG	2151.343135	15.936
		MISALTRE	2722.796135	20.169
		MISEMOT	1080.888135	8.007
Total		identity	21279.000140	
		MISTIME	101824.000140	
		MISCYCLE	22756.000140	
		MISCONSE	85114.000140	
		MISPERS	54969.000140	
		MISTREAT	28667.000140	
		MISILLCO	24692.000140	
		MISEMOTI	4415.000140	
		TREATMEN	160672.000140	
		MISLOGAN	16459.000140	
		MISPOSAP	15166.000140	
		MISSUPPO	13676.000140	
		MISPROB	17439.000140	
		MISCOGAV	7243.000140	
		MISRESIG	8930.000140	
		MISALTRE	6141.000140	
		MISEMOT	4415.000140	
Corrected Total		identity	1572.421139	
		MISTIME	1805.686139	
		MISCYCLE	2306.971139	
		MISCONSE	2445.400139	
		MISPERS	3780.936139	
		MISTREAT	2198.250139	
		MISILLCO	3215.171139	
		MISEMOTI	1534.821139	
		TREATMEN	9397.686139	
		MISLOGAN	2638.421139	
		MISPOSAP	3168.743139	
		MISSUPPO	2191.543139	
		MISPROB	2730.250139	
		MISCOGAV	2045.793139	
		MISRESIG	2456.400139	
		MISALTRE	2769.793139	
		MISEMOT	1534.821139	

a R Squared = .170 (Adjusted R Squared = .145)
b R Squared = .090 (Adjusted R Squared = .063)
c R Squared = .218 (Adjusted R Squared = .195)
d R Squared = .274 (Adjusted R Squared = .252)
e R Squared = .089 (Adjusted R Squared = .062)

f R Squared = .048 (Adjusted R Squared = .020)
g R Squared = .051 (Adjusted R Squared = .023)
h R Squared = .296 (Adjusted R Squared = .275)
i R Squared = .080 (Adjusted R Squared = .053)
j R Squared = .083 (Adjusted R Squared = .056)
k R Squared = .049 (Adjusted R Squared = .021)
l R Squared = .017 (Adjusted R Squared = -.012)
m R Squared = .143 (Adjusted R Squared = .118)
n R Squared = .124 (Adjusted R Squared = .098)

8.13. Appendix M. Table of partial correlational analysis for variables with depression and anxiety as covariants

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Identity															
2. Timeline	.16														
3. Timeline cyclical	**.19***	.15													
4. Consequence	**.25****	**.46****	**-.18***												
5. Personal Control	.02	**-.27****	**.18***	**-.25****											
6. Treatment Control	.03	**-.26****	**.17***	**-.28****	**.58****										
7. Illness Coherence	.08	**-.21****	**.20***	.11	.05	.02									
8. Emotional Perceptions	.00	.05	.01	.10	-.01	.02	.10								
9. Logical Analysis	.11	.06	.06	-.01	**.16***	.06	-.14	**.16***							
10. Positive Appraisal	.14	.01	.12	-.05	**.22****	.10	-.01	.04	**.62****						
11. Seek Support	.14	.11	.07	-.03	.15	**.16***	-.01	**.29****	**.43****	**.37****					
12. Problem Solve	.16	.00	.03	.11	.13	.14	-.04	**.16***	**.65****	**.63****	**.45****				
13. Cognitive Avoidance	.14	**.17***	.08	-.04	.12	.08	**.19***	**19***	.07	**.20***	.10	.10			
14. Resignation	.02	-.10	.03	-.03	**-.20***	**-.17***	.07	**.24****	.02	-.02	.12	-.06	**.30****		
15. Alternative Reward	.00	**-.16***	.01	-.03	.14	**.16***	-.00	**.33****	**.39****	**.44****	**.38****	**.51****	**.25****	-.01	
16. Emotional Discharge	.00	.08	-.06	-.03	-.01	.02	.10	**1.0****	**.16***	.04	**.29****	**.16***	**.19***	**.24****	**.33****

N = 158 * = $p < .05$ ** = $p < .01$

Means

Identity	11.69 (S.D. 3.56)	Logical Analysis	9.90 (S.D. 4.18)
Timeline	26.52 (S.D. 3.67)	Positive Appraisal	9.49 (S.D. 4.67)
Timeline Cyclical	12.34 (S.D. 4.09)	Seek Support	9.07 (S.D. 4.01)
Consequences	23.75 (S.D. 4.59)	Problem Solve	10.11 (S.D. 4.48)
Personal Control	19.41 (S.D. 5.81)	Cognitive Avoidance	6.31 (S.D. 4.05)
Treatment Control	14.08 (S.D. 3.99)	Resignation	6.95 (S.D. 4.25)
Illness Coherence	12.38 (S.D. 4.86)	Alternative Rewards	5.30 (S.D. 4.67)
Emotions	4.82 (S.D. 3.86)	Emotional Discharge	4.82 (S.D. 3.56)