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FACULTY OF SOCIAL AND HUMAN SCIENCES

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Factors and Processes involved in Adjustment to Multiple Sclerosis

by

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ABSTRACT

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FACTORS AND PROCESSES INVOLVED IN ADJUSTMENT TO MULTIPLE SCLEROSIS

By Laura Dennison

Multiple sclerosis (MS) creates numerous ongoing challenges which, for some, result in negative outcomes such as depression, poor quality of life, and impaired functioning. This thesis aimed to investigate the nature of psychological adjustment to MS and elucidate factors that interventions could address in order to promote successful adjustment. A review of the theoretical literature on chronic illness and a systematic review of the empirical MS literature suggested that various theoretical approaches are useful for explaining aspects of adjustment to MS but no single existing theory offered a comprehensive framework. An integrative cognitive behavioural model of adjustment to MS was proposed and elements of this were examined in the empirical chapters.

In an initial qualitative study, people with MS (*n*=30) were interviewed about their experiences of living with the disease. Inductively-derived themes characterised the context and process of adjustment and the resources, actions, thoughts and feelings that have a bearing on it. Findings supported and elaborated on the model, and new insights were used to revise it. The quantitative studies were nested within a trial of interventions for adjustment to MS (*n*=94). A cross-sectional study using pre-therapy data found that cognitive and behavioural variables explained substantial variance in distress and functional impairment. Unhelpful beliefs and behaviours relating to MS itself (illness perceptions and responses to symptoms) appeared most relevant for explaining functional impairment. Beliefs about the self and about experiencing and sharing emotions were important correlates of distress. In an analysis of change within the treatment trial, reductions in unhelpful cognitions and behaviours mediated the improvements observed within interventions. Cognitive and behavioural variables also moderated the effects of the interventions on outcomes. A final qualitative study (*n*=30) explored participants' experiences of the adjustment interventions. The set of interlinked themes provided insights into the broad range of positive outcomes of interventions, perceived therapeutic processes and factors that appear to promote engagement in interventions in this patient group.

Overall, the suggested cognitive behavioural model appears to be a useful means of understanding adjustment. This thesis pinpointed a number of potential cognitions and behaviours which may be important targets for adjustment interventions. Continued research efforts to understand factors that determine a range of adjustment outcomes and to determine what people with MS find helpful and appropriate is necessary for a more complete understanding of successful adjustment to MS and how it can be promoted.

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DECLARATION OF AUTHORSHIP

I, Laura Dennison, declare that the thesis entitled "Factors and Processes involved in adjustment to Multiple Sclerosis" and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
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ABBREVIATIONS

ANCOVA	Analysis of Covariance
ANOVA	Analysis of Variance
BES	Beliefs about Emotions Scale
BIPQ	Brief Illness Perception Questionnaire
CB variables	Cognitive Behavioural variables
CBRSQ	Cognitive and Behavioural Responses to Symptoms Questionnaire
CBT	Cognitive Behaviour Therapy
CIs	Confidence Intervals
CSM	Common Sense Model
DMT	Disease Modifying Treatment
DV	Dependent Variable
EDSS	Expanded Disability Status Scale
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
MS	Multiple Sclerosis
PPMS	Primary Progressive Multiple Sclerosis
PVS	Psychological Vulnerability Scale
pwMS	People with Multiple Sclerosis
QoL	Quality of Life
RCT	Randomised controlled trial
RRMS	Relapsing Remitting Multiple Sclerosis
saMS trial	Supportive Adjustment for Multiple Sclerosis trial
SEM	Structural Equation Modelling
SL	Supportive Listening
SPMS	Secondary Progressive Multiple Sclerosis
WSAS	Work and Social Adjustment Scale

Chapter One: Multiple Sclerosis and its Psychosocial Consequences

1.1. Chapter Overview

This chapter introduces the key features of multiple sclerosis (MS), including its aetiology, symptom presentation, epidemiology, diagnosis, prognosis, and treatment. It proceeds to discuss specific features of MS which can make it a particularly difficult disease to live with. This chapter then reviews empirical literature attesting to the nature and extent of psychosocial difficulties experienced by people with MS (pwMS). Literature on the contribution of clinical and socio-demographic factors to determining psychosocial outcomes is summarised and the role of psychological variables is discussed. The chapter ends with a rationale for the programme of research undertaken in this thesis and a discussion of the context in which the empirical work was conducted.

1.2. About multiple sclerosis

1.2.1. Pathophysiology and symptoms

MS is a chronic and potentially disabling disease of the central nervous system (CNS). It is thought to be an auto-immune condition, where the immune system attacks the myelin sheaths that coat nerve fibres. When myelin is stripped from nerve fibres, lesions or plaques occur. This disrupts the transmission of nerve impulses from the brain to various parts of the body by slowing down, distorting or preventing the communication of messages. Damage to the actual nerve fibres appears to be responsible for accumulation of disability over time (Murray, 2006).

As MS is a disease of the CNS, multiple areas of the body can be affected. A wide range of symptoms (or neurological 'signs') can occur which differ between individuals, and over time. Symptoms can be mild or severe, and brief or persistent. Common symptoms include visual disturbances such as blurred or double vision, bowel or bladder dysfunction, cognitive impairment, balance disruption and disturbances in sensation such as tingling, numbness or pain. Patients also commonly experience fatigue, sexual dysfunction, stiffness and spasms in muscles, tremor, and difficulties with speech and swallowing (Compston & Coles, 2008).

1.2.2. MS types and courses

MS is considered to be one disease, with different clinical phenotypes, or courses (Confavreux & Vukusic, 2006). It is commonly divided into relapsing remitting MS (RRMS), primary progressive MS (PPMS) and secondary progressive MS (SPMS). RRMS is characterised by unpredictable relapses or exacerbations of symptoms with periods of full or partial remission in between. Relapses involve the appearance of new symptoms, or the return of old symptoms and can vary in duration (days, weeks, or months) and severity. In RRMS, accumulation of disability tends to be gradual and slow as a result of residual damage from relapses. Eighty-five percent of pwMS are initially diagnosed with this form of the disease (Murray, 2006). However, around 65% of those who begin with RRMS change to a more progressive course, SPMS, within fifteen years of diagnosis (Koch, Uyttenboogaart, van Harten, & De Keyser, 2008). At this point, disability accumulates because symptoms do not cease following relapses. In PPMS, a patient's condition deteriorates from disease onset and progression of disability tends to be faster. Around 15% of patients are diagnosed with PPMS (Thompson et al., 2001; Murray, 2006). Another category, 'benign MS', is sometimes used to describe individuals (possibly around 10-30% of all patients) who, after many years, demonstrate minimal progression and little or no disability (UK MS Society, 2008).

The time taken for disability to accumulate and the ultimate level of disability acquired differs considerably between individuals. However, for most patients the course of MS becomes increasingly progressive and disabling as years go by (Goodkin, 1998). Fifteen years post-diagnosis 80% of patients have some functional limitations, 50-60% require assistance with ambulation and 70% are limited or unable to perform activities of daily living (Hauser & Oksenberg, 2006).

MS is not immediately life-threatening but does shorten life expectancy somewhat compared to the normal population. MS does not itself cause death, but when neurological disability is high, it increases the risk of bladder, skin, lung and chest infections; from which two thirds of pwMS ultimately die (Compston & Coles, 2008). Recent estimates suggest that the life expectancy of pwMS is reduced by five to ten years (Bronnum-Hansen, Koch-Henriksen, & Stenager, 2004).

1.2.3. Epidemiology and aetiology

MS is the most common disabling neurological disease in young British adults and is estimated to affect around 100,000 people in the UK (UK MS Society, 2011) and 2.1 million worldwide (National MS Society, 2011). Recent research indicates a prevalence of around 0.3% in Northern Europeans (Compston & Coles, 2008). MS tends to be diagnosed in early adulthood (peaking at age 20-40) with women almost twice as likely to develop it than men (Mohr & Cox, 2001). Different rates of MS are also observed across different parts of the world; higher rates are observed in countries further from the equator whereas it is rare in countries close to the equator (Pugliatti, Sotgiu, & Rosati, 2002). Some studies suggest an increased incidence of MS over time, but these findings may reflect heightened awareness and new diagnostic techniques (Compston & Coles, 2008).

The cause or trigger of the demyelination characteristic of MS is not yet fully understood. Although experts agree that the aetiology is likely to be complex and multifactorial, so far there is no complete model of pathogenesis. We are yet to understand the complex interplay between genetic and environmental factors and their relevance to both susceptibility and outcomes (Dyment, Ebers, & Dessa Sadovnick, 2004; Hauser & Oksenberg, 2006; Compston & Coles, 2008). Studies suggest that racial susceptibility is an important determinant of the worldwide uneven geographic distribution of the disease (Pugliatti et al., 2002). An inherited susceptibility within families has been identified (Compston & Coles, 2008). However, environmental factors also determine risk (Ebers, 2008). The country in which a person spends their childhood appears to be important and the geographical distribution of MS has been hypothesised to be due to exposure to viruses during early life. According to the hygiene hypothesis, individuals who are not exposed to bacterial or viral infections early in life due to their environment may have abnormal responses when they contract these infections in young adulthood (Compston & Coles, 2008). Measles, mumps, rubella and the Epstein-Barr virus have all been implicated as possible triggers. Research has also examined the role of lack of sunlight, vitamin D deficiency, diet, and exposure to pollutants and toxins. However, attempts to isolate environmental triggers have so far proved largely unproductive, with no single environmental exposure consistently identified (Hauser & Oksenberg, 2006; Marrie, 2004).

1.2.4. Diagnosis and treatment

To receive a diagnosis of MS, a patient must demonstrate two or more episodes or relapses characteristic of MS, involving two or more areas of the CNS over time. Since the early 1980's the Poser criteria were used to classify MS, which relied on clinical evidence of lesions scattered in time and space (Poser et al., 1983). More recently, the McDonald criteria have been adopted which allow earlier confirmation of the diagnosis by incorporating both clinical and laboratory evidence such as magnetic resonance imaging into the diagnostic criteria (McDonald et al., 2001; Polman et al., 2005).

There is no cure for MS, despite active research in this area. Therefore, long-term management is the treatment goal (Tselis & Lisak, 1999). Increasingly, the co-ordination of care for pwMS is delivered through specialist nurses (Compston & Coles, 2008). Medication can treat some acute symptoms, such as bladder problems, pain and spasm (Murray, 2006). Patients may also benefit from physiotherapy and occupational therapy. Serious relapses which are painful, distressing or disabling may be treated with steroids, for which a patient may be hospitalised (Murray, 2006).

Since the mid 1990s, disease-modifying therapies (DMTs) have become available. The most commonly used are beta-interferon and glatiramer acetate. These therapies are thought to suppress the immune response against myelin and appear to reduce the number and severity of relapses. Pivotal studies showed a reduction in frequency of relapses by around 30% over two or three years and extension studies suggested that these effects persist (Compston & Coles, 2008). However later systematic reviews produced less optimistic results (Filippini et al., 2003; Munari & Filippini, 2004). Furthermore, there is little evidence for longer-term effects on disease progression and ultimate levels of disability acquired (Goodin, 2008; Rudick, 1999). Additionally, these drugs do not reverse acquired deficits (Compston & Coles, 2008). DMTs are suitable for patients with active RRMS and are available on the National Health Service. However, these drugs show no benefits for those with PPMS and only limited benefits for those with SPMS. DMTs are injected intravenously or intramuscularly (daily or once or twice per week) and can produce unpleasant side effects. Furthermore, around one in twenty patients treated with beta-interferon develops neutralising antibodies against the drug within two years, making the treatment less efficacious (Murray, 2006). A number of other disease modifying

treatments are sometimes used and research continues to explore the potential of other agents.

1.2.5. MS as a disease with high burden

Various factors concerning the nature of MS suggest that it is an extremely difficult disease to live with. There may be a period prior to diagnosis where the patient is perplexed and worried by unexplained symptoms. The process of diagnosis can be protracted and the delivery of the diagnosis often results in shock, fear and bewilderment (Edwards, Barlow, & Turner, 2008). Following diagnosis, patients are faced with high levels of uncertainty about their disease course. They have to live with a chronic, incurable condition that poses the threat of severe disability and loss of independence in the future. Symptoms can be unpleasant, painful, embarrassing, disabling, unpredictable and alarming. Because symptoms can be transitory and invisible to others (e.g. fatigue, sensation disturbances) they may not be taken seriously and the presence of illness may be doubted by others (Robinson, 1988). Symptoms may cause functional impairment and may affect the whole spectrum of life domains including work and income, social life, relationships and family life, and tasks of daily living. Life goals may be thwarted (Courts, Buchanan, & Werstlein, 2004; Edwards et al., 2008; Malcomson, Lowe-Strong, & Dunwoody, 2008). Physical limitations that might have been anticipated in older age occur unexpectedly early, at a time when people are developing careers and building families or romantic relationships (Robinson, 1988). Finally, if patients are eligible for disease-modifying treatments, these regimes carry a high burden and possible side effects (Wekerle, 2002).

Given, the nature of MS it is not surprising that research demonstrates high levels of negative psychosocial outcomes in this population. Literature regarding these outcomes is outlined in the following section.

1.3. Psychosocial consequences

1.3.1. Mental health

As early as the nineteenth century the presence of psychiatric symptoms in pwMS has been noted (Charcot, 1879). In the last 50 years, research has steadily built up consistent evidence for high rates of mental health problems and low mood in pwMS.

1.3.1.1. Depression

Prevalence rates of major depression have been shown to be extremely high in MS compared to rates in the normal population and other chronic illnesses (Patten, Beck, Williams, Barbui, & Metz, 2003). Estimates differ depending on populations and methodology but annual prevalence rates may be as high as 20% and lifetime prevalence may be around 50% (Siegert & Abernethy, 2005; Ghaffar & Feinstein, 2007). For example, in a study using structured psychiatric interviews 54% of quasi-randomly selected patients with MS from a clinic register met diagnostic criteria for depression at least once since diagnosis, whereas only 14% had met these criteria prior to diagnosis (Minden, Orav, & Reich, 1987). Another study using structured psychiatric interviews with 221 consecutive MS clinic attendees found a lifetime prevalence of 50% for major depressive disorder (Sadovnick et al., 1996).

Research which considers depressive symptoms (rather than clinical diagnoses) also suggests elevated levels in pwMS compared to healthy people, and (albeit less consistently) people with other chronic illness (Schubert & Foliart, 1993). A recent meta-analysis found a large effect size for studies comparing depressive symptoms in pwMS and healthy comparison groups. The effect size was small and non-significant for studies comparing pwMS to people with other chronic conditions. It appeared that some other conditions had consistently higher depression scores (e.g. chronic fatigue syndrome) and some had consistently lower scores (e.g. spinal-neuromuscular conditions) (Dalton & Heinrichs, 2005). In a study of 739 pwMS, 42% reported symptoms of clinically significant depression; 29% were classified as moderate to severe cases (Chwastiak et al., 2002). A survey study found significant depressive symptoms in 50-60.2% of 495 participants over the course of a three phase longitudinal study (Sollom & Kneebone, 2007).

There has been come critique regarding some measures used to assess depressive symptoms. Specifically, the inclusion of items tapping physical symptoms which may be a

result of the disease processes (e.g. sleep disturbance, fatigue), may artificially inflate ratings of prevalence and severity (Nyenhuis et al., 1995). Furthermore, the use of clinic samples in research may overestimate the prevalence of depression disorder as people coping well in the community would not be included (Siegert & Abernethy, 2005). Nonetheless, studies using appropriate measures which do not include confounded items have also found elevated levels of depression in MS, as have large samples from communities (e.g. Patten et al., 2003).

A meta-analysis found that both pharmacological and psychological treatments are effective for depression in MS. However, left untreated depression appears to worsen over time (Mohr & Goodkin, 1999).

1.3.1.2. Suicide

Rates of attempted and completed suicide are known to be elevated in pwMS (Minden, 2000). One investigation of death records of MS patients found the proportion of suicides as a cause of death were 7.5 times higher than an age-matched healthy population (Sadovnick, Eisen, Ebers, & Paty, 1991). A study of Danish records of death in 5525 pwMS (1953-85) found cumulative lifetime risk of suicide from onset of MS was 1.95% (Stenager et al., 1992). A more recent study in Sweden confirmed the higher risk of suicide (Fredrikson, Cheng, Jiang, & Wasserman, 2000).

1.3.1.3. Anxiety

Although not as well researched as depression in MS, there is evidence that the prevalence of anxiety disorders is also elevated and levels of anxiety symptoms are high. In one study, structured clinical interviews with 140 consecutive MS clinic attendees found that the lifetime prevalence of any anxiety disorder was 35.7%. Generalised anxiety disorder, panic disorder and obsessive compulsive disorder were the most common diagnoses (Korostil & Feinstein, 2007). Another study of 95 consecutive patients reported elevated anxiety scores on the Hospital Anxiety and Depression Scale (HADS) (Zorzon et al., 2001). Another study found 34% of 101 recently diagnosed patients had clinically high levels of anxiety symptoms (Janssens et al., 2003). A study of 152 consecutive patients in a

Canadian MS clinic found clinically significant anxiety in 25% of patients (Feinstein, O'Connor, Gray, & Feinstein, 1999). Social anxiety symptoms appear to be elevated in MS. A study of 251 patients found 30.6% had clinically significant social anxiety symptoms, often co-morbid with high scores on general anxiety and depression measures (Poder et al., 2009). Anxiety related to self-injection of DMTs has also been noted (Mohr, Cox, Epstein, & Boudewyn, 2002). Studies also suggest that anxiety is often overlooked and untreated in MS (Feinstein et al., 1999; Korostil & Feinstein, 2007).

1.3.1.4. Distress

High levels of general psychological distress have also been recognised in pwMS compared to healthy populations, and other medical populations (Dalos, Rabins, Brooks, & O'Donnell, 2004). Even in early-stage MS patients with minimal to no neurological disability, distress levels were higher than healthy controls (Kern et al., 2009). A study of recently diagnosed patients found 36% had severe distress relating to MS (Janssens et al., 2003).

1.3.2. Social and role functioning

PwMS may need to alter their working patterns, type of work or give up employment completely as a result of the disease. Studies from UK, US and Canada consistently show a heavy economic cost to individuals and their families (De Judicibus & McCabe, 2005). This appears to be predominantly as a result of loss of earnings from reduced employment and early retirement. A population-based survey of pwMS in Hampshire, UK found 53% who were employed at time of diagnosis gave up jobs and 37% reported declined standards of living as a result of MS (Hakim et al., 2000). The cost of MS to society also appears to be high, with informal care and lost employment being major costs (McCrone, Heslin, Knapp, Bull, & Thompson, 2008).

Social roles and activities often change as a result of neurological impairment. Social role functioning was found to be worse in pwMS than an age and sex-matched control group of patients with other conditions (Murphy et al., 1998). Another study found the ability to maintain social contacts and leisure activities was reduced in pwMS (Hakim et al., 2000).

A small (n=19) UK longitudinal study found extremely high rates of divorce when one member of the couple had MS; a 21% annual incidence over an 18 month study period (Coles, Deans, & Compston, 2001). However, elevated divorce or separation rates were not found in a larger and more representative population-based UK study (Hakim et al., 2000). Nonetheless, MS also appears to have a deleterious effect on romantic relationships. In one study, around 20% of patients endorsed questionnaire items relating to deterioration in marital/romantic relationships (Mohr et al., 1999).

MS can have a range of negative psychosocial consequences for spouses and partners. Hakim et al. (2000) found high levels of depression and anxiety symptoms in partners and spouses of pwMS, particularly when the patients' disability and cognitive impairment was severe. However, distress in partners/spouses have also been noted in a sample with newly diagnosed MS and fairly mild disease severity (Janssens et al., 2003). Qualitative research with such a sample highlighted problems relating to social isolation, helplessness and anxiety about the future (Bogosian, Moss-Morris, Yardley, & Dennison, 2009). Children who have a parent with MS also appear to be vulnerable to negative psychosocial consequences (Bogosian, Moss-Morris, Bishop, & Hadwin, 2010).

1.3.3. Quality of Life

Quality of life (QoL) is a broad and multidimensional concept which relates to an individual's evaluation of a number of domains including their physical and emotional wellbeing and their social, occupational and role functioning. Various studies have found that pwMS have lower QoL ratings than the general population (Nortvedt, Riise, Myhr, & Nyland, 1999; McCabe & McKern, 2002). Other research found lower scores in pwMS compared patients with other conditions (Murphy et al., 1998; Rudick, Miller, Clough, Gragg, & Farmer, 1992). However, in a recent study, health-related QoL was only statistically and clinically significantly worse than the general population for questionnaire subscales that tapped physical health and wellbeing. Other domains were similar to the general population. Furthermore, 77% of MS patients reported being mostly satisfied or delighted with their overall QoL (Pittock et al., 2004).

1.3.4. Positive outcomes

It is important to note that negative psychosocial outcomes are not pervasive in MS. Whilst the above studies show that significant numbers of pwMS experience negative outcomes, this still leaves a large proportion of pwMS who do not exhibit mental health problems, social and role dysfunction, or poor QoL. An early longitudinal study suggested that the majority of pwMS maintain positive self concepts over a seven year period, despite the chronic and progressive nature of the disease (Brooks & Matson, 1982). Another study found that around two thirds of the 94 people studied achieved positive psychosocial wellbeing (Devins, Seland, Klein, Edworthy, & Saary, 1993). Furthermore, some patients report benefit or gain from adversity, including perceptions of personal growth and strengthening of relationships (Mohr et al., 1999; Pakenham, 2005). It is important that, in the focus on addressing problems and deficits, positive aspects of the illness experience and good psychosocial outcomes are not overlooked.

1.4. Explaining individual differences in adjustment outcomes

In trying to explain the variability of psychosocial consequences of MS, research has considered various determinants. These include disease-related variables, socio-demographic variables and differences and psychological variables. The following sections discuss evidence for the contribution of each of these in turn.

1.4.1. Disease related predictors

1.4.1.1. Neurological damage

There is debate about whether depression in MS is a direct consequence of disease processes, or a response to the chronic stress of living with the condition (e.g. Haussleiter, Brune, & Juckel, 2009). It has been contended that depression in MS may be a result of specific MS-related autoimmune disease processes as well as the damage these processes cause in the form of lesions in the brain (Mohr & Cox, 2001). A number of fairly small studies have tried to establish whether MS-related damage to specific areas of the brain is responsible for depression in MS (Feinstein et al., 2004; Honer, Hurwitz, Li, Palmer, & Paty, 1987; Rabins et al., 1986; Zorzon et al., 2001) Existing literature does not

consistently identify any specific pattern of neurological involvement with depressive symptoms or disorders. Existing studies vary in design and rigour and reviews have concluded that few if any unequivocal conclusions can be drawn (Siegert & Abernethy, 2005; Patten & Metz, 1997). However, most researchers agree that MS-related neurological damage is unlikely to be the key or unique factor that contributes to depression and believe it is best conceptualised as a response to the experience of living with this difficult disease. A recent theoretical conceptualisation is that lesions or brain atrophy explain only a limited proportion of variance in depression. Fatigue, disability, cognitive dysfunction and pain also contribute to the experience of depression but these have weak and inconsistent effects because they are moderated by psychological variables such as coping and social support (Arnett, Barwick, & Beeney, 2008).

1.4.1.2. Clinical variables

Neurological disability, an indicator of MS disease severity, is usually measured by the Expanded Disability Status Scale (EDSS) (Kurtzke, 1983). A large study of a community sample found higher levels of depressive symptoms in patients with higher (worse) EDSS scores (Chwastiak et al., 2002). Newly diagnosed patients also appear to have higher distress and depression when their disease severity is high (Janssens et al., 2003; Kern et al., 2009). However, some studies have not found links between MS severity and depression or emotional distress (e.g. Provinciali, Ceravolo, Bartolini, Logullo, & Danni, 1999; Dalos et al., 2004). Studies of the relationship between depression and various disease parameters are inconsistent and confusing (Minden, 2000). Furthermore, anxiety appears to be unrelated to clinical variables such as EDSS (Zorzon et al., 2001; Poder et al., 2009).

QoL appears to be associated with neurological disability, such that indicators of more severe disease are linked to poorer ratings of QoL (Kern et al., 2009; Wynia, Middel, van Dijk, de Keyser, & Reijneveld, 2008). However, several studies have found that disease severity only appears to have a strong link to subscales on QoL measures which tap physical health and physical/role functioning. Disease severity has weaker associations with subscales measuring social and emotional wellbeing aspects of QoL (Nortvedt et al., 1999; Rudick et al., 1992; Turpin, Carroll, Cassidy, & Hader, 2007; Pittock et al., 2004). A recent review concluded that the relationship between health-related QoL and measures

of impairment and disability (e.g. EDSS) is surprisingly weak, accounting for only 2-29% of the variance in outcomes (Mitchell, Benito-Leon, Morales Gonzalez, & Rivera-Navarro, 2005).

Few studies have investigated links between disease course (e.g. RRMS, SPMS, PPMS) and psychosocial outcomes. One large study found no relationship between disease course and depression symptoms (Chwastiak et al., 2002). Another study found no relationship between disease course and health-related QoL (Ford, 2001).

There does, however, appear to be an association between psychological distress and disease activity with several studies suggesting that patients experiencing relapse have higher distress than those in remission (Dalos et al., 2004; Kroencke, Denney, & Lynch, 2001; McIvor, 1984). QoL also appears to be poorer in patients with unstable disease (Aronson, 1997).

Some research suggests that psychosocial outcomes are particularly poor in the first few years following diagnosis. Higher levels of depressive symptoms have been identified in people who had a short duration of MS (Chwastiak et al., 2002; McGuigan & Hutchinson, 2006) and the first few years following appears to be particularly risky in terms of suicidal intent and attempts (Stenager et al., 1992). However, findings regarding time since diagnosis or symptom onset are inconsistent. Some studies have found links between longer disease duration and high depression (McIvor, Riklan, & Reznikoff, 1984). Others have found no links between distress and disease duration (e.g. Fruewald, Loeffler-Stastka, Eher, Saletu, & Baumhacki, 2001). Furthermore, whilst some studies have linked longer disease duration to worse physical health aspects of QoL (e.g. Pittock et al., 2004), others have not found these associations (e.g. Rudick et al., 1992; Fruewald et al., 2001). Different sampling methods and ways of determining disease duration and outcome measures may account for some of these discrepancies, as may different approaches to analysis. The influence of disease duration per se is likely to be linked to, and interact with, other variables such as disease course, progression, activity and severity which determine what the experience of the illness will have been like throughout the disease duration. So far, studies have rarely pulled apart these factors.

A number of specific MS symptoms are thought to be particularly important in determining psychosocial outcomes. Severity of fatigue affects both physical and mental health aspects of QoL (Mitchell et al., 2005) and appears to be related to worse dyadic adjustment (Smith & Arnett, 2005). A review reported that most but not all studies show an association between cognitive deficits and low QoL (Mitchell et al., 2005). A recent study found that cognitive impairment was a key QoL predictor (Wynia et al., 2008). Other specific symptoms have also been linked to poorer outcomes; bladder dysfunction and sexual dysfunction were associated with a marked reduction in QoL (Nortvedt et al., 2001).

1.4.2. Socio-demographic predictors

Findings regarding the relationship between social and demographic variables and psychosocial outcomes in pwMS have been rather inconsistent.

Some studies suggest that depression symptoms or clinical diagnoses to be more common in younger people (e.g. Chwastiak et al., 2002; Patten, Metz, & Reimer, 2000). Others have found depression to be more of a problem for older patients (McIvor et al., 1984). Yet more studies suggest age is unrelated to psychosocial adjustment variables (Dalos et al., 2004; Mohr et al., 1999). Links between age and QoL are more consistent. Age is associated with worse ratings of physical aspects of QoL (e.g. Turpin et al., 2007), probably due to age being associated with likelihood of disease progression.

An early study suggested that females are more likely to maintain a positive self concept over the course of the disease (Brooks & Matson, 1982). However, other research suggests that being female is a risk factor for depression in MS populations (Patten et al., 2000). That said, males (especially young males) appear to have a heightened risk of suicide (Stenager et al., 1992; Fredrikson et al., 2000). Females, however, appear to be at higher risk of anxiety disorders (Korostil & Feinstein, 2007). Other studies have not identified gender as a predictor of distress (Dalos et al., 2004; Chwastiak et al., 2002). One study found poorer physical health-related QoL in females. With mental health aspects of QoL an interaction was found between gender and age such that QoL declined with age in men but improved with age in women (Turpin et al., 2007).

A large study found marital status was not an important associate of depression (Chwastiak et al., 2002). Another study found that marital status was generally unrelated to psychosocial adjustment outcomes, although being married was linked to higher deterioration of relationships (Mohr 1999). Living alone, however, has been shown to predict suicidal intent (Feinstein, 2002).

Socio-economic variables may also be important influences on adjustment outcomes. Low income and lack of employment appear to be related to maladjustment (De Judicibus & McCabe, 2005; Brooks & Matson, 1982) and depressive symptoms tend to be higher in patients with less education (Chwastiak et al., 2002).

1.4.3. Psychological predictors

Overall, existing research has yielded few definitive results about the relationship between clinical or socio-demographic variables and adjustment outcomes. Moreover, although knowledge of clinical and socio-demographic predictors of psychosocial outcomes may help identify those who may be most vulnerable, there is little scope to use this knowledge to inform endeavours to improve outcomes. Socio-demographic variables are, for the most part, unchangeable (e.g. gender, age). Furthermore, there is usually little scope for changing disease variables, beyond the medical treatment patients already receive.

Reviews of the literature on psychosocial outcomes have discussed the importance of understanding variation by considering individual differences in how people think, feel and behave in addition to disease variables (Antonak & Livneh, 1995; Mitchell et al., 2005; Mohr & Cox, 2001; Patten & Metz, 1997; Siegert & Abernethy, 2005). Many empirical studies have demonstrated that psychological variables including factors such as stress and coping, uncertainty, helplessness, and ways of responding to MS symptoms are important in predicting adjustment outcomes, and may account for a larger proportion of variance in psychosocial outcomes than the sorts of clinical and demographic variables discussed in the sections above (Aikens, Fischer, Namey, & Rudick, 1997; Mullins et al., 2001; Shnek, Foley, LaRocca, Smith, & Halper, 1995; Skerrett & Moss-Morris, 2006). Studies in this domain contribute to both conceptual models of adjustment to MS, and clinical interventions to improve outcomes for patients.

1.5. Thesis rationale and overview

This thesis investigates psychological factors and processes involved in achieving positive psychosocial outcomes in MS. The empirical studies are conducted with a view to understanding the nature of psychological adjustment to MS and elucidating factors that interventions could address in order to promote successful adjustment. In chapter 2, literature around the concept of adjustment to chronic diseases, and theories and frameworks from which adjustment has been studied is reviewed and critiqued. Chapter 3 is a systematic review which synthesises evidence on the relationships between psychological factors and positive and negative adjustment outcomes in MS. Chapter 4 is a large qualitative study exploring how individuals experience the process of adjusting to MS. Chapters 5 and 6 are cross-sectional and longitudinal analyses of a selection of cognitive and behavioural variables which may explain or predict adjustment. Chapter 7, the final empirical chapter, is a qualitative study of adjustment and change processes within psychological interventions. Chapter 8 contains the discussion and conclusions from the thesis.

1.6. Context of the research programme

The empirical work for this thesis was nested within data collection for a larger research project. This project, the saMS trial (Supportive Adjustment for Multiple Sclerosis), involved developing and testing a cognitive behavioural intervention for adjustment to early stage MS (Moss-Morris et al., 2009). A randomised controlled trial (RCT) was run in which ninety-four pwMS were randomly allocated to either Cognitive Behaviour Therapy (CBT) or a Supportive Listening (SL) comparison condition. I was employed as the trial co-ordinator which involved developing the CBT manual, planning and running the RCT, recruiting participants, administering screening and assessments, and assisting with data analysis and dissemination. The findings from the trial itself do not form part of this thesis. However, I used this opportunity of working on the trial to collect data for this thesis. I conducted a systematic review, included extra measures in the questionnaire packs, and undertook substantive qualitative studies alongside the main data collection in order to obtain data for my thesis research

Chapter Two: Theoretical and methodological approaches to understanding adjustment to MS

2.1. Chapter Overview

This chapter considers approaches to investigating adjustment to MS. Firstly, difficulties with conceptualising adjustment are discussed and the definitions used within this thesis are specified. The subsequent sections discuss theories and models of adjustment within the existing MS and wider chronic illness literature. The theoretical perspectives adopted within this thesis are then outlined. The final section discusses qualitative and quantitative methodology and ends with a rationale for the mixed methods approach adopted in this thesis.

2.2. Conceptualising Adjustment

2.2.1. Chronic illness and the need for adjustment

Chronic illnesses are prolonged, do not resolve spontaneously, and are rarely cured completely (Centers for Disease Control and Prevention, 2003). Critically, they have ongoing effects on a person's ability to function normally (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). People who suffer from chronic illnesses are confronted with a lifetime of altered functioning and difficult situations which threaten their psychosocial wellbeing. In order to maintain acceptable physical, social and psychological functioning individuals need to find ways of adjusting to their altered condition. A large body of research has described the experiences of people with chronic diseases and investigated factors which might explain individual differences and help and hinder this adjustment. Various models and theories have been advanced to account for clinical and empirical observations and to guide efforts to assist people with adjustment.

2.2.2. Defining adjustment

Despite academic interest, the terminology around adjustment is surprisingly ill-defined and consensus on how it should be measured is absent. Dictionary definitions of 'adjustment' include 'a small alteration or movement made to achieve a desired fit, appearance, or result' and 'the process of adapting or becoming used to a new situation'. A related term, 'adaptation' is 'the process of change by which an organism or species becomes better suited to its environment' (Online Oxford Dictionaries, 2011). Each

definition refers to processes and actions directed towards change and better fit with a situation. In line with these definitions, a recent review defined adjustment to chronic illness as 'the healthy rebalancing by patients to their new circumstances' (de Ridder et al., 2008). Another review described adjustment to chronic disease as affecting a range of life domains, unfolding over time and varying considerably between individuals (Stanton, Revenson, & Tennen, 2007). Thus, adjustment appears to be something that unravels over time, helping people move towards best possible functioning within the constraints of the illness. Nonetheless, in the empirical literature the emphasis on a process is relatively neglected. Adjustment is frequently conceptualised in terms of specific desirable endstates or observable outcomes and change or movement towards positive outcomes has received little attention (Brennan, 2001). The presence of a psychiatric diagnosis or symptoms is often used as a measure, or marker of maladjustment. However, the necessity of thinking more broadly about indicators of adjustment has also been highlighted (de Ridder et al., 2008; Folkman & Greer, 2000; Stanton et al., 2007). Stanton, Collins and Sworowski (2001) delineated five conceptualisations of adjustment to chronic disease: mastery of adaptive tasks, preservation of functional status, perceived QoL in various life domains, absence of psychological disorder, and low negative affect. De Ridder et al. (2008) suggested consideration of wellbeing as an additional important outcome. Although investigated less frequently than mental health outcomes, these broader ways of conceptualising adjustment are evident in the literature. For example, studies have considered health-related QoL (Stanton et al., 2000), life satisfaction (Carver et al., 1994) self-concept (Brooks & Matson, 1982), positive and negative affect (Carver et al., 1994; Wootten et al., 2007), adversarial growth (Bellizzi & Blank, 2006). illness-specific distress (Yi, Vitaliano, Smith, Yi, & Weinger, 2008). illness-related stress (Levin et al., 2010). social functioning (Curtis, Groarke, Coughlan, & & Gsel, 2005), sexual and role functioning (Helgeson & Cohen, 1996) and combinations of these variables as indicators of adjustment to chronic diseases in adult populations.

2.2.3. Conceptualisation of adjustment within this thesis

Within this thesis, the de Ridder et al. (2008) conceptualisation of adjustment as a healthy rebalancing to new circumstances is adopted. Given the unpredictable and progressive or relapsing nature of MS, the thesis conceptualises adjustment as a series of ongoing 'rebalancing acts' rather than a one-off accomplishment and recognises that pwMS may

also need to adjust to possible *future* circumstances as well as current states. Distinctions are also made between:

1. Change over time that moves individuals towards more positive or adaptive outcomes. This is referred to as '*the adjustment process'*
2. Indicators of the success of the adjustment process (e.g. avoiding mental health problems). These are termed '*adjustment outcomes'*
3. Factors involved in the adjustment process. This includes both events that people experience (e.g. deterioration in physical status), and the ways that they respond (e.g. behaviourally, cognitively, intentionally and unintentionally). These are *'adjustment process variables'.*

The main interest of this thesis is exploring how positive *adjustment outcomes* are achieved in order to inform interventions to improve psychosocial outcomes for pwMS. In other words, it seeks to understand the adjustment process and the variables involved.

2.3. Models and frameworks for understanding adjustment to MS

The following section summarises and critiques a number of theoretical approaches for understanding adjustment to MS. It begins with an examination of a MS-specific theory of adjustment, and then proceeds to discuss theories that were developed to account for psychological adjustment more generally but can be applied to MS.

2.3.1. MS-specific theories of adjustment

The only theoretical adjustment model specific to MS was proposed by Matson and Brooks in 1977. This model aimed to fill the gap between models setting out stages of dying (e.g. Kubler-Ross, 1969) and those describing becoming ill and recovering (e.g. Suchman, 1965) in order to provide a theory suitable for pwMS. Matson and Brooks specified that the adjustment process is characterised by four stages: denial, resistance, affirmation and integration. Newly diagnosed patients enter a Denial stage characterised by disbelief and attempting to carry on as normal. With time, a minimal acceptance of the diagnosis emerges, leading to a Resistance stage characterised by seeking information and attempting to control or fight the disease. An Affirmation stage is then entered where the patient

realizes the necessity of rearranging priorities due to illness and grieves for losses, whilst trying to construct new meanings for their situation. The final stage, Integration, is characterised by dealing with MS problems as they arise and with minimal emotion, spending energy and thought on things other than health, reorganising values, and having a fuller appreciation of life. Matson and Brooks (1977) do not specify how long people spend in each stage, and recognise that people may not follow the stages in order, may not progress through all of them or might regress with new MS exacerbations and vulnerabilities.

Matson and Brooks' theory is often cited as the first major academic work on MS adjustment. However, it has not been further elaborated or verified nor has it been used for guiding contemporary research or designing and delivering interventions. There are a number of reasons for this. First, it does not explain how movement between stages is achieved and what factors help or hinder the achievement of positive outcomes. Therefore, its predictive or therapeutic value is limited. Secondly, the authors conceptualised adjustment as positive self-concept so the work provided a narrow view of what adjustment is and what factors and processes are relevant. Thirdly, although the model is presented alongside results from a cross-sectional analysis of medical and coping factors which influence self-concept and some qualitative interview findings it is unclear how the research findings led to the proposed stages. The research methods, as well as the idea of stage theories of adjustment have become outdated with developments in psychological theory and methods. Furthermore, the model was derived from a small US sample nearly forty years ago, before DMTs for MS became available. Both the social and medical context is likely to be different today. Despite its limitations, this work and the authors' subsequent longitudinal study (Brooks & Matson, 1982) had important implications. They demonstrated that PwMS can attain positive adjustment and drew attention to psychosocial factors that influence adjustment as well as disease factors; marking the start of research into identifying important psychological variables.

2.3.2. Broader adjustment theories relevant to the MS context

In recent years, MS adjustment research has drawn on theories and frameworks from health, clinical and cognitive psychology. The section below reviews some of the theoretical perspectives used to understand adjustment to chronic disease. The literature

potentially relevant to adjustment to chronic disease is vast and a detailed review is beyond the scope of a single thesis. This section, therefore focuses on theoretical approaches that have been prominent in the existing chronic disease literature and offer helpful insights for interventions to improve adjustment. The extent to which they have been influential within the MS adjustment literature is also described.

2.3.2.1. Stage theories

Like Matson and Brooks' (1977) MS-specific adjustment model, many early theoretical approaches conceptualised adjustment to chronic disease as a series of stages through which an individual proceeds (Parker, Schaller, & Hansmann, 2003). Adjustment was seen as being a series of temporally and hierarchically ordered reactions (Antonak & Livneh, 1995). The multiple theories that have been published have tended to describe reasonably similar patterns beginning with shock, then denial, followed by acknowledgment and distress, and often anger or hostility. They usually conclude with acceptance and integration (Antonak & Livneh, 1995). Despite their popularity, there is little consistent evidence to support either a predictable trajectory through a fixed sequence or the existence of mutually exclusive stages (Parker et al., 2003). Stage theories also explain little about inter and intra-individual variability or what prompts or supports progression through the stages. For these reasons, these descriptive stage models have fallen out of favour with researchers and the models described below have become more popular. However, ideas of stages persist in clinical and lay understandings of adjustment (Parker et al., 2003; Paterson, 2001; Telford, Kralik, & Koch, 2006).

2.3.3. Cognitive models of psychopathology

Some MS adjustment literature has been influenced by cognitive models of psychopathology. These theories view dysfunctional beliefs and faulty information processing as causes and maintaining factors in mental health problems.

The key influence, Beck's cognitive model of emotional disorders, describes depressive thinking as a cognitive triad: negative views of the self, the world and the future (Beck, 1976). Beck proposed that these self-defeating attitudes are maintained because people

predisposed to depression have longstanding and entrenched depressogenic schemas. Schemas are stable cognitive patterns which develop from early experience and are used to interpret and organise experiences. Dysfunctional schema foster selective attention to negative incoming information and create distorted interpretations of experiences. Systematic errors in thinking maintain negative thinking about the self, experiences and the future even in the presence of information to the contrary. These include; arbitrary inference, overgeneralization, selective abstraction, magnification of negatives (catastrophising) and minimization of positives, personalization and dichotomous thinking. Other theorists have highlighted other cognitive biases that appear to contribute to mental health outcomes. Negative attributional style, a tendency to attribute negative events to internal, stable and global causes have been implicated in depression (Peterson & Seligman, 1984; Seligman, 1981). Biases in processing threat-related information including biases in selective attention and stimulus evaluation appear important for clinical anxiety (Mathews & MacLeod, 1985; Mogg & Bradley, 1998). Habitual cognitive patterns relating to the self and ones' value such as perfectionism, dependence and self-criticism have also been proposed to create a vulnerability to poor psychological outcomes in stressful situations (Sinclair, Wallston, Dwyer, Blackburn, & Fuchs, 1998).

Understanding of adjustment issues in MS has been influenced by cognitive models of psychopathology in two ways. First, research has established that various unhelpful biases and negative thinking patterns are linked to symptoms of depression in MS (e.g. Kneebone & Dunmore, 2004; Shnek et al., 1997). Secondly, modification of unhelpful thinking has formed part of interventions to improve adjustment in people with MS (e.g. Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001; Mohr et al., 2000). Research that has adopted cognitive models of psychopathology to study MS adjustment appears to conceptualise depressed mood in pwMS as equivalent to clinical depression in people without MS. Although not explicitly articulated, the model appears to indicate that maladaptive cognitive styles predate MS onset. In line with conceptualisations of predisposition and precipitation of depression (e.g. Beck, 1979) negative schemas which have previously remained latent may be activated or triggered by MS-related experiences, leading to distress.

Cognitive models of psychopathology may be most helpful for predicting who might develop depression or anxiety in the context of MS. For example, somebody predisposed

to catastrophise and to make internal, stable, global attributions for aversive events is likely to experience distress when living with MS because they may focus on the worst case scenario regarding MS progression, interpret potentially benign symptoms as a sign of worsening MS, believe that symptoms will not remit, and worry that MS will also affect other parts of the body. Dichotomous thinking and perfectionism may mean they consider themselves 'a complete failure' when unable to meet high standards in work or family life because of MS-related impairment. Cognitive models of psychopathology are also useful because they pinpoint cognitions which can be targeted for intervention using well-established intervention approaches (i.e. cognitive therapy, or CBT). However, this theoretical approach was developed to explain and improve mental health outcomes, whereas a broader range of outcomes such as social and role functioning are important facets of adjustment. Furthermore, a focus on dysfunctional thinking about the self, experiences and the future may not be the most appropriate approach to explaining how people react and respond to chronic health conditions, as opposed to how psychopathology develops. Other theoretical models, discussed next, concentrate on cognitive processing specific to the illness and symptoms, and also consider illness-related behaviour.

2.3.3.1. The common sense model

The common sense model (CSM) was specifically developed to describe reactions to illness (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984; Leventhal, Leventhal, & Cameron, 2001). Like the cognitive framework for understanding psychopathology described above, the CSM emphasises cognitive processes as a determinant of adjustment outcomes. Again, the concept of schemas for information-processing which are derived from experience features in this model, however these are illness-specific schemas.

The CSM is set out in Figure 1. According to this model individuals' personal, common-sense beliefs about their illness (i.e. illness representations or schema) are activated by illness-related stimuli such as a diagnosis, or the experience of somatic symptoms. Five key dimensions of illness representations have been recognized: illness identity (the label and associated symptoms) consequences (expected effects) cause (why the illness developed), timeline (how long it is expected to last), and control/cure (the extent to which

the disease can be managed or cured). Illness representations are schematic, acquired through firsthand and vicarious experience and are not necessarily medically accurate (Leventhal et al., 1980; Cameron & Leventhal, 2003). Representations can be both abstract/conceptual (e.g. 'MS is a disease of the central nervous system') and concrete/experiential (e.g. a vivid memory of a bed-bound relative). The latter tend to be particularly salient. As work on the CSM has developed, the coherence of illness representations has been recognised as important (Moss-Morris, Weinman, Petrie, Horne, & Cameron, 2002).

The CSM proposed that cognitive and emotional processing occurs in parallel (Leventhal et al., 1980; Cameron & Leventhal, 2003). Cognitive representations of illness influence the selection of behaviours to cope with the illness threat, and emotional representations guide behaviour to cope with the emotional response. Outcomes of coping responses are appraised in terms of their success, which feeds back into illness representations and coping behaviours. Illness representations therefore appear to be important factors determining adjustment outcomes.

Chronic illness adjustment research has tended to concentrate on individual components of the CSM rather than the full model of dynamic and complex bidirectional relationships between illness representations, coping, outcomes and appraisal of outcomes (Hagger & Orbell, 2003). The CSM has not been extensively used in existing MS research. However, initial research inspired by this framework has identified illness representations that are associated with positive or negative adjustment outcomes (e.g. Jopson & Moss-Morris, 2003) and has also started to illustrate the importance of cognitive representations of symptoms and the behaviours chosen to manage symptoms (e.g. Skerrett & Moss-Morris, 2006). Where illness coping responses have been investigated this has tended to be within stress and coping frameworks (see below) and has not yet been investigated in terms of links to illness representations.

Research emanating from the CSM offers insights into cognitions that may influence adjustment to MS; either directly or via their effects on coping responses. CSM-based approaches have the advantage that they can explain individual differences in a range of emotional and functional adjustment outcomes and delineate both adaptive and maladaptive adjustment processes. The CSM has a strong evidence base. Research across

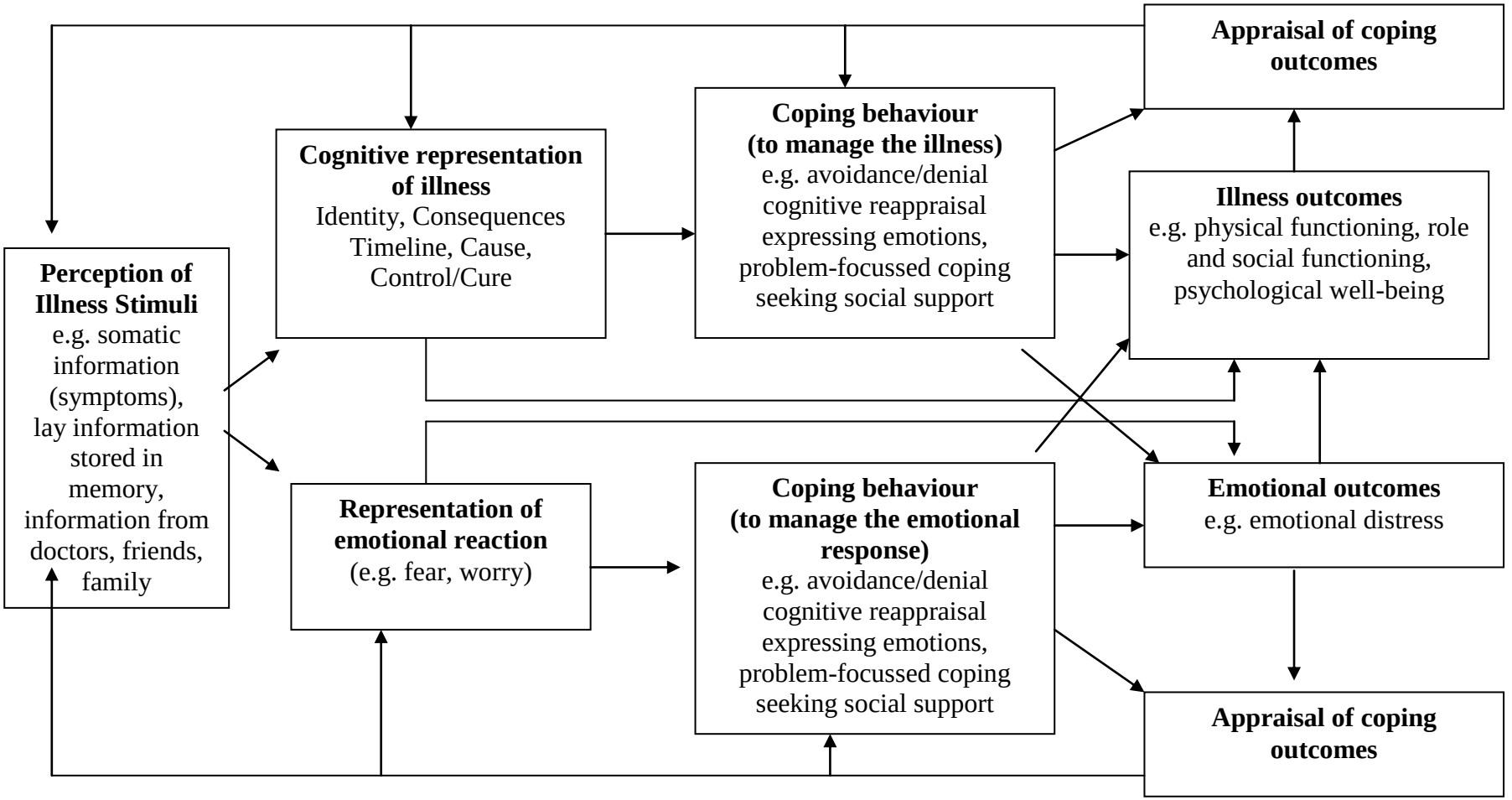

Figure 1: The Common Sense Model of illness cognition and behaviour

Adapted from Hagger and Orbell (2003) and Cameron and Moss-Morris (2010)

multiple chronic illnesses has consistently found logical interrelationships between dimensions of illness representations and coherent associations with illness status and psychological adjustment outcomes (Hagger & Orbell, 2003). The model suggests a range of illness-related cognitions and behaviours which can potentially be modified through psychological intervention in order to improve adjustment outcomes. Therefore, the CSM represents an important model on which interventions for improving adjustment might be based.

2.3.3.2. Stress and coping frameworks

Another dominant approach to studying chronic illness is the stress and coping framework. Like the CSM, stress and coping models focus on cognitive processing of potentially threatening stimuli and responses that the individual selects for managing these. The most influential model, the transactional theory of stress, conceptualises stress as a dynamic process centred around appraisal of a potential stressor and ones' ability to cope (Folkman & Lazarus, 1991; Lazarus & Folkman, 1984). A version of the model is depicted in Figure 2. Individuals first make a primary appraisal, a judgement of whether the potential stressor represents a threat. A secondary appraisal follows, which relates to one's perceived coping ability.. Coping incorporates a range of cognitive and behavioural efforts to manage demands that are appraised as taxing (Lazarus & Folkman, 1984). The individual experiences stress when he/she appraises the situational demands as exceeding their ability to cope. Distinctions are often made between approach-based (e.g. seeking information) and avoidant strategies (e.g. denial, distraction) (e.g. Roth & Cohen, 1986) and between attempts to modify or eliminate source of stress (problem-focused strategies) and attempts to alter the emotional response to it (emotion-focused strategies) (e.g. Lazarus & Folkman, 1984). Following efforts to cope, the stressor is evaluated in light of the success or failure of coping attempts (reappraisal).

The transactional stress and coping framework applied to adjusting to chronic illness conceptualises illness as a stressor (or series of stressors) and proposes that cognitive appraisal, coping strategies and available coping resources are important determinants of

adjustment outcomes such as distress (Maes, Leventhal, & de Ridder, 1996). A similar, but illness-specific coping theory ('crisis theory'; Moos & Schaefer, 1984) assumes that illness creates crises, and that individuals appraise the situation and attempt to return to equilibrium through illness-specific (e.g. dealing with pain) and general coping tasks (preserving emotional balance) using various coping skills.

Of all the components of stress and coping models, coping has received the most attention in the chronic disease literature. Broad styles of coping with chronic illness that tend to be either adaptive (e.g. approach and problem-focused) or maladaptive (e.g. avoidant) have been identified (e.g. Taylor & Stanton, 2007; Roesch et al., 2005; Moskowitz, Hult, Bussolari, & Acree, 2009), including a number of studies specifically examining MS (see chapter 3). However 'coping' is a broad concept, incorporating both behavioural and cognitive efforts to manage a stressor as well as its emotional impact. Many other theoretical approaches that have not been extensively applied to the context of MS provide useful ways of considering the coping aspect of stress and coping frameworks in a more detailed and sophisticated way (see Cognitive Adaptation, Acceptance and Emotional Regulation Processes sections below).

Coping resources, or internal and external factors that are available to individuals when coping with a stressor have also been well-researched within chronic illness literature. The presence and adequacy of social support has been extensively studied and has been established as having both a general direct beneficial effect, and a buffering effect against the negative effects of stressful events (Cohen & Wills, 1985). Personality traits and their interaction with coping styles and strategies and adjustment outcomes have also been discussed and researched. Such internal 'resources' include trait optimism (Scheier, Carver, & Bridges, 2001) information-seeking style (Miller, Brody, & Summerton, 1988) and sense of coherence; a tendency to see the world as comprehensible, meaningful and manageable (Antonovsky, 1987). Certain personality factors appear to buffer the effects of stress; acting as protective resources. Importantly, some of these characteristics may be fairly stable and entrenched, and therefore less relevant for targets for interventions. However, understanding the influence of the coping resources which the person can draw on may help explain why some people struggle more with adjustment and may help

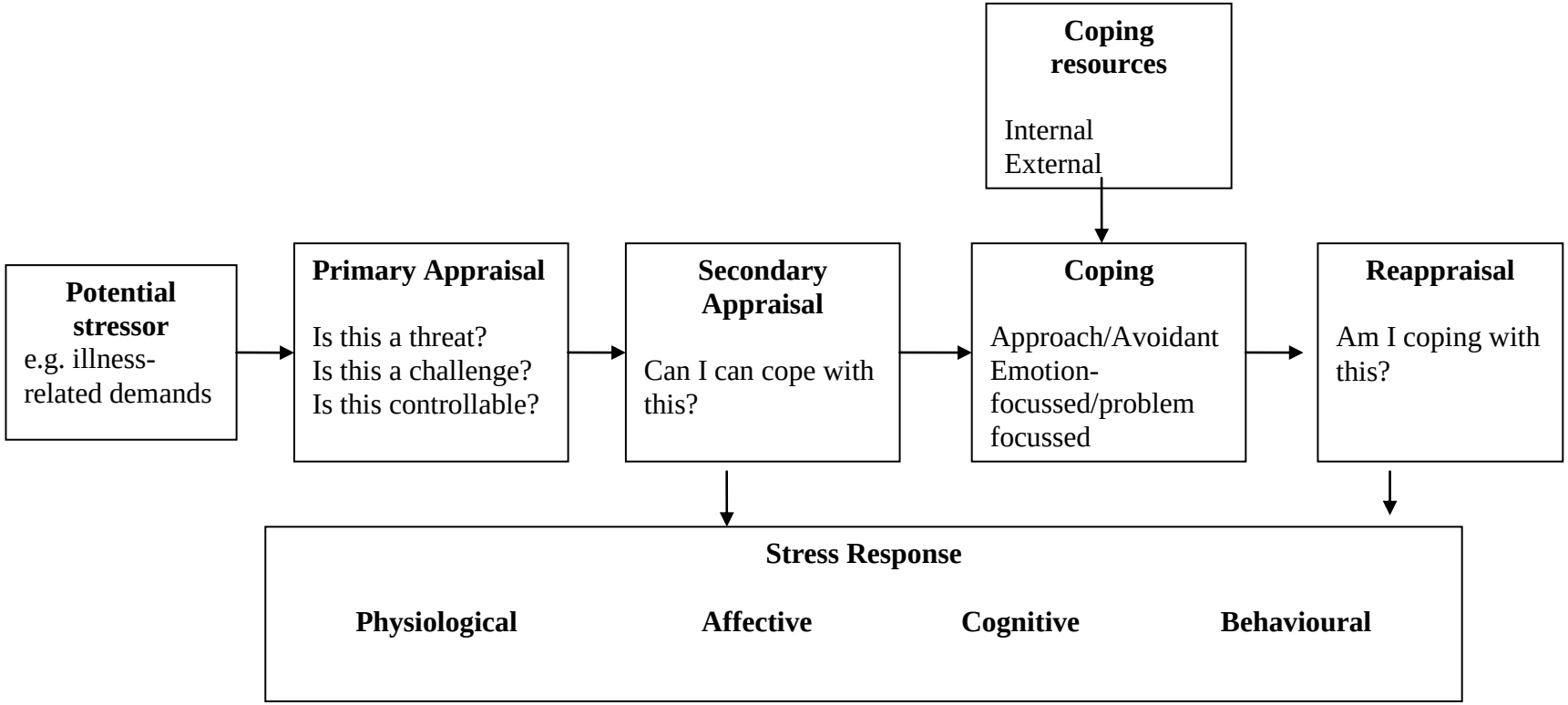

Figure 2: A Stress and Coping Model based on Lazarus & Folkman (1984) and adapted from Taylor (2009) and Ayers and De Visser (2011)

identify people who may benefit from interventions to boost more modifiable determinants of adjustment outcomes.

Stress and coping frameworks offer useful overall models showing a dynamic process of thinking and behaving determining adjustment outcomes in the context of illness-related stressors. The approach is flexible enough to incorporate many variables under its broad definition of coping and coping resources. It can also be used to explain multiple adjustment outcomes since it conceptualises stress as consisting of emotional, cognitive, behavioural and physiological components. Stress and coping frameworks, are also not limited to explaining responses to the illness itself. They are general enough to explain responses to both illness- and symptom-related stressors as well as broader life stresses which may or may not be directly related to MS, but may still influence adjustment outcomes such as distress and QoL.

So far, MS research has not typically tested stress and coping theory in its entirety or explored the specific hypotheses it generates regarding the buffering influences of appraisal and coping on negative outcomes. Instead, research has tended to focus on isolated elements of the theory (e.g. Aikens et al., 1997; McCabe, McKern, & McDonald, 2004; Wineman, Schwetz, Goodkin, & Rudick, 1996). MS research appears to have restricted its analysis of coping to simple distinctions between approach/avoidance and problem/emotion-focused strategies and has not made use of a range of frameworks which can usefully elaborate on coping responses in chronic illness. Nonetheless, stress and coping frameworks elucidate key areas that influence adjustment which can be potentially modified within psychological interventions: cognitive appraisal of stressors, coping strategies and coping resources.

2.3.3.3. Cognitive adaptation

Various theoretical models have emphasised the importance of adopting helpful ways of thinking about the self, and the situation. Taylor (1983) argued that successful adjustment requires the development and maintenance of cognitive illusions in these domains, which protect against current and future threats to wellbeing. Park and Folkman (1997) argue that a serious illness can shatter sets of beliefs individuals have accumulated which help to

predict and negotiate life and propose that reinterpretation of the meaning of the event or revisions of fundamental beliefs are necessary to restore emotional equilibrium

Another approach highlighting cognitive adaptation specifies that a phenomenon called 'response shift' buffers the impact of deteriorating health or abilities on psychological wellbeing. Response shift involves changing how a target construct (e.g. good QoL) is evaluated by changing internal standards of measurement, changing values, or reconceptualising the construct (Sprangers & Schwartz, 1999).

Control Process theory (Carver & Scheier, 1990; Carver & Scheier, 2000) also suggests that positive adjustment in the face of adversity and goal disruption can be achieved by shifts in 'reference' or goal values. For instance, in the face of increasing physical impairment, the reference value for an acceptable amount of time to spend on a task is increased. Another way that discrepancies between reference values and reality can be reduced is by scaling back or relinquishing goals (Rasmussen, Wrosch, Scheier, & Carver, 2006; Carver & Scheier, 2000).

Sharpe & Curran (2006) recognised commonalities between the various theories based around cognitive adaptation and synthesised key ideas into a model. The model incorporates various cognitive coping strategies relating to reframing or reconceptualising including downward social comparison, benefit-finding, response shift, and reprioritising goals. Individuals first initiate changes in recently-acquired and less rigid beliefs. If this fails to restore equilibrium, more fundamental beliefs are changed. The theory suggests that poor psychological function results when individuals cannot successfully develop more helpful views of the illness, their world or themselves.

2.3.3.4. Acceptance

The idea of acceptance has long featured in theories of successful adaptation to adverse life events, including illness (e.g. Telford et al., 2006; Kubler-Ross, 1969). The concept has recently been operationalised within the acceptance and commitment therapy (ACT) framework (Hayes, Strosahl, & Wilson, 1999). ACT emphasises psychological flexibility as critical for positive mental health. Acceptance, a key element of flexibility is conceptualised as a willingness to experience psychological events (i.e. thoughts, feelings,

sensations) without changing, avoiding, or controlling them, accompanied by taking action congruent with one's values and goals (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Acceptance has received little attention within MS literature, although it has intuitive appeal for understanding helpful responses to an incurable, unpredictable disease which inherently involves some degree of hardship. The ACT framework has proven useful for understanding and promoting positive adjustment in other chronic conditions (Hayes, Luoma, Bond, Masuda, & Lillis, 2006).

2.3.3.5. Emotional regulation processes

Emotional regulation refers to the processes by which we influence which emotions we have, when we have them, and how we experience and express them (Gross, 1998). The importance of emotional regulation is gaining momentum within the illness adjustment literature. For example, the CSM was recently expanded to delineate how people regulate emotional responses to health threats (Cameron & Jago, 2008). Emotion regulation can be divided into processes which reduce or avoid the experience of emotion and processes which modulate an emotional response which is already in action (Gross, 1999). Maladaptive regulation appears to include repression, suppression and denial of emotions and conscious efforts to avoid distressing thoughts or emotional expression. These responses tends to be linked to increased distress, difficulties with social interaction and even physiological reactivity which may contribute to disease progression (de Ridder et al., 2008; Gross, 2002). In contrast, acknowledgement, processing and expression of emotions has been shown to promote good adjustment (de Ridder et al., 2008; Gross, 2002).

Emotion regulation style is considered a relatively stable individual characteristic. Nonetheless, interventions that teach more effective emotional regulation strategies appear to benefit people who have maladaptive ways of regulating emotional responses to their chronic condition (de Ridder et al., 2008). Willingness to experience negative emotions also characterises several interventions which are accumulating evidence for their efficacy in reducing distress in populations with and without chronic diseases (e.g. ACT, Hayes et al., 1999; Mindfulness, Teasdale et al., 2000).

2.3.4. Theoretical approaches within this thesis

This chapter began by highlighting the multifaceted nature of adjustment and the importance of considering a broad range of psychosocial outcomes as indicators of successful adjustment. Given the broad scope of the phenomenon of interest, a range of many different factors and processes were expected to be important. A selection of the many theories and frameworks that have been used to understand adjustment to chronic illness have also been briefly discussed. All of these appear to have some relevance to understanding and promoting adjustment to MS, or may have useful elements. Given that there is no clear indication as to why one theory may be better than another the next chapter contains a systematic review of existing research which has investigated psychological factors involved in adjustment to MS. The review confirms that a large array of variables from a range of different theoretical perspectives are associated with various adjustment outcomes in pwMS. These are then brought together to present a working model of adjustment to MS, elements of which are tested and built upon in the empirical chapters that follow.

2.4. Methods for investigating adjustment

The following sections present a brief outline of qualitative and quantitative research methods. It then proceeds to discuss how the two approaches can complement each other, and how their contributions will be maximised within this thesis to help build understanding of MS adjustment.

2.4.1. Characteristics of quantitative and qualitative research methods

Quantitative research is generally associated with the realist or positivist paradigms (Yardley & Bishop, 2009). This approach has traditionally dominated psychology as it has strived to demonstrate its ‘scientific’ status. It has particularly permeated health psychology due to its links to medical science (Dures, Rumsey, Morris, & Gleeson, 2011). Realists seek to ascertain objective truths and generalisable laws through careful observation and experimentation. Discrete, precisely operationalised variables are assessed using standardised measures with established reliability, procedures are applied

consistently, representative samples are sought, and where possible, experimental procedures are used to reduce or eliminate confounding variables.

Qualitative research is typically associated with interpretive or constructivist paradigms. This tradition challenges the possibility of 'objective' knowledge and contends that our understanding of the world is inevitably shaped by our particular subjective and socio-cultural experiences (Yardley & Bishop, 2009). Qualitative researchers collect data in ways that avoid participant responses being constrained or dictated by the researcher. Often this involves interviews or focus groups. This data provides rich and detailed non-numerical data on subjective meanings and experiences, preserving detail and context.

The methods used by each tradition have, of course, been heavily criticised by followers of the other. Realists criticise qualitative research as subjective, unscientific and lacking generalisability. Constructivists typically respond that the realist focus on generalisable laws and unbiased measurement is outdated and that a qualitative approach is more enlightened and appropriate (Michell, 2004). They contend that the human mind and behaviour is not reducible to quantitative investigation and alternative means of gaining understanding are required (Yardley & Bishop, 2009).

2.4.2. Combining qualitative and quantitative research

Qualitative and quantitative approaches have traditionally been portrayed as rivals, inhabiting two incompatible paradigms, and divided over fundamental philosophical issues. However, the differences and unease between the two may have been overstated (Yardley & Bishop, 2009; Pope & Mays, 1995). An approach increasingly advocated within psychology and health services research is that both methods are valuable and acceptable and that by combining insights gained from both the strengths of one can be used to address some of the weaknesses of the other and achieve a broader understanding of the topic under study (Dures et al., 2011; e.g. Kelle, 2006; Pope & Mays, 1995; Yardley & Bishop, 2009).

It is argued that qualitative methods allow access to areas not amenable to quantitative research (Pope & Mays, 1995). Understandings gained from qualitative research can help formulate hypotheses, operationalise variables and theoretical concepts and construct

research instruments for quantitative studies with sensitivity perhaps otherwise unrecognised by researchers outside of that sociocultural context (Kelle, 2006). Qualitative research allows people with experience of the phenomenon under study to articulate their personal experiences and viewpoints, rather than conforming to categories and terms imposed on them by others (Sofaer, 1999). Unlike quantitative methods, which seek to remove sources of bias and variability to achieve reliability and precision, qualitative research tends to have high ecological validity; preserving context and nuanced detail. The open-minded inductive approach allows qualitative research to challenge current understandings and definition, question taken-for-granted concepts and illuminate unspoken assumptions. Key weaknesses of qualitative research: its lack of generalisability and its subjective nature, can be complemented by the strengths of quantitative approaches. Observations or hypotheses drawn from small, unrepresentative samples in qualitative studies can be further examined and tested in large-scale quantitative studies with steps taken to enhance reliability and reduce bias. Quantitative studies can address issues of generalisability, causality, and the magnitude and consistency of associations or differences and make strong claims, since alternative explanations have been excluded or controlled. Further qualitative research can then shed light on unexpected or incomprehensible statistical findings. Use of both quantitative and qualitative evidence has been specifically recommended throughout the process of developing and evaluating complex interventions such as psychological interventions (Campbell et al., 2000; Campbell et al., 2007). The wider perspective of qualitative methods can be vital in adequately understanding an intervention's processes of action and outcomes (Sofaer, 1999).

It is recommended that the strengths of different methods be considered when selecting the method most appropriate to the research question. In addition, research findings should be integrated with insights gained from other approaches (Yardley & Bishop, 2009; Kelle, 2006) Several commentators suggest that best practice often involves an iterative process of alternating steps of qualitative and quantitative research (Kelle, 2006) although this may not always be realistic within time and funding constraints (Yardley & Bishop, 2009).

2.4.3. Challenges with mixing methods

Despite the advantages in combining methods, the practice inevitably raises issues because of the profound differences in epistemology and ontology underlying the two research traditions. The philosophical tradition of pragmatism, however, offers a framework in which both approaches can be used and valued for their distinct contributions. Pragmatism does not aim to establish objective knowledge independent from human experience A functional definition of knowledge is adopted whereby knowledge is correct depending on its consequences; the extent to which it helps achieve its goal (Yardley & Bishop, 2009; Tashakkori, 2006). By adopting pragmatism, researchers are not bound by one epistemology and can use either qualitative or quantitative approaches or both to enhance scientific understanding of human experience (Dures et al., 2011).

Another challenge for combining qualitative and quantitative methods is effective and appropriate integration. A recent tendency to combine qualitative and quantitative methods without consideration of the aforementioned debates and controversies has been criticised (Kelle, 2006). Without sufficient understanding of the paradigms researchers may inadvertently violate assumptions of one or other of the approaches or fail to maximise the unique potential of each method. For example, qualitative research is frequently employed as an adjunct to quantitative research and used merely to elaborate or illustrate quantitative findings rather than using its potential to challenge and discover. Furthermore, if findings are contradictory, qualitative evidence risks being discounted as weaker and less objective, rather than being interpreted as a different level of evidence, enriching understanding (Yardley & Bishop, 2009). There are no easy solutions to these issues. However, researchers have been urged to be clear about the reasons for adopting methods, the specific aims of each component, how findings from different paradigms will be integrated, and which approach, if any, will be prioritised (e.g. Yardley & Bishop, 2009; Dures et al., 2011).

Whilst the term ‘mixed methods’ is frequently adopted the extent to which the methods can and should actually be *mixed* has been debated. Preserving unique aims and characteristics of each methods, and integrating their findings in a manner that respects the different, but often complimentary contributions of each is recommended. Yardley and Bishop (2009) propose the terminology ‘composite analysis’ to describe the approach of conducting separate studies which are acknowledged as providing overall insights that are greater than the sum of these parts.

A related point is the necessity of evaluating different methods according to criteria that are consistent with their disparate philosophies and objectives. Many criteria for judging quality appear universally applicable to scientific research (e.g. impact and importance and transparency of methods) whereas other criteria are specific to particular methods (Yardley, 1999; Elliot, Fischer, & Rennie, 1999). For instance, ensuring statistical power, and removal of bias are issues only relevant to quantitative research. Attention to issues such as owning one's perspective (Elliot et al., 1999) and sensitivity to context, commitment and rigour (Yardley, 1999) have been proposed as important issues for judging qualitative research.

2.4.4. Research methods within this thesis

Although several qualitative studies of experiences of MS have been conducted, the realist, quantitative approach is dominant within MS adjustment research. Whilst powerful and appropriate for many research questions, the quantitative dominance may also have restricted the study of adjustment. As described earlier in this chapter, adjustment has typically been narrowly defined and conceptualised as a mental health outcome with discrete predictors rather than a personal, complex and evolving process. Variables to be studied tend to originate from previous research, theory or clinical observations rather than from a sensitive examination of the experiences of pwMS. Qualitative methods have been declared highly appropriate for the study of dynamic processes (Braun & Clarke, 2006; Yardley, 1999) and the subtleties and personal meanings inherent in living with chronic illness (Conrad, 1990). Therefore, further work on MS adjustment would benefit from qualitative as well as quantitative investigation.

This thesis adopts a pluralist research strategy consisting of a systematic review of quantitative research studies, two original quantitative studies and two original qualitative studies. A pragmatic philosophy underlies the research programme. Methods are chosen in order to best match research aims and complement other thesis components with neither perspective considered superior. Each empirical study contains a rationale for and discussions of findings draw on insights from earlier chapters with different methods. The final chapter integrates findings and draws conclusions from across the empirical and review chapters, and reflects on the value of this composite analysis research strategy.

Chapter Three: A systematic review of psychological correlates of adjustment outcomes in people with MS

3.1. Introduction

Much of the existing research into adjustment to MS has involved hypothesising psychological variables that may be associated with, predict, or explain positive or negative adjustment outcomes, and conducting studies which measure these factors and analyse their relationships. In recent years the number of such studies has been increasing rapidly. Although there have been review papers which have discussed adjustment issues in MS (e.g. Mohr & Cox, 2001) to date the large body of literature exploring psychological correlates of adjustment outcomes in pwMS has not been reviewed in a thorough or systematic manner which means it is difficult to obtain a reliable overall impression of the findings from this body of research. As multiple similar studies accrue, a review and synthesis of the research becomes increasingly important. The purpose of this review was therefore to systematically review existing literature which addressed *psychological factors* that may be associated with, predict, or explain *adjustment outcomes* in MS.

The aims were to

a) identify what types of psychological factors have been studied to date
b) gain an overview of the strength of evidence for relationships between a range of psychological variables and adjustment outcomes in MS
c) Identify common methodological weaknesses in the research, gaps within the literature, and directions for future research.

For the purposes of this review it was necessary to make a conceptual distinction between factors that might be involved in predicting or explaining positive or negative outcomes, and the outcomes themselves. Thus, the term *psychological factors* is used within this review to conceptualise factors relating to the individual's attitudes, thoughts, feelings, and behaviours that would be relevant and possible to address in psychological interventions. The term *adjustment outcomes* relates to indicators of positive or negative psychosocial adjustment such as psychological or emotional wellbeing, social adjustment, QoL, and subjective, self-reported impact of the illness on psychosocial life domains.

3.2. Method

3.2.1. Search Strategy

Electronic databases (Medline, Embase, Web of Science, Cinahl and PsychInfo) were searched for studies published in English between 1980 and April 2007 that examined psychological factors relating to adjustment outcomes in MS. Search terms (see appendix A) were customised to each database and involved combining key word searches for a list of adjustment terms (e.g. 'psychosocial adjustment', 'depression', 'quality of life', 'emotional adjustment'), terms such as 'determin$', 'predict$', 'correlat$', and the term 'Multiple Sclerosis'. Medline retrieved 338 articles. Embase, Web of Science, Cinahl and PsychInfo retrieved 509, 225, 126 and 53 articles respectively. After removing duplicates 677 articles remained. Initial inspection of these abstracts found that 575 (85%) clearly did not address the research question. However 102 were potentially relevant. Full versions of these articles were obtained and reviewed against inclusion criteria.

Fifty nine of the papers identified through the electronic searches were ultimately included in the review. Examination of the reference lists of these included articles obtained another 24 potential articles of which ten met inclusion criteria. Hand-searching the three journals which published the largest number of identified studies (Multiple Sclerosis, Journal of Psychosomatic Research and Nursing Research) located three more studies which were obtained and scrutinized; two met inclusion criteria. One additional paper was identified, reviewed and included following examination of the reference lists of these articles. Ultimately the search strategy resulted in identifying a total of 72 studies eligible to be included in the review

Studies were included if they were empirical quantitative research reports published in peer reviewed journals. Studies had to examine relationships between psychological factors and adjustment outcomes in pwMS. Where studies involved control or comparison groups, results for the MS participants had to be reported separately. A number of fundamental methodological quality control criteria were applied. Studies were excluded if they did not analyse or report data using appropriate inferential statistics or did not use published or appropriate and replicable multi-item measures to assess both psychological factors and adjustment outcomes.

3.2.2. Data Extraction

Information from the 72 included studies that was relevant to the research question and in line with inclusion criteria was systematically extracted and tabulated in order to aid comparison and synthesis of the studies. Data not corresponding to review inclusion criteria were not considered even if the study as a whole was eligible for review. Thus, for some studies, certain results were extracted and others disregarded. Extracted data comprised publication data (author/s, date), sample details (size, context, mean age, gender proportions, type/course of MS, relapse/remission status, mean time since diagnosis, mean EDSS scores) study details (design, statistical analyses used, adequacy of statistical control for measures of illness severity, measures used to gauge psychological factors and adjustment outcomes) and key findings relating to the review question. Appendix B is an abridged version of this table.

3.2.3. Synthesis

The broad and multifaceted nature of the research question and the heterogeneity of included studies precluded meta-analysis. Therefore, a narrative synthesis was conducted, guided by methods described by Popay et al. (2006). In line with the aim of getting an overview of the strength of evidence for different types of psychological factors, psychological factors were grouped into overarching conceptually or thematically related categories (e.g. social support, coping strategies, control-related variables). Mini-reviews on each category of predictors were then conducted. The importance of each psychological factor was considered by combining a count of the studies that identified or did not identify significant relationships with attention to their methodological quality. Patterns in the data were examined and possible sources of heterogeneity between studies were explored including moderators of results such as sample size, characteristics or methodology. Consideration was also given to identifying discrepancies, uncertainties, and unanswered questions.

3.3. Results

3.3.1. Overview of the included studies

3.3.1.1. Designs and methodology

The majority of studies (*n*=58) were cross-sectional, measuring both psychological factors and adjustment outcomes at one point in time. Twelve studies used longitudinal designs with study follow-up periods ranging from just 3-6 weeks to 5 years. Sample sizes varied from 18 to 1310 participants with most sample sizes falling between 50 and 150 (*n*=40). However, a few included studies comprised less than 25 participants or more than 500.

Most studies used self-report data for measurement of both psychological factors and adjustment outcomes, frequently in the form of postal questionnaires. However, many studies also used some form of structured interview for some of the measures. The included studies examined an array of adjustment outcomes. Depression was the most common outcome of interest in the papers, although other aspects of mental health and emotional wellbeing and factors such as QoL, relationship satisfaction, social adjustment, and life satisfaction were also studied.

Results were typically presented as correlational data or regression analyses. Only 28 studies made some attempt to control for the confounding effects of disease severity on adjustment outcomes in their analyses (e.g. by conducting partial correlation or hierarchical multiple regression with disease severity entered on the first step). A range of different disease severity measures were employed in this regard, from objective, clinician-rated EDSS scores to less valid and robust self-reports on physical subscales of QoL indexes or sickness impact measures.

3.3.1.2. Sample characteristics

The majority of included studies were conducted in the USA (*n*=31), Australia (*n*=15) and Canada (*n*=8). Most studies recruited participants via patient organisations and support groups (*n*=31) or via health services such as neurologists, MS clinics and hospitals (*n*=28). The remainder used a mixture of sources (*n*=11). Two studies failed to report the source of

participants. All studies reported including participants with either clinically definite or probable MS. Many cited using the Poser criteria for diagnosis (Poser et al., 1983) as study entry criteria.

Gender proportions were reported by 68 studies. All studies contained more women than men. 59 studies reported the mean age of their overall sample. Most samples had a mean age of between 41 and 50 (*n*=53). Forty-eight studies reported the mean time since participants' MS diagnoses. Although there was a broad range, many (*n*=27) used samples that had been diagnosed an average of 7-11 years previously and very few study samples had a mean diagnosis of less than five years or more than fifteen years previously. Just 19 studies reported mean EDSS scores of the sample. Of these, most people in the samples had moderate disability but were able to walk without aid for around 200 meters. No studies had a mean EDSS of over 7 (essentially restricted to a wheelchair). Only 34 studies reported the course/type of MS. Of these, most (*n*=18) studies included a relatively balanced proportion of RRMS and progressive disease. Eleven studies included exclusively or predominantly patients with RRMS and four included solely or mainly participants with progressive forms. Studies rarely stated the proportion of patients currently experiencing exacerbation or relapse of symptoms. Of those that did report this data it was common for no participants to be currently in exacerbation (due to the studies' exclusion criteria) or for a small minority to currently be in exacerbation.

Table 1 depicts the wide selection of psychological factors examined within the 72 included studies. With the exception of a number of studies guided by stress and coping frameworks (Lazarus & Folkman, 1984) and cognitive models of psychopathology (e.g Beck, 1976) few of the reviewed studies were based around theoretical models or frameworks of adjustment.

The following sections summarise and synthesise findings regarding the relationships between psychological factors (grouped into thematically or conceptually-related categories) and adjustment outcomes. Given the large number of studies reviewed, a detailed presentation of individual studies is beyond the scope of this chapter. The focus is therefore on providing a broad overview of the evidence available to date including the theoretical or conceptual backgrounds of the research.

Table 1: Psychological factors examined in relation to adjustment outcomes

Category	Psychological factor	*N* studies	Study reference number/s[a]
Stress and Coping	Perceived Stress	11	1,11,14,24,28,35,45, 50,53,54, 61,
	Stress Appraisal	3	44,45,70
	Coping strategies	30	1,2,3,5,7,12,13,18,19 ,20,25,26,28,29,30,3 1,32,33,34,35,36,39, 40,43,44,45,46,49,70 ,71
Social Support and interactions with others	Perceived social support	14	11,14,24,32,37,43,45 ,50,53,56,57,61,62,6 8
	Relationship characteristics	1	61
	Partner/Spouse responses	1	57
	Family characteristics	2	28,57
Cognitive models of Psychopathology	Dysfunctional cognitions/thinking errors	3	22,58,59
	Attributional style	1	23
	Affective memory biases	1	6
Illness and symptom cognitions	Illness representations	2	21,55
	Illness uncertainty	9	15,25,26,38,41,68,69 ,70,71
	Symptom attribution	1	64
	Cognitive and behavioural responses to symptoms	1	60
	Pain-related cognitions	1	43
	Hypochondriac beliefs	1	64
Perceptions of control and self-efficacy	Control	5	9,16,18,27,28
	Helplessness	4	22,58,59,66
	Self-efficacy	10	4,8,12,13,52,5,59,61, 62,67
	Outcome expectancies	1	67
Positive Psychology	Optimism	5	7,8,12,13,15
	Hope	3	18,26,51
	Benefit-finding	3	47,48,49
	Acceptance	2	10,17
	Spirituality	2	5,38
Health behaviours	Health-promoting behaviours	4	17,61,62,63
	Perceived barriers	2	61, 62
Miscellaneous	Magical ideation	1	65
	Denial	1	42
	Personality traits	2	72, 66

[a] Study reference numbers correspond to the table in Appendix B

3.3.2. Stress and Coping

As outlined in the previous chapter, the stress-coping model of Lazarus & Folkman (1984) is a dominant paradigm in the field of adjustment to chronic illness. According to this model, adjustment is influenced by the individual's appraisals of stressors, and the coping strategies they use for managing these demands. The following sections deal first with the appraisal aspect of the model and then the coping aspects.

3.3.2.1. Stress perception and appraisal.

Experiencing stressful life events may be associated with more adjustment difficulties. However, since this review was concerned with *modifiable* psychological factors, studies that simply investigated occurrence or frequency of life events were not eligible for inclusion. Included studies which investigated stress had to gauge the subjective, perceived degree of stress reported by the participant. Eleven such studies were reviewed (Table 1).

Across studies, high perceived stress was associated with worse adjustment. This link was found across types of perceived stress (e.g. MS-related stress, everyday hassles, ongoing general stress, psychosocial stress or financial stress). The stress-adjustment relationship was also evident across a wide range of outcomes: depression (Aikens et al., 1997; Gilchrist & Creed, 1994; Pakenham, 1999; Patten et al., 2000), anxiety disorders (Korostil & Feinstein, 2007), psychopathology (Ron & Logsdail, 1989), mood, life satisfaction and psychological wellbeing (Marks & Millard, 1990), suicidal intent (Feinstein, 2002), QoL (McCabe & De Judicibus, 2005; Rumrill, Jr., Roessler, & Fitzgerald, 2004; Stuifbergen, 1995), distress (Pakenham, 1999) and social adjustment (Pakenham, 1999).

In the only longitudinal study, perceived life stress was strongly associated with depression, both concurrently and prospectively, predicting 34% of its variance at baseline and 19-20% at six and twelve months (Aikens et al., 1997). Out of the seven cross-sectional studies that performed regression analysis, perceived stress explained a significant proportion of the variance in at least some of the adjustment outcomes examined in five studies (Aikens et al., 1997; McCabe & De Judicibus, 2005; Pakenham, 1999; Patten et al., 2000; Rumrill, Jr. et al., 2004) whilst two studies found it was not an important predictor (Feinstein, 2002;

Stuifbergen, 1995). Three studies accounted for disease severity in their models and two of these still identified perceived stress as a predictor (Aikens et al., 1997; Pakenham, 1999).

Three studies specifically examined the link between cognitive appraisal of MS-related stressors, and levels of adjustment (Table 1). Appraisal involves an interpretation of a stressor; including appraisal of threat, challenge and controllability (Lazarus & Folkman, 1984). In the only longitudinal analysis appraisal did not predict change in adjustment outcomes at 12 months; baseline levels of adjustment predicted the majority of the variance (Pakenham, 1999). However, all three studies found that appraisal was related to *concurrent* adjustment after taking into account MS severity; threat appraisals were the most important type of appraisal and were consistently related to worse adjustment. Appraisal explained 29% of variance in emotional wellbeing (Wineman, Durand, & Steiner, 1994) and between 6% and 14% of variance in depression, distress and social adjustment (Pakenham, Stewart, & Rogers, 1997; Pakenham, 1999).

3.3.2.2. Coping strategies.

As discussed in the previous chapter, coping strategies, or efforts to manage stressors, are often broadly classified into emotion or problem-focused strategies. Emotion-focused strategies are directed at reducing the emotional distress elicited by the stressful situation, whereas problem-focused strategies are directed at altering the source of stress (Lazarus & Folkman, 1984).

Thirty reviewed studies considered the relationships between coping strategies and adjustment outcomes (Table 1). Links were consistently demonstrated between choice of coping strategy and a range of adjustment indices including depression, distress, anxiety, QoL, relationship satisfaction, and social adjustment. Across studies, use of certain emotion-focused strategies was consistently and strongly related to negative adjustment outcomes. Specifically, wishful thinking (e.g. hoping a miracle might happen) and escape-avoidance coping (e.g. trying to forget the whole thing) were regular and strong correlates or predictors of worse adjustment (Aikens et al., 1997; Arnett, Higginson, Voss, Randolph, & Grandey, 2002; Beatty et al., 1998; de Ridder, Schreurs, & Bensing, 2000; Fournier, de

Ridder, & Bensing, 1999; Fournier, de Ridder, & Bensing, 2002; Jean, Beatty, Paul, & Mullins, 1997; Kroencke et al., 2001; Lynch, Kroencke, & Denney, 2001; McCabe, 2006; McCabe & McKern, 2002; McCabe et al., 2004; McCabe, 2005; McCabe & De Judicibus, 2005; Mohr, Goodkin, Gatto, & Van der Wende, 1997; Pakenham et al., 1997; Pakenham, 1999; Mohr et al., 1999). In contrast, problem-focused coping, seeking social support (e.g. talking to someone to find out more about the situation) and the more adaptive emotion-focused strategy of positive re-appraisal (e.g. rediscovering what is important in life) tended to relate to better adjustment (Aikens et al., 1997; Arnett et al., 2002; Arnett & Randolph, 2006; de Ridder et al., 2000; Kroencke et al., 2001; Marks & Millard, 1990; McCabe, 2006; McCabe & McKern, 2002; McCabe et al., 2004; McCabe, 2005; McCabe & De Judicibus, 2005; Mohr et al., 1997; Mohr et al., 1999; Pakenham, 2001; Pakenham, 1999; Pakenham, 2006). However, the strength of these positive relationships tended to be of a lesser magnitude than findings regarding the less adaptive emotion-focused coping strategies.

Although taken as a whole, findings regarding which types of coping are associated with better or worse adjustment were consistent, findings about the importance and strength of coping strategies as correlates or predictors of adjustment were much more mixed. Six studies reported simple correlations; four of which found clear and consistent relationships between coping and outcomes (Beatty et al., 1998; Jean, Paul, & Beatty, 1999; Marks & Millard, 1990; Mohr et al., 1999). Of the twelve cross-sectional studies using regression analysis, nine found coping strategies predicted adjustment (Arnett et al., 2002; Kroencke et al., 2001; Lynch et al., 2001; McCabe & McKern, 2002; McCabe et al., 2004; McCabe & De Judicibus, 2005; Osborne, Jensen, Ehde, Hanley, & Kraft, 2007; Pakenham, 2001; Pakenham et al., 1997) whilst three did not (McCabe, 2002; Wineman et al., 1994; Wineman et al., 1996). Out of six longitudinal regression studies, four demonstrated that coping predicted future adjustment (Aikens et al., 1997; McCabe, 2005; Pakenham, 1999; Pakenham, 2006) but two did not (McCabe, McKern, McDonald, & Vowels, 2003; McCabe & Di Battista, 2004). There were large differences in the reported amount of variance explained by coping strategies between studies. In concurrent analyses variance explained ranged from 3% to 39%. In longitudinal analyses, prior coping tended to play a smaller role accounting for 4% to 15% of the variance in adjustment outcomes. Interestingly, of the seven studies that controlled for level of disability or disease severity, five found coping was still an important predictor, over and above this influence.

Interpretation of the variability of reported findings is fraught with difficulties because studies had multiple sources of heterogeneity. Studies differed widely in terms of sample size (*N*= 31, Marks & Millard 1990; *N*=502, Pakenham, 2006), variables controlled for in regression analyses, types of adjustment outcomes assessed, coping instruments employed, and the stressors or contexts with reference to which participants are asked to describe their coping efforts. Studies also differed in whether they reported detailed findings from specific coping strategy subscales (e.g. confrontive coping, distancing etc) or only overall results from higher-order coping domains (e.g. problem or emotion-focused). Potentially, these differences between studies might explain some of the discrepancies in reported findings. However, scrutiny of the available data did not reveal any clear relationships between such study features and results.

In summary, the stress studies were fairly consistent in demonstrating that high perceived stress both correlates with, and predicts worse adjustment and is important regardless of disease severity. Cognitive appraisal of MS also appears to be important; evaluation of the illness as threatening is associated with worse outcome across several adjustment domains. However, only three studies were reviewed and longitudinal evidence is lacking. Coping studies are plentiful and most have demonstrated a consistent relationship between certain emotion-focused coping such as avoidance and wishful thinking and worse adjustment. Other strategies such as positive reappraisal and seeking social support appear to be related to better adjustment. However, beyond this general finding, there is little agreement between studies and their considerable heterogeneity precludes clear statements regarding the strength of coping as a predictor of adjustment.

3.3.3. Social Support and Interactions with Others

A key theme in the adjustment to chronic illness literature is the importance of coping resources, particularly the support provided by other people, in protecting against or moderating the negative psychological impact of physical illness. Fourteen of the reviewed studies (Table 1) examined links between social support and a range of adjustment outcomes by using measures which gauge the individual's evaluations of whether support is available and satisfactory. Twelve out of fourteen studies identified relationships between high perceived support and better adjustment. Few studies reported its unique

contribution as a predictor of adjustment, although those that did found it predicted 2-9% of the variance in depression and mental health after controlling for clinical and demographic factors (McCabe et al., 2004; Pakenham, 1999; Schwartz & Frohner, 2005).

Despite studies being fairly consistent in discerning a support-adjustment relationship much of the reviewed research is methodologically weak. All but one study employed a cross-sectional design, reporting simple correlations without taking into account possible confounding factors. Furthermore, four studies are problematic to interpret since they employed a measure which combines social support and stress into one summary score (Feinstein, 2002; Gilchrist & Creed, 1994; Korostil & Feinstein, 2007; Ron & Logsdail, 1989). The only longitudinal study which controlled for the influence of disease severity and relevant demographic variables and used a comprehensive social support measure, did not find that social support played a strong role in adjustment (Pakenham, 1999). Unfortunately the reviewed studies provide little detail regarding specific aspects of social support that are important in adjustment. They have tended to link a generic social support score to adjustment outcomes without examining details such as different support providers (e.g. family, friends, medical professionals) or types of support (e.g. instrumental or social companionship). One study that did separate social support into different domains found interesting results. Perceived support bore little relation to the adjustment outcome (depression) but perceived unsupportiveness was strongly linked to worse depression (Wineman, 1990).

In a slightly different approach to the mainstream social support literature, a handful of studies have examined specific features of relationships with others in relation to adjustment. One study found that patients' perceptions of reciprocity in relationships were positively correlated with QoL whereas perceptions of conflict were negatively correlated with QoL (Stuifbergen, 1995). In another study, patients' perceptions of their spouse's responses to their illness influenced the patient's adjustment. Solicitous responses to disability were associated with worse adjustment. Encouraging responses to 'well behaviours' correlated with lower depression, but negative responses to disability were associated with worse mental health (Schwartz & Kraft, 1999). Two studies investigated perceptions of family characteristics. In one study, patient-perceived family cohesion and expressiveness was correlated with better outcomes on mood, life satisfaction and psychological distress (Marks & Millard, 1990). In another, perceived conflict was related

to worse mental health whereas perceptions of family independence were related to better mental health (Schwartz, 1999). Each of these studies consisted only of cross-sectional evidence from small samples and did not control for influences of disease severity. Nonetheless, perceptions of relationship characteristics and other people's responses seem to be related to adjustment and merit further investigation.

In summary, despite some methodological weaknesses, available research is fairly consistent in demonstrating that having satisfactory social support and positive interactions with significant others is associated with better adjustment, whilst unsupportiveness, and over-solicitous or critical responses are related to worse adjustment.

3.3.4. Cognitive Models of Psychopathology

Seven studies applied cognitive models of psychopathology to adjustment to MS (Table 1). As outlined in the previous chapter, this framework views poor adjustment (in particular depressed mood) as resulting from distorted information processing in the form of cognitive biases or errors (e.g. Beck, 1976). These thinking biases or errors are generic and applicable to life situations in general, rather than being specific to the experience of MS.

One study found that a range of dysfunctional cognitions relating to perfectionism, negative attributions, dependency and need for external sources of approval were associated with depressive symptoms (Kneebone, Dunmore, & Evans, 2003). Two similar studies examined response to vignettes about both general and MS-related situations (Shnek et al., 1995; Shnek et al., 1997). Cognitive errors such as catastrophising, overgeneralization, personalization and selective abstraction in response to the vignettes were positively correlated with depression. However, when measures of helplessness and self-efficacy about MS (discussed in section below) were included in the regression equation along with cognitive errors, helplessness became the strongest predictor.

A separate study considered attributional style (Kneebone & Dunmore, 2004). Results of the study showed that stable (the cause will continue to affect you) and global (the cause will affect other areas of life) attributions of hypothetical problems were significant

predictors of depression. Furthermore, global attributions interacted with reported negative life events (e.g. MS relapse) to predict depression.

Another study examined cognitive biases in relation to depression and pain (Bruce, Polen, & Arnett, 2007). Negative affective memory biases, or the tendency to recall more negatively valenced information, were positively correlated with depression. Cognitive biases were unique predictors, and also interacted with pain to predict depression; around 18% of variance was explained by cognitive biases, pain and their interaction. Patients with negative biases experienced more depressive symptoms as pain increased, whereas positive biases appeared to play a protective role.

Overall, research guided by a cognitive model of psychopathology has suggested links between dysfunctional beliefs and information-processing and poor adjustment. However, only a handful of studies have yet been reported and they have all considered depression as the outcome of interest rather than more broad adjustment outcomes such as wellbeing and QoL. Furthermore, since all extant studies are cross-sectional it is impossible to conclude that cognitive errors or biases preceded depression, rather than being a result of a depressive state.

3.3.5. Illness and Symptom Cognitions

Whereas clinical psychologists have focused on understanding depression in MS using cognitive models, researchers using health psychology models have studied a number of illness-specific cognitive constructs that may be involved in adjustment.

Inspired by the CSM (Leventhal et al., 1984; Leventhal et al., 2001; Leventhal, Brissette, & Leventhal, 2003), two studies investigated illness representations in relation to adjustment in MS and found discrepant results. In a longitudinal study representations were generally unrelated to concurrent and later depression, after accounting for demographic factors (Schiaffino, Shawaryn, & Blum, 1998). The other study (Jopson & Moss-Morris, 2003) was cross-sectional and used a more established measure of illness representations, the Illness Perceptions Questionnaire Revised (Moss-Morris et al., 2002). This study found a strong role for illness representations; they predicted significant

variance in a variety of adjustment outcomes, ranging from 11% of subjective physical dysfunction to 52% of emotional response to illness. Most findings held when disease severity (as measured by ambulatory ability) was factored in. Different illness representations were differentially important for different adjustment domains. However, certain representations were consistently associated with worse adjustment: a tendency to attribute a wide range of symptoms to MS, beliefs of lack of personal control over the illness, perceptions of severe illness consequences, representations of a cyclical illness timeline, believing MS was caused by psychological factors, and a lack of a coherent understanding of MS.

Nine cross-sectional studies have specifically investigated the role of illness uncertainty in adjustment. The concept of illness uncertainty includes perceptions of ambiguity, complexity, deficiencies in information and unpredictability regarding symptoms, diagnosis, treatment, relationships and future plans (Mishel, 1988). All studies demonstrated associations between high uncertainty and worse adjustment. The eight studies that employed regression analysis found that uncertainty predicted aspects of wellbeing such as depression, psychosocial adjustment, distress and mood. Those studies that reported its unique contribution to explaining such outcomes found it accounted for between 12.5% and 32% of the variance (McNulty, Livneh, & Wilson, 2004; Wineman et al., 1994; Wineman, O'Brien, Nealon, & Kaskel, 1993; Wineman et al., 1996). Although not all studies considered disease severity in their analyses, those that did found uncertainty was an important predictor over and above illness severity.

Another line of enquiry has looked at patients' cognitive interpretations of symptoms. One study looked at symptom attribution (Taillefer, Kirmayer, Robbins, & Lasry, 2002). Contrary to expectations, the extent to which participants endorsed somatising, psychologising and normalising attributions for everyday symptoms was unrelated to adjustment. However this study had a small sample size (N=40). Another larger study took a broader approach and examined a range of ways of interpreting and responding to symptoms (Skerrett & Moss-Morris, 2006). A number of unhelpful cognitive and behavioural responses were associated with worse social adjustment, explaining 26% of variance after taking into account disease severity factors. Embarrassment about symptoms and avoiding activity and resting in response to symptoms were particularly strong predictors. Another study investigated cognitions regarding pain (Osborne et al., 2007).

Catastrophic pain beliefs, beliefs that emotions influence pain and beliefs that other people should respond solicitously to pain were associated with worse adjustment after controlling for demographic factors, disease and pain severity.

In a slightly different line of enquiry, one study investigated beliefs associated with hypochondriasis including the conviction that one is ill, feeling more sensitive to pain, vulnerable to illness, and feeling that one's illness is insufficiently validated by others (Taillefer et al., 2002). Such beliefs were correlated with depression but did not predict mental and subjective physical functioning.

Overall, research investigating beliefs about illness and symptoms is in its infancy. Although there is fairly consistent evidence that illness uncertainty is linked to worse adjustment, other factors have only been investigated by one or two studies and existing evidence is somewhat mixed. However, a handful of well-designed studies using comprehensive measures have found that illness and symptom-specific cognitions can explain a significant amount of the variance in a range of adjustment outcomes.

3.3.6. Perceptions of Control and Self-efficacy

A number of reviewed studies examined control-related concepts in relation to adjustment outcomes (Table 1). Theories and existing research relating to control-related concepts predict that perceptions of a high degree of personal control over the achievement of desired outcomes are generally adaptive (e.g. Bandura, 1977; Rotter, 1966) whereas beliefs in the uncontrollability of situations tend to be maladaptive (Seligman, 1975).

Perceived control reflects an individual's beliefs about the degree of control achievable by themselves or others in different situations. A related concept, locus of control, refers to beliefs about responsibilities for outcomes (Rotter, 1966). Five cross-sectional studies investigated these control beliefs and yielded mixed results. The two studies that looked at generic control perceptions (i.e. in a range of life domains) found relationships between high internal or personal control and lower depression and distress, more positive mood and more life happiness (Devins et al., 1993; Halligan & Reznikoff, 1985).

A perception of helplessness regarding MS was investigated in four cross-sectional studies. All found positive correlations between helplessness and depression. In two studies helplessness was a very strong predictor, accounting for around 30% of the variance even after controlling for demographic factors and disease severity (Shnek et al., 1995; Shnek et al., 1997). However, one study found that despite a helplessness-depression correlation, helplessness was not responsible for differences in depression between two groups of pwMS (Kneebone et al., 2003).

Interestingly, the studies that examined health-specific locus of control (Hickey & Greene, 1989; Marks & Millard, 1990; MacLeod & MacLeod, 1998) found no relationships with adjustment outcomes. Conceivably these small studies may have been underpowered to detect what could be rather modest relationships. On the other hand, whilst feeling helpless may be maladaptive, strong beliefs in personal control over MS may not necessarily be helpful given the reality that MS is incurable and unpredictable.

Self-efficacy is the individual's appraisal of the extent to which they have the capabilities required to manage prospective situations (Bandura, 1977). Ten studies investigated the role of self-efficacy in adjustment. Three cross-sectional studies (Fournier et al., 2002; MacLeod & MacLeod, 1998; Stuifbergen, 1995) and one longitudinal study (de Ridder, Fournier, & Bensing, 2004) examined self-efficacy for life difficulties in general. These studies all employed different designs and found mixed evidence. Self-efficacy was associated with some adjustment outcomes but not others and no consistent patterns emerged across studies. In contrast, the seven studies which examined self-efficacy for health management found some evidence that it was linked to better adjustment. In prospective analyses, self-efficacy for functional ability and managing MS symptoms (Riazi, Thompson, & Hobart, 2004) and for controlling mood and maintaining social life (Barnwell & Kavanagh, 1997) predicted better adjustment at follow-up. Cross-sectional studies also found associations between positive outcomes and self-efficacy for managing MS (Shnek et al., 1995; Shnek et al., 1997) and self-efficacy for health-promoting behaviours (Stuifbergen, 1995; Stuifbergen, Seraphine, & Roberts, 2000). One small study found that self-efficacy for psychosocial adjustment predicted better adjustment cross-sectionally. Outcome expectancies (beliefs that illness management behaviours would produce a favourable outcome) did not add to the predictive power of self-efficacy alone (Wassem, 1992). Interestingly, self-efficacy for disease management was related to *worse*

adjustment. Since research tends to find that self-efficacy is beneficial for adjustment to chronic illness (e.g. Edwards, Telfair, Cecil, & Lenoci, 2001) this counter-intuitive finding may be a chance finding in a small study. Alternatively, this study may have tapped certain self-efficacy beliefs that relate to *controlling* the disease which may indeed be unhelpful in the context of MS.

Overall, people who have a high sense of personal control over their lives in general seem to adjust better to MS but beliefs about control over health appear to be less important, as long as the individual does not feel helpless. Self-efficacy appears to show the opposite pattern: more disease-specific constructs seem to have a stronger relationship with adjustment outcomes than more general self-efficacy. Finally, in all the research on control-related beliefs, only a handful of very heterogeneous studies have been conducted on each variable and large, longitudinal, methodologically robust studies are lacking.

3.3.7. Positive Psychology

In contrast to research that has examined dysfunctional cognitions and unhelpful responses to illness, some studies have approached adjustment from a positive psychology perspective and investigated a range of factors thought to enhance happiness and wellbeing (Table 1).

Optimism is expected to be related to better adjustment outcomes since optimists tend to continue with adaptive coping efforts when confronted with adversity (Carver et al., 1993). Five studies investigated aspects of optimism. Four cross-sectional studies found links between dispositional optimism, or a tendency to hold positive expectations of the future, and better adjustment. Optimism was associated with lower depression (de Ridder et al., 2000; Fournier et al., 1999; Fournier et al., 2002; Gold-Spink, Sher, & Theodos, 2000), less anxiety (Fournier et al., 2002), less negative affect and more positive affect (Fournier et al., 1999) and better physical, social and psychological adjustment (de Ridder et al., 2000). Pessimism was related to worse adjustment (de Ridder et al., 2000). Results regarding unrealistic optimism, an inclination towards wishful thinking and underestimation of risks of negative events, were more mixed. In one study unrealistic optimism was related to less depression (Fournier et al., 1999) and in another it was

unrelated to mental health outcomes (Fournier et al., 2002). In the only longitudinal study, neither type of optimism demonstrated a strong role in predicting adjustment at six month follow-up (de Ridder et al., 2004). However, the study is limited by its small sample consisting of participants with low levels of disease severity and short illness duration.

According to hope theorists (Synder, Rand, & Sigmon, 2002) a sense of hope, or the belief that we can find pathways to desired goals and become motivated to use those pathways, drives positive emotions and wellbeing. Three cross-sectional studies investigated hope-adjustment relationships. All found correlations between low hope and increased depression (Hickey & Greene, 1989; Lynch et al., 2001; Patten & Metz, 2002). Only one study performed regression analysis. Hope predicted lower depression in a model that included uncertainty, coping, disability and demographic factors. However the variance it explained was not reported (Lynch et al., 2001).

Benefit-finding is a specific type of adaptive coping strategy whereby despite adversity, people positively evaluate their circumstances and report gains such as personal growth, improved relationships and changes in priorities and personal goals (Pakenham, 2005). Three reviewed studies investigated benefit-finding and found it was positively correlated with positive adjustment and to a lesser extent inversely correlated with negative adjustment domains. The one study that reported regression analyses showed that benefit-finding explained significant variance (3-11%) in positive affect, dyadic adjustment and life satisfaction after demographic, clinical and stress variables were considered (Pakenham, 2005). However, it did not predict subjective health status, distress and negative affect. Across studies, perceptions of improved family relations was more strongly and consistently associated with adjustment than was a sense of personal growth.

Acceptance of illness, and an integration of changes into a person's sense of self and way of life (Stuifbergen et al., 2000), is widely thought to be beneficial for adjustment. However, only two reviewed studies investigated acceptance. Both only examined its impact on marital relationships. In one, lower acceptance was associated with worse impact (Harrison, Stuifbergen, Adachi, & Becker, 2004). In the other, it was unrelated to relationship satisfaction (Dupont, 1996).

Various researchers have suggested that spirituality is related to better adjustment to illness, possibly by providing a sense of coherence and meaning so that people understand their role in the universe, the purpose of life, and develop the courage to endure suffering (George, Larson, Koenig, & McCullough, 2000). Two reviewed studies investigated spirituality (Table 1). In one, spirituality was unrelated to distress (Beatty et al., 1998). In the other, it was were associated with better psychosocial adjustment (McNulty et al., 2004), explaining up to 18% of overall psychosocial adjustment and up to 34% of distress after accounting for demographic and illness factors. However, findings may be confounded since one subscale of the measure seemed to also tap aspects of adjustment outcomes.

Overall, studies tentatively suggest that various constructs associated with positive psychology are related to better adjustment outcomes. Dispositional optimism is fairly consistently related to better mental health and wellbeing. Hope appears to be related to less depression. Benefit-finding is also important, and appears to be more related to achieving positive adjustment (e.g. life satisfaction) rather than a lower likelihood of negative outcomes such as distress. Evidence regarding spirituality and acceptance is currently too limited to draw conclusions. Unfortunately, many studies fail to consider objective measures of disease severity. This precludes conclusions that the link between factors such as optimism, hope and benefit-finding and positive psychosocial adjustment are more than merely a reflection of less severe illness. Furthermore, the lack of longitudinal evidence means that nothing can be concluded regarding causal or temporal relationships between positive attitudes and positive adjustment.

3.3.8. Health Behaviours

Four studies explored relationships between adjustment and health behaviours; the frequency that a person reports engaging in activities to promote his or her physical and mental health (Table 1). These behaviours include physical exercise, healthy eating, and stress-management techniques. All studies discerned links between more health-promoting behaviours and better adjustment in terms of QoL (Stuifbergen, 1995; Stuifbergen et al., 2000; Stuifbergen, Blozis, Harrison, & Becker, 2006) and marital relationships (Harrison et al., 2004). One of these studies was longitudinal and found that continuation of exercise

behaviour over time predicted continuation of enhanced QoL. Furthermore, two studies found that perceived barriers to health-promoting behaviours were associated with worse QoL (Stuifbergen, 1995; Stuifbergen et al., 2000). Further research linking health behaviours to a wider range of outcomes would be valuable.

3.3.9. Miscellaneous Factors

A selection of studies found links between poor adjustment and magical ideation (te Wildt & Schultz-Venrath, 2004), denial defence mechanisms (Noy et al., 1995), and a range of personality traits (Zeldow & Pavlou, 1988; van der Werf, Evers, Jongen, & Bleijenberg, 2003). However, each of these studies was small, cross-sectional and methodologically weak. Without further study insufficient data is available to draw conclusions about the importance of these factors.

3.4. Discussion

3.4.1. Summary of key findings

This review aimed to identify studies which addressed *psychological factors* that may be associated with, predict, or explain *adjustment outcomes* in MS. Specifically, its aims were to determine which factors had been researched to date, synthesise the findings and achieve a summary of the evidence. It also sought to identify methodological problems with existing studies, and offer directions for future research.

Many studies have been conducted which examine relationships between psychological variables and positive or negative adjustment outcomes. Evidence is accumulating that a wide range of factors are consistently associated with certain adjustment outcomes. Of the factors reviewed, the strongest available evidence was for the link between perceived stress and certain avoidant emotion-focused coping strategies and negative adjustment outcomes. In line with the adjustment literature for other chronic illnesses (e.g. Curtis et al., 2005; Stanton et al., 2007), these factors were fairly consistently associated with worse adjustment outcomes and there was some evidence that they were important in predicting them over time. Some degree of evidence was also found for relationships between

adjustment outcomes and variables concerned with social support and interactions with others, psychopathology models, illness cognitions, control perceptions, positive psychology, and health behaviours.

3.4.2. A working model of adjustment to MS

Figure 3 depicts a working model of adjustment developed from the results of the systematic review. The model is intended as a useful way of conceptualising the complex process of adjustment to MS; something which was absent from the reviewed studies. The model adds to the existing MS adjustment literature by making sense of the numerous research studies which each identify different cognitive and behavioural factors and their relationships to specific adjustment outcomes. It draws on various theoretical frameworks which, standing alone, explain only isolated elements of the adjustment process.

The upper portion of the model concerns distal factors which may influence adjustment to MS. This part of the model is not unique and is based largely on Beck's cognitive model of emotional disorders (Beck 1974). The model suggest that an individual's personality and early experiences feed key beliefs about self and others. These beliefs influence goals, values, and behaviours. MS is conceptualised as a critical event (or indeed a series of critical events) whereby changes such as developing symptoms, getting a diagnosis, having a relapse or experiencing disease progression will often challenge existing values, goals and behaviours, disrupting the individual's emotional equilibrium and posing difficulties for maintaining wellbeing and QoL. At times like this emotional distress and personal disruption are to be expected. However, if they are prolonged and severe this constitutes adjustment difficulties.

The remaining sections of Figure 3 concern more proximal influences on adjustment outcomes. The model stipulates that the way that the individual thinks, behaves and the resources he/she has access to when dealing with life with MS are key influences on whether their psychosocial adjustment is successful (minimal distress and acceptable QoL) or unsuccessful (substantial ongoing distress, high impact of MS on many aspects of life, and unacceptable QoL). The figure summarises the psychological factors which this systematic review established were linked to either successful adjustment or difficulties

with adjustment and indicates the strength of existing research evidence for each variable. The model therefore, attempts to account for both how MS-related adjustment challenges develop, and suggest a range of factors that might be important in determining the extent of ongoing difficulties. For example, an individual may be driven by personality factors and messages early on in life to believe in the importance of being conscientious, striving and hard-working. She behaves in line with these values and goals and this serves her well until the critical event of an MS diagnosis and a serious relapse threatens her normal activities and goals (working hard, taking care of her family). She experiences a strong emotional reaction and her QoL is disrupted. However, a range of cognitive, behavioural and social/environmental factors contribute to the continuing extent of the negative impact of MS. If she appraises MS as a threat which she is helpless to understand and control, thinks very negatively about the illness and the symptoms and copes by avoidance or wishful thinking she is more likely to continue having difficulties adjusting to living with MS. However, if she is able to use problem-focused coping strategies, feels she has high levels of social support on which she can draw, and accepts her illness as an inevitable, but manageable part of her life she may find that she is able to return to a less distressed state.

Later sections of this thesis consider whether evidence supports various aspects of this model, and try to elaborate on its details. Specifically, the two quantitative chapters test hypotheses about relationships between potentially helpful and unhelpful proximal cognitive behavioural factors and adjustment outcomes. The qualitative studies are broader, inductive investigations of the experience of adjustment from the perspective of pwMS which also offer insights into whether the model represents a helpful way of conceptualising MS adjustment.

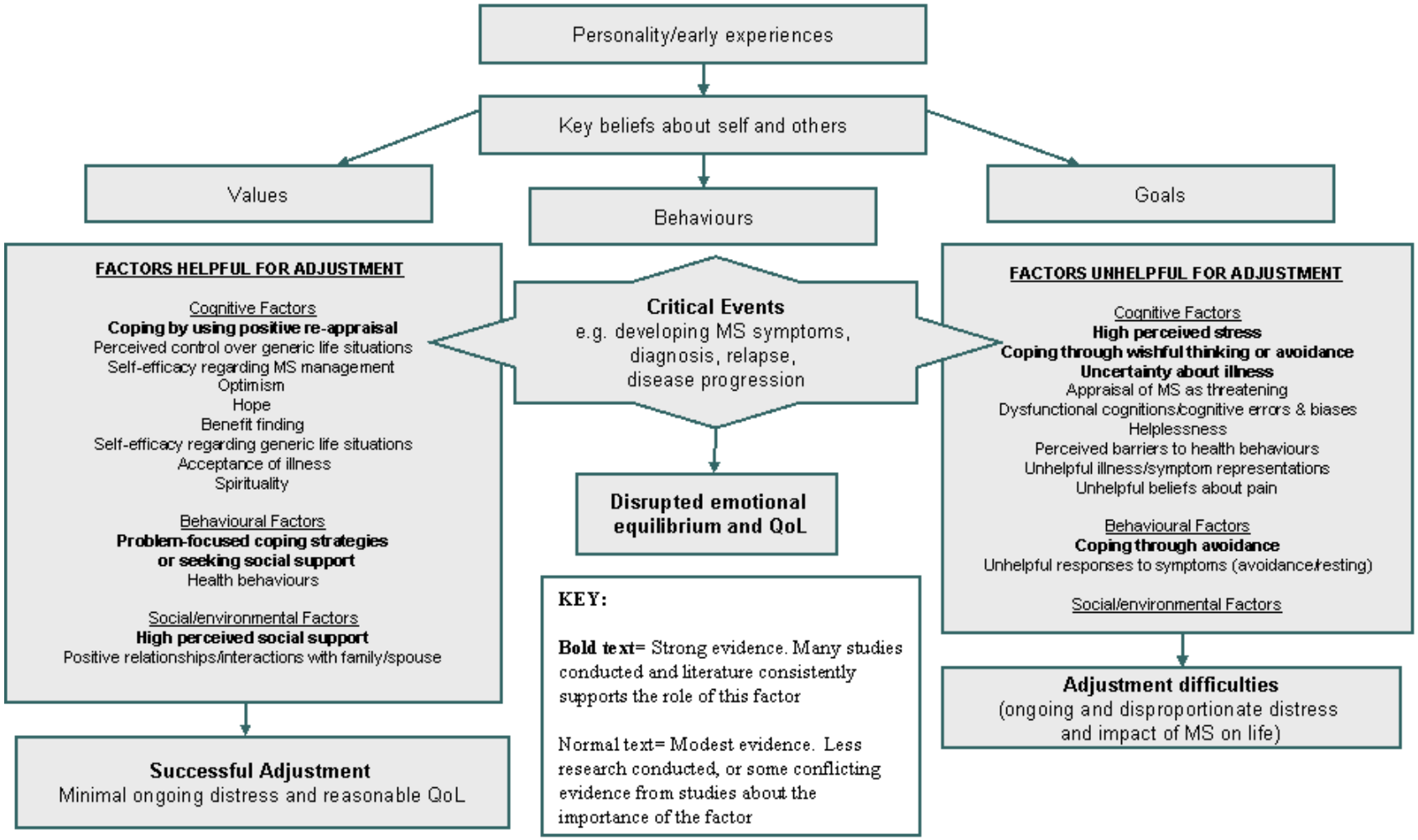

Figure 3: A working model of adjustment to MS

3.4.3. Implications for improving adjustment in people with MS

In the absence of causal evidence from research studies it is somewhat premature to make strong clinical recommendations for how to improve adjustment outcomes. However, the fact that some psychological factors are consistently associated with adjustment outcomes suggests they could be useful targets for interventions and that changing one variable may have an impact on the other. As important factors involve a range of cognitions or behaviours, CBT appears a particularly useful framework.

Perceived stress could be tackled by a number of techniques. Stress-management techniques such as relaxation may be appropriate. Furthermore, in line with the Lazarus and Folkman (1984) framework, targeting the person's appraisals, coping resources and coping strategies should also moderate the negative effects of stress. Interventions could aim to modify threat appraisals of MS or other life stresses to bring about appraisals of challenge or opportunity. Interventions could also explore coping strategies used in response to different types of illness and life stressors and guide patients in moving away from maladaptive emotion-focused strategies including denial and avoidance and encouraging strategies that have been shown to be more adaptive such as problem-focused strategies, positive reframing and seeking social support. Improved perceived social support may also be targeted through helping the patient to consider people available in their social networks for different types of support and examining ways of eliciting support. Furthermore, since spouse responses and family and relationship characteristics appear to influence adjustment, inclusion of family members in interventions and examining relationship and communication issues may also be important.

Interventions could also address factors relating to control. Feelings of uncertainty could be addressed through identification of realistic risks and prognosis. Interventions could also help patients to develop strategies to deal with the reality that many aspects of the disease are indeed uncertain and beyond their control. However, helplessness could be reduced and feelings of personal control and self-efficacy enhanced via exploration of aspects of the illness, and the day-to-day experience of living with MS that are controllable or manageable. This could include improving confidence, developing plans and setting

goals to enable the individual to maintain control over important aspects of their lives and their health. Encouraging health behaviours may also be helpful targets for interventions; goal-setting, addressing barriers, and introducing pacing techniques for physical activity could be useful. Encouraging benefit-finding by searching for meaning and positivity in difficult situations could sometimes be appropriate. Instilling a sense of realistic hope, and encouraging optimistic attitudes might be achieved via giving balanced and realistic information and by inspecting and exploring the patient's illness beliefs. Helping patients to recognise their negative or unhelpful beliefs and maladaptive responses regarding symptoms and illness and providing them with strategies for generating more helpful ones is also a possible fruitful target for intervention. Tackling more generalised maladaptive cognitions such as negative attributions and cognitive distortions may also be beneficial.

3.4.4. Methodological limitations of reviewed studies

Whilst existing studies have begun to build up a consistent picture of factors that are associated with positive or negative adjustment outcomes, few studies have clearly established that these factors predict future adjustment. Furthermore, none of the available evidence comes from studies whose designs permit the conclusion that the psychological factor precedes, let alone plays a causal role in the adjustment outcome.

A fundamental limitation of the reviewed research is that most studies (58 out of 72) were cross-sectional; without longitudinal evidence, temporal and causal relationships between psychological factors and outcomes cannot be established. A related issue is that many studies only reported bivariate correlations between psychological factors and adjustment. Potentially any role for psychological variables could become insignificant if other variables were taken into account. In particular it would be expected that disease and symptom severity variables would be important here. Both psychological factors and adjustment outcomes might be somewhat influenced by the extent of disability or illness. Encouragingly though, in several of the well-designed studies that did control for objective measures of disease severity (e.g. entering EDSS scores into a partial correlation or a hierarchical multiple regression), psychological factors were still demonstrated to be important above and beyond this influence.

Another key problem with the reviewed research is that many studies (especially when they were the first or only study in the field) used small samples. Small samples could render studies underpowered to detect relationships. They could also mean that positive findings may not generalise to larger or different populations. The representativeness of study samples in the reviewed studies also merits consideration. Very few studies included newly diagnosed participants or those within the first few years of living with MS. Of studies that reported on disease severity, most included participants with mild or moderate MS. Many studies excluded patients with severe cognitive impairment, co-morbid physical or psychiatric illnesses, and those experiencing exacerbations or relapses. This sample composition may bias studies towards including those less severely affected by MS and in better overall physical and mental health; a sample that therefore may be expected to be better adjusted. Furthermore, studies whose sampling strategy relied on the recruitment from MS Societies and similar organisations may have a tendency of including a particular type of person with MS; specifically people who are engaged with MS-related activities and research and who are motivated to understand and actively deal with their disease.

Inadequate reporting of participant characteristics by some of the studies (particularly early studies) makes it difficult to interpret study findings or make judgements about their generalisability. Some studies failed to report key demographic data. More importantly, many studies failed to report important medical characteristics about participants including MS type, disease severity, time since diagnosis, and current relapse status. Of studies reporting these key illness characteristics, very few stated that this data was verified via a physician; many used patient-reported data. This data collection method could be a weakness because patients' perceptions of the type and severity of their MS may not always match medical opinion.

Other weaknesses concern measurement. The studies relied overwhelmingly on self-report measures for both psychological factors and adjustment outcomes. Results might therefore be influenced by shared-method variance. Furthermore, some studies adapted standard, validated instruments for measuring adjustment (e.g. removing items in depression measures that overlap with MS symptoms). Although these changes render measures appropriate for MS patients it also makes comparing results across studies more difficult.

Furthermore, across the studies there appeared to be confusion regarding conceptualisations and definitions. For example, there were inconsistencies about what authors considered measures to be tapping; in one study the Sickness Impact Profile was used to measure subjective patient adjustment outcomes, where as in another it was used as a measure to control for severity of disability. There also seemed to be an element of contamination of concepts within measures. Some measures of psychological factors (e.g. hopelessness, spirituality) appeared to also tap aspects of adjustment outcomes (e.g. depression). A clear distinction between predictors and outcomes is, in reality, rather false. However, such a distinction was necessary for decision-making within this review and it is important to consider that in some cases relationships between psychological and adjustment variables may be inflated due to such issues.

Reporting of statistics was also sometimes inadequate, and the failure to report results in conventional formats (e.g. a regression analysis table including beta coefficients and R^2 values) sometimes prevented the interpretation of results about the relative importance of psychological factors.

3.4.5. Implications for future research

All of the psychological factors studied so far would benefit from more exploration through further, well-designed studies addressing the methodological problems identified by this review. Further studies should also expand the scope of what has been studied to date.

Longitudinal studies are required in order to establish whether the psychological factor precedes and predicts the outcome and to better tease apart potential cause and effect. It is important to move away from simple observational research and try to better establish whether psychological factors play a causal role in adjustment outcomes by using experimental designs. Data from psychological interventions which specifically aim to change particular thoughts and behaviours, could be used to analyse whether psychological factors are responsible for any improvements in adjustment over time.

Research that investigates multiple psychological factors within one study would also be useful in order to ascertain the most powerful psychological predictors and their relationships with each other. Studies that investigate relationships and interactions between psychological factors (and interactions with illness, demographic and other relevant variables) would also be valuable in order to establish mediator and moderator roles as well as direct influences. Work which develops or tests theories and models of adjustment is also warranted.

Future studies should use larger sample sizes so that they are powered to conduct complex analyses of multiple variables. They should also examine wider populations, so that the available evidence comes from a more representative sample of pwMS. In particular newly diagnosed patients would be of interest. Those in the later and more progressive stages with high levels of disability would also be important to study. Where feasible, external validity could be enhanced by not excluding people with comorbidities or complicating physical or mental health problems.

Future research should also try to measure and statistically control for MS severity. This is important in order to adequately describe the characteristics of the sample. It also allows the researcher to produce better evidence that the psychological factor (e.g. optimism) is linked to the adjustment outcome (wellbeing), rather than optimism and wellbeing both simply being an indication of mild disease severity. The participant's EDSS score, the main indicator of disease severity used in clinical practice and medical research, would be an ideal measure. Unfortunately, obtaining EDSS scores in small, low-budget studies is problematic since the score is formed through an extensive clinical examination conducted by a neurologist. Researchers should find alternative ways of tapping disease severity using questionnaire measures which do not confuse more objective MS severity (e.g. extent of problems with mobility, bladder function), with participants' subjective rating of the impact of the disease (e.g. unable to engage in social activities).

The scope of future studies could be extended to move away from some of the more commonly-studied psychological factors such as stress and social support, and start to look at some of the lesser researched but promising constructs. These include illness and symptom-specific cognitions and behaviours and more generic maladaptive cognitions and biases. It is also important for future studies to look in more detail at constructs that seem

to be important in the reviewed studies. For example, whilst we can currently conclude that perceived social support is important for positive adjustment, future studies could shed more light on exactly what types of support, from whom, and under what circumstances, are important. Furthermore, it would be interesting to establish precisely what strategies people mean they are using and what thoughts they have when they endorse questionnaire responses concerned with concepts like 'problem-solving coping' and 'self-efficacy for disease management'. There is potential to elaborate on these issues and potentially to discover relationships between currently unresearched factors and adjustment outcomes using qualitative research. Novel findings and rich, descriptive, and detailed data may come from this type of research where the participant's perspectives and experiences are the primary focus and data collection is less constrained by the researchers' ideas and theories.

3.4.6. Limitations of the systematic review

A number of limitations to this review should be considered. Firstly, due to the large number of studies available in the domain of interest, it was decided that only studies published in peer-reviewed journals would be considered. It was beyond the scope of the review to locate unpublished research and search the 'grey literature'. Regrettably, this decision could introduce a potential for bias in the results since unpublished data is more likely to demonstrate no significant relationships. Nonetheless, because the inclusion criteria for this review required basic levels of methodological robustness (e.g. with respect to statistical analysis and use of replicable measures), it is plausible that few good quality unpublished studies were missed by the chosen search strategy.

Secondly, the review included only research that provided statistical evidence regarding relationships between psychological factors and adjustment outcomes. This meant that qualitative studies were excluded. Although qualitative research cannot address specific questions about the extent to which one variable influences another or definitively establish relationships, they could be useful for shedding light on phenomena and proffering explanations for mixed and confusing findings.

Another weakness of the review was that it was conducted by one researcher. Although a second researcher was involved in supervising the overall review process, only one reviewer searched for, selected, extracted and synthesised the studies. This increases the potential for human error and bias in the synthesis.

Finally, the choice of research questions to address in this review meant that a large number and broad range of studies were included. This approach was useful since although there have been general reviews of psychosocial aspects of MS there has been no systematic review of the many psychological factors that relate to adjustment outcomes. However, the chosen approach also had its drawbacks. Because the inclusion criteria were broad the studies were vastly heterogeneous, and so not conducive to a metaanalysis or a single, overall synthesis. Furthermore, the liberal inclusion criteria meant that some studies were methodologically weak and inadequate to provide robust evidence of associations, particularly temporal and causal relationships. Hopefully this review will draw attention to the paucity of good quality evidence, improve the quality of future research, and highlight areas in which future studies could be usefully directed.

3.5. Relevant research published since completion of this review

3.5.1. Review update procedure

Prior to submission of the thesis, a systematic search was conducted in order to update the review. The original search terms were used, and the same databases searched (see section 3.2.1) with a limiter applied to only return results published between 2007 and June 2011.

Searching the electronic databases yielded 1791 results. A further nine articles were identified through other means, including using Google Scholar. Screening by title found 64 articles which appeared potentially relevant to the review question. Upon inspection of abstracts and/or full text, 25 papers were excluded., leaving 39 new articles that were relevant to the review aims and met the original inclusion criteria. One of the papers was my own, reporting the study from chapter 5 of this thesis. Appendix C shows a summary table of the remaining 38 studies.

It is beyond the scope of the thesis to review and discuss all additional studies in depth. Therefore the studies are briefly summarised below. New studies that have particular relevance to the research questions, results and discussions of remaining thesis chapters are discussed in more detail within those chapters.

3.5.2. Characteristics and findings of new studies

Many of the new papers addressed research questions already well-represented by articles included in the review. For example, six new studies added to the evidence that perceived stress is linked to undesirable adjustment outcomes (Beeney & Arnett, 2008; Gay, 2010; Johnson, Terrell, Sargent, & Kaufman, 2007; McCabe & O'Connor, 2009; Vargas & Arnett, 2010; Brown et al., 2009). Six new coping studies report findings in line with the 30 studies already included in the review (Aarstad, Lode, Larsen, Bru, & Aarstad, 2010; Brajkovic et al., 2009; Chalk, 2007; Moreau, Schmidt, Joyeux, Bungener, & Souvignet, 2009; Rabinowitz & Arnett, 2009; Brown et al., 2009) and thirteen new studies supported findings of associations between perceived social support and adjustment outcomes (Bambara, Turner, Williams, & Haselkorn, 2010; Bamer, Cetin, Johnson, Gibbons, & Ehde, 2008; Chalk, 2007; de Groot et al., 2008; Gay, 2010; Jaracz et al., 2010; Johnson et al., 2007; Krokavcova et al., 2008b; Phillips & Stuifbergen, 2009; Ryan et al., 2007; Stuifbergen, Brown, & Phillips, 2009; Vargas & Arnett, 2010; Brown et al., 2009).

Some newly-identified studies explored variables that had previously received only scant research attention. For example, two new studies of illness perceptions confirmed previous reports of associations with a range of adjustment outcomes (Neter, Litvak, & Miller, 2009; Spain, Tubridy, Kilpatrick, Adams, & Holmes, 2007) as did a study of beliefs about and responses to symptoms (in this case pain) (Douglas, Wollin, & Windsor, 2008). Two new studies supported a role of information processing biases in depression in pwMS (Beeney & Arnett, 2008; Vargas & Arnett, 2010). The possible association between control-related beliefs and positive outcomes was strengthened by two studies of perceived control (de Groot et al., 2008; Brown et al., 2009) and four studies of self-efficacy (Krokavcova et al., 2008a; Lester, Stepleman, & Hughes, 2007; Stepleman et al., 2010; Yorkston et al., 2008). One study replicated findings linking threat and harm appraisals to negative outcomes and challenge appraisals to positive outcomes (Chalk, 2007). Emerging links between health-related behaviours such as physical exercise and positive outcomes was strengthened and

extended by six studies that found associations with depression and role adjustment as well as QoL. (Motl, McAuley, Snook, & Gliottoni, 2008; Stroud & Minahan, 2009; Stuifbergen et al., 2009; Suh, Motl, & Mohr, 2010; Tyszka & Farber, 2010; Brown et al., 2009). The relationship between positive outlook and better adjustment was strengthened by new studies of optimism (Hart, Vella, & Mohr, 2008; Brown et al., 2009) and benefit-finding (Hart et al., 2008; Pakenham & Cox, 2009). Furthermore, a reasonably large, prospective study of acceptance of MS suggested that acceptance is indeed associated with positive outcomes, and predicts positive affect and distress over time (Pakenham & Fleming, 2011).

A number of the new papers examined constructs not previously addressed within the reviewed studies. For example, one study found that appropriate disengagement with unreachable goals and re-engagement with new goals was an important factor in explaining outcomes, with people who disengaged but did not re-engage having particularly poor adjustment outcomes (Neter et al., 2009). Another study found that a strong sense of coherence (the extent to which a person tends to experience stressful situations as comprehensible, manageable and meaningful) was related to better adjustment (Ytterberg, Johansson, Holmqvist, & Koch, 2008). Several new papers examined how people perceive and process emotions. Two new studies suggested a link between depression in MS patients and alexithemia (a personality construct characterized by difficulty in identifying and describing feelings to others, restricted imaginative processes and an externally oriented cognitive style) (Bodini et al., 2008; Gay, 2010). Another study examined emotional regulation strategies: people who infrequently used emotional re-appraisal strategies tended to have poorer QoL, whereas suppression of emotion was unrelated to QoL (Phillips et al., 2009).

3.5.3. Conclusion

As a whole, the exercise to update the review confirmed that there is currently substantial research interest regarding adjustment to MS. Many different psychological factors, from various different theoretical frameworks continue to be researched, especially using simple cross-sectional designs. New studies tended to share the same designs (mostly cross-sectional questionnaire studies) as previous work, and many of the weaknesses already discussed. Taken as a whole, the recent studies reinforce the review's conclusions and

recommendations regarding future research directions, but do not substantially extend understanding. Overall, the new studies support the suggested model of adjustment whereby a range of modifiable cognitive and behavioural factors play a role in determining various adjustment outcomes.

Chapter Four: A qualitative study of factors and processes involved in adjustment to MS

4.1. Introduction

4.1.1. The need for a qualitative approach to research on adjustment to MS

As demonstrated in the systematic review in chapter 3 there is a large body of existing psychosocial MS literature which has focused on identifying factors involved in 'successful' or 'unsuccessful' adjustment to MS. These studies consider levels of psychiatric morbidity, levels of distress, and measures of QoL as indicators of adjustment, and have had some success in explaining or predicting adjustment outcomes from psychological factors such as perceived stress, coping strategies, social support, self-efficacy, and MS-specific cognitions and behaviours.

In contrast, fewer studies have been conducted which consider and describe the dynamic process of adjustment to MS over time. Various authors have proposed that rather than viewing adjustment as a desirable end state, a more interesting question is about how people continuously adapt as they manage the changes that serious and chronic illness brings to their lives (Brennan, 2001; Sharpe & Curran, 2006). Brennan (2001) suggests studying the components involved in adjustment to illness, what is it that is being adjusted and what is involved in this process. Chronic illnesses like MS are not single, static stressors, to which one can successfully adapt, but complex ones that change over time and create ongoing problems and challenges. In the case of MS, the course of the illness is particularly unpredictable and the future unclear. In order to get insight into how people manage the adjustment process it is important that adjustment is studied in detail, in context, and from the perspective of the person with MS. Qualitative methodologies, where an open-minded exploration of the person's experience is fundamental, are particularly well placed to address these issues. The current chapter reports on such a study.

4.1.2. Existing qualitative research on adjustment to MS

Studies of experiences of MS using qualitative methodologies were rare until the late 1990s but there has been a proliferation of such studies during the 2000s. Many of these

studies can provide some insight into the adjustment process, although surprisingly few have chosen this as a specific research question or given it particular focus during data collection, analysis and publication.

Many existing studies have been geared towards understanding specific symptoms, difficulties or experiences. For example, qualitative research has explored decision-making regarding motherhood (Prunty, Sharpe, Butow, & Fulcher, 2008), experiences of self-catheterisation (Shaw, Logan, Webber, Broome, & Samuel, 2008), experiences with different types of wheelchairs (Dewey, Rice-Oxley, & Dean, 2004), the impact of cognitive impairment (Shevil & Finlayson, 2006), the impact of fatigue on communication (Blaney & Lowe-Strong, 2009), the experience of severe impairment (Edmonds, Vivat, Burman, Silber, & Higginson, 2007) and the experience of disease modifying drug treatments (Burgess, 1998; Miller & Jezewski, 2001). Many of these studies originate from researchers in nursing, or occupational therapy who have used qualitative data to categorise, describe and understand patient experiences in order to identify patients' needs and inform service provision.

Relatively fewer studies have deliberately set out to examine adjustment in terms of how the process unfolds, and what people do to manage difficulties and obtain positive adjustment outcomes. A few studies have focused on specific features of the adjustment process rather than looking more broadly at the way participants describe dealing with the multiple and diverse challenges that MS brings. For example, some in-depth analyses have focused on meaning-making (Russell, White, & White, 2006), sense-making (Pakenham, 2008), managing positive self-concept (Boeije, Duijnstee, Grypdonck, & Pool, 2002; Reynolds, 2003), and precursors for change (Kirkpatrick Pinson, Ottens, & Fisher, 2009). A handful of other studies have presented findings that address, in a more general sense, how people deal with MS and achieve positive psychosocial outcomes (Edwards et al., 2008; Irvine, Davidson, Hoy, & Lowe-Strong, 2009; Malcomson et al., 2008; Reynolds & Prior, 2003b). Furthermore, a wider pool of studies exist that can provide some findings of relevance despite not focusing on the adjustment process specifically as a research question These studies of the patients' lived experience of MS inevitably elicit some relevant findings regarding the patient's own process of psychological adjustment (e.g. Clayton, Rogers, & Stuifbergen, 1999; Edmonds et al., 2007; Finlayson & van Denend, 2003; Finlayson, Van Denend, & DalMonte, 2005; Olsson, Lexell, & Soderberg, 2008; Olsson,

Lexell, & Soderberg, 2005; Somerset, Sharp, & Campbell, 2002; Wollin, Yates, & Kristjanson, 2006; Mohr et al., 1999). When participants are given the opportunity to tell their stories about MS they frequently describe the challenges they encounter (what it is that needs to be adjusted to) and expand on if and how they have dealt with and tackled these issues (the adjustment process) and their past and current levels of distress, and satisfaction with life (adjustment outcomes).

Generally speaking, studies appear to be of reasonable quality, with reporting becoming more transparent, detailed, and reflexive over time. Many studies also detail features of the analysis aimed at improving validity of findings and interpretations such as searching for discrepant cases, and eliciting participant validation or feedback on themes. This allows more confidence that many recent studies are of high quality and validity (Elliot et al., 1999; Yardley, 1999).

4.1.2.1. Key findings regarding adjustment emerging from qualitative studies

Overall, qualitative studies converge in presenting a complex mixture of negative MS-related experiences, intertwined with some positive experiences. Most studies have presented an optimistic picture of adjustment to MS; despite the fact that MS imposes a number of upsetting and debilitating challenges many people are able to respond to these in ways that mean they are able to maintain an acceptable or good QoL alongside the illness. There are many individual differences in how people respond to challenges, and the success they have in achieving a reasonable level of adjustment. However, some overall themes are apparent across multiple studies, which are detailed below.

The symptomatic period prior to diagnosis is often described as a time of confusion and frustration. Diagnosis seems to be almost always experienced as devastating and feelings of grief, depression, and fear are commonly described, sometimes accompanied by relief at having their symptoms identified and validated (Edwards et al., 2008). Many studies identify a lack of psychological or emotional support and insufficient information about MS from health professionals at this time as factors that contribute to distress (Edwards et al., 2008; Irvine et al., 2009). Participants' stories often feature struggles with experiencing symptoms, and living in a body which is unrecognisable and in conflict with their mind

(Olsson et al., 2008). Participants often identify the impact of symptoms and disability on employment, mobility and independence as being key challenges of the disease and ongoing losses related to MS symptoms cause grief and distress (Boeije et al., 2002; Edmonds et al., 2007; Finlayson et al., 2005; Wollin et al., 2006). Participants tend to place emphasis on the wider social impact of the disease; dwindling opportunities for a satisfying social life, changes in social roles, identity, and changes and challenges regarding interactions with friends and loved ones (Boeije et al., 2002; Edmonds et al., 2007; Irvine et al., 2009; Mohr et al., 1999).

The uncertainty surrounding both long-term prognosis and day-to-day functioning is considered a key difficulty which hinders attempts to adjust (Finlayson et al., 2005; Somerset et al., 2002). However, participants often describe information about MS as empowering in the battle of coping with MS (Edwards et al., 2008; Malcomson et al., 2008). Interactions with others with MS are commonly described as valuable (Malcomson et al., 2008). Participants discuss trying to take control and self-manage their disease, with a complex mixture of fighting spirit and resignation to its ongoing presence in their lives (Malcomson et al., 2008; Reynolds & Prior, 2003a). In living with MS, many participants stress the necessity of adopting a positive attitude as well as the importance in finding realistic ways to add or maintain pleasure and value in their lives (Malcomson et al., 2008; Olsson et al., 2008; Reynolds & Prior, 2003b). Some participants are able to find meaning or even benefits in their experience of MS (Finlayson et al., 2005; Olsson et al., 2008; Pakenham, 2008; Russell et al., 2006; Mohr et al., 1999)

4.1.2.2. Limitations of studies of adjustment

Existing qualitative studies have tended to sample people who have lived with the disease for a fairly long time; often the mean time since diagnosis for study samples exceeds 10 years. Sometimes this is because the of a specific research interest in older adults (e.g. Finlayson, Van Denend, & Hudson, 2004; Finlayson et al., 2005), or people in the advanced stages of the disease (e.g. Boeije et al., 2002; Edmonds et al., 2007). However, several studies had deliberate eligibility criteria in order to sample participants with longer experience of living and coping with MS, presuming that early on following diagnosis, people have not yet experienced adjustment, and/or are not ready to discuss their

experiences (e.g. Irvine et al., 2009; Malcomson et al., 2008). Furthermore, because of the higher prevalence of MS in females and the probability of different domains of impact and importance for different genders, women have often been the sole focus of studies (e.g. Kirkpatrick Pinson et al., 2009; Olsson et al., 2008; Reynolds & Prior, 2003a; Reynolds, 2003). This has led to the adjustment experiences of males being left relatively neglected. As a result of these limits on sampling, the qualitative findings to date have been based predominantly on data from females, people who have been diagnosed for many years, those with moderate to severe MS, and people in middle and older age.

Secondly, the source of participants for most existing studies has been from MS Societies and other similar organisations. This raises the concern that existing samples are biased towards particular types of pwMS: those who choose to deal with their MS by seeking information and support from others with experience of the disease. It is possible that the ethos of these patient support groups may socialise people into ways of talking about, thinking about, and responding to MS such as placing importance on engagement in positive thinking, and pro-active management. These participants, therefore, may not represent the adjustment process of those patients who do not choose to become part of these organisations.

Thirdly, the reporting of participant characteristics, particularly medical ones, is poor across studies. Studies often omit to give details of the type and severity of MS in the sample. This makes it very difficult to judge whether reported themes are arising from people dealing with very progressive, disabling disease or those with fewer symptoms and minimal impairment, but the uncertainty of whether devastating progression will occur in the future.

Finally, a minority of studies claimed to have used qualitative methodology, but on closer inspection take a more quantitative approach such as content analysis, reporting percentages of people reporting each theme, and/or using statistical methods to relate themes to demographic variables or adjustment outcomes measured using standardised quantitative scales (Finlayson et al., 2005; Pakenham, 2008). Most studies, however, analyse their findings using some variant of thematic analysis, interpretative phenomenological analysis, or grounded theory; and end up with results in the form of sets of descriptive themes; sometimes rich, analytical and thought-provoking, but sometimes

rather superficial. It is rare to see qualitative studies that are influenced by, incorporate, or generate theoretical models or frameworks of adjustment. Often, results sections of papers lack coherence due to a large number of inductively derived distinct themes or categories identified without an obvious storyline, framework, structure, map, or diagram.

4.1.3. The current study

The aim of the current study was to add to the growing body of qualitative research in MS by using in-depth interviews and qualitative analysis to explore how people describe their psychosocial adjustment to living with MS. The focus of this study was on adjustment in the first few years following diagnosis. In both the qualitative and quantitative MS adjustment literature, this period has not received as much attention as later stages of the disease which tend to be more symptomatic and disabling. However, significant distress is often experienced in the early stages of MS (Janssens et al., 2003). Furthermore, it is during this period that people start learning about the illness and its effects on their lives and developing ways to manage the issues they encounter. Presumably early experiences of dealing with and adapting to MS may set the scene for future adjustment. The study will seek to explore the experiences of both males and females. This study will also sample people from NHS MS services as well as patient organisations in order to obtain the voice of those who do not choose to become involved in the MS community.

The original aim was to explore how people with early stage MS report their experiences of adjusting to the disease; how they address any difficulties they encounter and what they find helpful and unhelpful. Whilst participants were asked about the difficulties and problems they experienced, the focus was on understanding how they respond to these problems; what they do, how they think, how they feel, and how this contributes to adjustment over time. Following an in depth inductive thematic analysis, the decision was made to map the themes onto, and discuss the themes in relation to the model of adjustment derived from the systematic review of the quantitative literature in chapter 3 (hereafter referred to as ‘the model’).

The inductive analysis was conducted before the systematic review had been completed and prior to the development of the model. This analysis therefore stayed true to the data, aiming to identify themes and patterns in the data without seeking to conform to pre-

existing terminology, concepts or processes. The second, deductive analysis took place after completion of the systematic review and the development of the model. This second, deductive analytic step meant that the themes could be compared to understanding gained from quantitative methods, examining the extent to which the two approaches converge in their findings and highlighting areas where qualitative findings deviate from, or expand upon the model derived from the quantitative literature. It is important to note that whilst the deductive analysis provides detail, illustrations, and elaborations on how the model can be applied in this particular sample, qualitative research is not suitable for testing or confirming models.

4.2. Method

Approval for this research was obtained from University and NHS ethics committees and research governance departments.

4.2.1. Recruitment

The sample of interest were people who were in the relatively early stages of living with MS. Therefore a diagnosis of MS within the past 8 years was chosen as the eligibility criterion. Participants were recruited either through the UK MS Society (*n*=18), or NHS MS services (*n*=12) to take part on a voluntary basis. All participants received a written information sheet (appendix D) and were given the opportunity to talk further about what the research involved with the researcher before providing written consent (appendix F).

4.2.1.1.1. MS Society

The MS Society is the largest UK charity for people affected by MS. It funds research, education and training on MS, runs respite and care centres, offers support services, and produces numerous publications in addition to maintaining a comprehensive website of information and advice. The MS Society also has a network of branches across the UK, where pwMS can meet regularly, as well as online forums and groups. Participants recruited from the MS Society made contact with the researcher by telephone or email after

viewing information about the project on the MS Society website, or hearing about the research from other members.

4.2.1.1.2. NHS

The NHS MS Services from which this study recruited were based in Hampshire (Southampton University Hospital Trust) and South East London (Kings College Hospital Trust). Both services are regional centres where pwMS are seen by teams of specialist neurologists and MS nurses in order to diagnose and manage their condition. The neurologists and nurses at both services agreed to give out participant information sheets to people who met the eligibility criteria. Within routine appointments they mentioned the research nature and aims. Because many pwMS have mild to moderate cognitive difficulties (e.g. memory, concentration, information processing) it was a concern that many potential participants would forget to return the forms, despite being interested in the study, or be put off by having to read a lengthy information sheet without having met or talked to the researchers. The risk was that a biased sample of only the most motivated and capable people would volunteer. Therefore if a patient expressed interest, the nurses or neurologists offered to complete a contact details form immediately and post it to the researchers (appendix E). This form acted as a statement of interest, rather than an official consent form, and permitted the researcher to make contact with people who were potentially interested and chat to them informally about the research before they made a decision whether or not to consent.

In total, 64 people expressed interest in participating, from whom 30 were purposively sampled in order to obtain a varied sample in terms of demographics and illness characteristics.

4.2.2. Participants

Table 2 summarises the sample characteristics. Although the thirty participants were varied in terms of their backgrounds and MS characteristics, most were White British and women. Many participants were in their 40s and 50s. All had at least a secondary school education

and around two thirds were married or cohabiting. Most had RRMS and around half were in employment. Many were able to walk unaided, and all but three were mobile without use of a wheelchair.

4.2.3. Procedure

Telephone interviews were chosen over face-to-face interviews due to the geographical spread of the participants, illness-related difficulties in attending in person or foreseeing a suitable time for a home visit. Interviews were arranged for times that were convenient to the participants and they were advised to find somewhere comfortable and private for the interview where they would not be disturbed. In consideration of MS symptoms (e.g. fatigue, difficulty concentrating, bladder disturbances) participants were advised to inform the interviewer if they wished to take a break or to cut the interview short.

Interviews were conducted by a researcher who started the interview by introducing herself and the research aims. It was emphasised that as a post-graduate student in health psychology she was not an MS expert, but was interested in finding out how people deal with its challenges, and that what was interesting and important was their own perspectives and experiences.

The interview itself consisted of a series of broad, open-ended questions about the participants' experiences of MS. Questions addressed what participants had thought and felt about being diagnosed with MS, what psychosocial difficulties they had encountered, how they had responded, and what they had found helpful and unhelpful in adjusting to living with the disease. Participants were asked about their experiences when they had first been diagnosed, as well as at the time of interview (appendix G[1]).

An inductive approach to the interviews was adopted whereby the interview schedule formed the basis for the conversation but leads that were offered by the participants were followed up with non-directive prompts (e.g. "can you tell me more about that?"). This

[1] The interview also contained questions about the participant's ideas of what would be helpful in a supportive psychological intervention (section B of the interview schedule). The latter questions and their responses, for the most part, were not relevant to the current analysis and were used for guiding the development of an intervention in a separate project.

allowed the interviews to progress in directions that had not been anticipated by the researcher but were important to the participants. Length of interviews ranged from 18-78 minutes (on average approx 45 minutes). During a few interviews signs of distress (e.g. tearfulness) were apparent as participants recounted difficult situations and feelings (e.g. disclosing their diagnosis to their children, admitting their worries about their future). Where these situations arose the interviewer checked whether the participant wanted to take a break to compose themselves or wished to bring the interview to a close. All chose to continue.

After the open-ended questions a short structured interview took place to collect demographic and illness data. This included gender, age, marital status, ethnic origin, education level, MS type, time since diagnosis, and recent relapses. MS severity was also assessed by posing a series of questions about walking ability on an average day.

Finally, the interviewer ensured that the participants were not unduly distressed and where appropriate, asked whether they would like to talk to one of the researcher's supervisors, an experienced clinician. All participants felt this was unnecessary. Participants were asked if they wished to receive a summary of the research results and all were eager to do so. All interviews were audio-taped and transcribed verbatim. The transcripts were then checked for accuracy against the tape recordings.

4.2.4. Analysis

Data analysis consisted of two stages: 1) an inductive bottom-up approach to ensure that themes were grounded in the data, 2) a deductive linking of qualitative findings to the model of adjustment originating from quantitative research.

The first step of data analysis broadly followed inductive thematic analysis approaches advocated by Braun and Clark (2006) and Joffe and Yardley (2000). The analysis approach also incorporated some grounded theory techniques as described by Charmaz (2006). First, recordings were listened to and transcripts were read and re-read in order to become immersed in the data. Next, around half of the transcripts were open-coded on a line-by-line basis, whereby labels were attached to segments of text which appeared to indicate

Table 2: Participant characteristics (N=30)

Characteristic	*N* (%)
Recruitment source	
NHS	12 (40%)
MS Society	18 (60%)
Gender	
Female	22 (73.3%)
Age	Range=24 to59 M=44.8,SD=9.3
Education	
Secondary school	15 (50.0%)
A levels or college	8 (26.7%)
University degree	7 (23.3%)
Marital status	
Married/co-habiting	19 (63.3%)
Separated/divorced	5 (16.7%)
Single	5 (16.7%)
Widowed	1 (3.3%)
Ethnic origin	
White British	27 (90.0%)
Other White	1 (3.3%)
Black British	1 (3.3%)
Chinese	1 (3.3%)
Employment status	
Working full time	11 (36.7%)
Working part time	5 (16.7%)
Unable to work	14 (46.7%)
Time since diagnosis	Range=2mths to 8yrs *M*=3.82yrs, *SD*=2.14
Disease type	
RRMS	18 (60.0%)
SPMS	8 (26.7%)
PPMS	4 (13.3%)
Disease activity:	
Recent relapse (last 6 months)	11(36.7%)
No recent relapses (last 6 months)	9 (30.0%)
Not applicable (does not have relapsing MS)	10 (33.3%)
Disability level[a]	
Fully ambulatory	15 (50.0%)
Limited ambulation, uses stick/crutches	12 (40.0%)
Wheelchair user	3 (10.0%)

common and salient themes. Where possible, participants' own words were used for code labels ("in vivo" codes; Glaser & Strauss, 1967) in order to avoid prematurely importing pre-existing theories and frameworks into the analysis.

An index of themes and their locations was created, which was developed into a coding manual as open-coding progressed through the remaining transcripts, and a more focused coding commenced. The analysis involved an iterative, dynamic process of moving between data and themes. Constant comparison was used, whereby the analyst's understanding of the text and descriptions of themes was continually checked against the transcripts in order to ensure that themes were applied consistently, sensitively, and as indicated by the data under study. Theme definitions were refined, themes were removed, added, fused together, clustered or linked and a detailed paper trail was maintained which consisted primarily of an evolving coding manual specifying theme labels definitions and illustrative quotations along with their locations in the transcripts. Emerging themes were discussed at meetings between the researcher and the supervisor in order to highlight clarifications or modifications that might be necessary to improve the coherence and consistency of the analysis and to highlight potential features of the data that the codes did not yet capture. As themes emerged, deviant cases (i.e. data that does not fit with the patterns identified) were deliberately sought out to ensure all data was incorporated into the analysis rather than only that which fit with the analyst's viewpoint. Where disconfirming cases were found, themes were further developed in order to accommodate the different patterns. As data analysis progressed, memoing and diagramming were used to develop analytic thinking and delineate links between themes. The themes were eventually incorporated into a hierarchy of categories, themes and sub-themes.

In the second step of data analysis, the inductive themes were then considered in the context of the model of adjustment arising from the review of quantitative literature in chapter 3. This part of the analysis was concerned with relating the qualitative findings to the model of adjustment and considering to what extent the findings could be viewed as consistent with the model. It considered whether a more detailed understanding of elements of the model could be gained, how the model could be usefully elaborated or modified and whether there were other important themes arising from the inductive analysis that were not adequately covered by the model.

4.3. Findings

4.3.1. Overview

The initial inductive thematic analysis resulted in delineating 35 themes relating to diverse aspects of adjusting to life with MS. These were organized into five superordinate categories: 1) the context adjustment takes place in, 2) properties of the adjustment process, 3) resources participants describe as helpful and unhelpful, 4) actions and strategies participants describe using to deal with life with MS and 5) attitudes and thoughts participants express characterising attempts to live well with MS. These five main categories and their themes and subthemes are depicted in Table 3. Appendix H contains an abridged version of the final coding manual in which each theme is briefly described and illustrative examples provided.

The remainder of this chapter will focus on the final, more deductive analysis and describe the findings by discussing key themes and their relationships to the model of adjustment. Themes are discussed under four broad headings which correspond to key elements of the model (page 59).

1. 'Pre-MS variables: '
2. 'Critical event/s' and 'Disrupted emotional equilibrium and current quality of life'
3. 'Factors helpful for adjustment'
4. 'Factors unhelpful for adjustment'

Themes from the inductive analysis that were expected and map clearly and readily onto concepts from the model are summarized in Appendix I. The text gives an overview of apparent links between the model and the inductively-derived themes but focuses on particularly interesting or novel themes and those which do not fit well with the model in its existing form. Relevant inductive theme labels are shown in capitalised italics. The identity of respondents has been protected by using participant numbers to identify quotations[2]

[2] In order to enhance the readability of the quotations, words such as 'umm' 'err' and repetitions of words have been removed. Whilst conducting this editing, care has been taken to preserve the meaning.

Table 3: Inductively-derived themes and subthemes

Category	Themes and subthemes
Context The context or starting points from which the adjustment process takes place	• The black picture • Feeling overwhelmed • Abandoned at diagnosis • Importance of diagnosis
Process Descriptions of the process of adjustment	• A process that takes time • Stages • Good days, bad days • Critical incidents • Intolerable intrusions • Precarious adjustment
Resources Resources deemed to be helpful/unhelpful in aiding adjustment	• Having help at hand • Having support • Having money • Personal attributes

Actions/ Strategies
Actions taken and changes made when dealing with life with MS
	• Arming self with information
	• Managing symptoms
	  ➢ Becoming familiar with symptoms
	  ➢ Putting up with symptoms
	  ➢ Tackling symptoms
	• Good management
	  ➢ Problem solving
	  ➢ Planning ahead
	• Adapting social and leisure activities
	  ➢ Scaling down
	  ➢ Replacing
	  ➢ Keeping it up
	  ➢ Withdrawing
	• Managing others' responses
	  ➢ Telling people
	  ➢ Educating others
	  ➢ Displaying disability
	  ➢ Becoming assertive
	  ➢ Rising above it
	  ➢ Considering loved ones
	• Learning to accept help
	• Putting on a brave face
	• Doing something valuable
	• Keeping a normal life
	• Managing emotions
	• Keeping in good shape
	• Joining or avoiding the cripple club
	  ➢ Interacting with people with MS
	  ➢ Feeling stigma
	  ➢ The spectre of what might happen
	  ➢ Not relating

Attitudes and thoughts Descriptions of ways of thinking about and viewing MS	• Trying to make sense of it • Don't dwell • Being positive • Feeling lucky • Focus on can not can't • Using humour • Changing priorities • Not giving in • Taking each day as it comes

4.3.2. Relating themes to the model of adjustment

4.3.2.1. ' Pre-MS variables'

The pre-MS factors from the model (personality and early experience, key beliefs about the self and others, values, goals, and behaviours) were rarely explicitly mentioned within interviews. This is unsurprising given that the interviews' focus was experiences and events since the development of MS and pre-MS experiences, beliefs or behaviours were not specifically probed. However, participants' accounts were in line with the proposal that the impact of critical events (such as losing physical strength, independence, and social life) is influenced by pre-MS factors; what people value, do and believe determines how challenging each critical event is for them (*PERSONAL ATTRIBUTES*).

> Anything where I wasn't independent. 'Cos I like to be independent. If anything took my independence away. [P4]

As expected from the model, pre-MS personality style, and ways of thinking and behaving appeared to influence how participants responded to critical events.

> I've always been quite a strong personality so I've always been positive about anything in my life … having a positive mental attitude really helped me. [P2]

4.3.2.2. "Critical event/s" and "Disrupted emotional equilibrium and current quality of life"

Some qualitative findings fit comfortably within the features of the model. As specified by the model, MS-related events were reported to disrupt equilibrium leading to distress and reduction in satisfaction with life. The interviews particularly highlighted diagnosis as a major critical event, with later challenges being related to symptom experience and increasing impairment interfering with valued life activities, roles, and self-identity.

One way in which participants' descriptions of their experiences seemed to depart from the model was that adjustment outcomes were described as very unstable states. Participants described emotional adjustment as something that fluctuated from day-to-day, rather than

being achieved and then remaining stable (*GOOD DAYS, BAD DAYS).* Participants described feeling low or even depressed from time to and appeared to consider this normal. Individuals' emotional responses and thoughts about MS were extremely variable, and dependent on shifts in factors such as symptom severity as well as other life stressors.

> You can get depressed with it. But, there are, I certainly have down days, when, you know, you get this dreadful tiredness, so you know, everything is an effort [P13]

Although the model was intended to be dynamic, with new critical events periodically renewing the need for adjustment responses, it perhaps does not depict strongly enough the changeability of adjustment outcomes on a short term basis.

Another insight from the qualitative findings was how a distinction between positive and problematic adjustment is too simplistic and that many participants appeared to fall into another category. Many participants described how although they currently felt happy, able to cope with MS, and able to live in an acceptable way, this positivity might only be possible in the context of no severe symptoms or relapse, a term I labelled *PRECARIOUS ADJUSTMENT*.

> I think it's because I've been relapse free for, for so long you know, if I'd have had a relapse like that every 6 months, I would be thinking differently, I'm sure. [P7]

It seemed that their emotional adjustment was precariously balanced, and contingent on having reasonable current and future health

> I'm okay with it, I, so long as it doesn't get any worse. [P7]

For 'precariously adjusted' participants, some threats for the future were perceived as unacceptable or intolerable and participants often stated that they would simply be unable to cope or adapt (*INTOLERABLE INTRUSIONS*). The main concerns were loss of ability to walk, drive, work and live independently.

> Ending up in a wheelchair […] that's the worst case, that is. It couldn't get any worse than that. [P7]

> I won't like that if I'm having to be cared for as it were. Sort of, I won't… yeah, I think I'll have trouble accepting it. [P4]

Interestingly, there were in fact no examples where a participant truly was unable to tolerate anything that they came up against; stories of past challenges ultimately ended in the person coping somehow, despite how difficult it was for them. A minority of participants had indeed encountered, and coped with, severe stressors such as the need to adopt a wheelchair, the necessity of being cared for by others, the loss of employment, driving licenses, and extremely upsetting (although mostly temporary) symptoms. For example, one participant almost completely lost her vision, but was gradually managing to find ways to continue with what she enjoyed in life.

> I am learning, and in fact I do get large print books out of the library and I do also get spoken tapes out [P5]

The experience of adapting to critical events previously viewed as intolerable appeared to contribute to moving from precarious to more positive adjustment. One participant's mobility became limited enough that he had to give up a hobby he had spent much of his life on, and which linked him to many of his social contacts. Yet, he managed to move forward from this loss.

> For many years I've been riding motorbikes and it was my sort of true love and things. But I found other things to sort of replace it with. [P4]

A third participant had temporarily lost the ability to walk but having encountered this distressing event now felt confident that there would be ways to manage future losses and intrusions.

> And not being able to walk, I couldn't see the strategies to manage it and I think that's the crucial thing. Knowing what to do to manage these things, because nothing makes them go away, it's simply good management. [P6]

Another key theme which featured strongly in the qualitative analysis but not in the model was the difficulty tolerating the idea of being a 'properly' disabled person (*JOINING OR AVOIDING THE CRIPPLE CLUB*). This theme concerned how participants describe their

engagement with, or (more commonly) avoidance of, the MS 'world', and other people who inhabit it. Thinking about and encountering people with advanced disease was frequently deemed to be unacceptable and frightening. This brought unwelcome reminders of 'the spectre of what might happen' [P6].

> It's almost like a different world. You know, which, you kind of know that you'll probably have to join sometime, but you're just kind of thinking well not yet please. [P5]

Many participants made efforts to avoid being exposed to and associated with reminders of intolerable intrusions such as disability and MS progression.

> I can put my hand on my heart, and really say I've not really seen anybody in a wheelchair that's got MS, because I choose not to go down that route. I just don't think I could stand to sit in a room with people that have got MS on the understanding that I could end up like that, but I'm not going to, you know [laughs]. So I don't think that would do me any good. It doesn't do your self-esteem any good I don't think. [P2]

> I was not ready for a walking stick. I wasn't ready for a wheelchair and I didn't want a catalogue to show them, to show me different sorts of them. I felt very, very upset and I was not prepared to talk about it at all, until I was ready. But it worried me. It frightened me. [P6]

Many aspects of the participants' accounts suggested that MS was experienced as a potentially stigmatising condition. The use of mobility aids was perceived as particularly threatening, symbols of having assumed the identity of somebody who is disabled, old and incapable. Many participants' descriptions of other pwMS tended to be of people who were 'properly' disabled, stigmatised, and certainly not like them.

> I'm not, I'm not dribbling or, you know. It sounds awful, but I'm not a, I'm not classically disabled. [P14]

Despite feeling that it would be useful, one participant had not been to her local MS support group. She worried that she wouldn't be accepted because she felt like a 'fraud' in

her current condition where her early-stage disease was virtually invisible; she did not feel 'ill' or 'disabled' enough. On the other hand, most participants who avoided MS clubs and societies stated that, actually, they would not want to be accepted into such groups as it was not desirable to be like these people. The ridicule or even contempt that the participants expressed towards others with MS or other disabilities was striking.

> I try really hard and I mean like they have various outings and things locally, but I just kind of think, 'Am I just making myself part of a cripple club' [laughs] sort of thing. And I don't know whether [laughs] I don't know whether I can cope with it. [P5]

Clearly, a major challenge and trigger for distress was the way in which gaining a diagnosis and experiencing physical impairments or the possibility of future impairments posed potentially severe threats to self and identity. Despite being a common and salient theme within the interviews this sort of stressor was not explicitly specified within the model, which focuses more on functional and emotional consequences of events relating to the disease itself (e.g. progression, relapse). Dealing with threats to self and identity resulting from confronting the prospect of severe MS and disability appeared to be a central challenge faced by people adjusting to MS and could fit into the concept of 'critical events'.

4.3.2.3. "Factors helpful for adjustment"

As is fundamental to the model, all participants described how the way that they responded to MS-related challenges could foster improved wellbeing and QoL. Many inductively-derived themes could be mapped fairly directly onto concepts in the model; participants perceived many factors which the model specified as helpful as, indeed, beneficial to them. This included factors such as social support, problem-focused coping, positive re-appraisal, reducing uncertainty, developing adaptive illness and symptom perceptions and responses, optimism, hope, benefit-finding, control and self-efficacy, and health behaviours.

The thematic analysis helped to fill out these aspects of the model, adding rich, contextual data, and thereby improving understanding of the different concepts and processes. For example, how 'problem-focused coping styles' are used, and why they tend to be useful is much clearer when examining themes which describe participants' experiences of using

practical, pro-active strategies and creative solutions to deal with symptoms, and manage to maintain a reasonable social life.

> I just try to find other ways of doing things. It wasn't gonna stop me doing things. I just had to be more creative in how I did them. [P28]

As another example, the HAVING SUPPORT and HAVING HELP AT HAND themes map well onto the concept of perceived social support in the model, but elaborate on the sources and nature of support that people want and need. As well as corresponding to the anticipated importance of family and friends for emotional and practical support, the themes underlined the importance of health professionals, especially dedicated MS nurses, for ongoing advice, information, and practical help.

> As soon as I met [nurse's name] who's our nurse here, I mean, I sort of, a lot of my black cloud lifted, because I thought, 'Well there is somebody there that I can either phone or I can email to', and I've done both of those over the past year. [P13].

The themes also highlighted how informal support from family and health providers was felt to be inadequate by some participants and that support in the form of psychological interventions was desired, especially during the period following diagnosis.

A set of themes related to social support that were not well captured by the model depicted the importance of dealing with other people's responses to MS (*MANAGING OTHERS RESPONSES*). These themes highlighted how participants had to change their behaviour and learn to modify their emotional responses in order to be able to benefit from the help and support other people could offer, and to minimise the distress that other people's insensitive behaviour caused them. Assertiveness and becoming more thick-skinned were important here.

> I have got so that I now am much more assertive and I ask for more, rather than assuming that they are going to read my mind, and that is quite a big thing for me. [P6]

> I'm sure I'd be exactly the same, you know. I'd be trying, looking for a way to try to reach out to somebody with this illness and so people do that to me and I, I just, I'm very patient and I smile. [P11]

Being able to articulate or display the nature of the illness was also described as a useful strategy, as was careful consideration of who to disclose the illness to and under what circumstances.

> You end up spending a lot of time educating other people to give yourself a better support base as well. Erm… you know, 'cos you're obviously gonna have to come across other people's reactions and you just have educate them as well to make your life less… not less awkward, or less… I don't know, just make it, make it easier. [P19]

Participants also described how it was necessary to learn to accept help and that although hard, this was ultimately beneficial (*LEARNING TO ACCEPT HELP*).

> It's a bit of a head change for me, not to do things myself, and it is quite hard for me to have to wait for things, and that has been difficult, but now I know that the key to it all is to get other people to do the things that I can't do, so that I can do the things I enjoy. [P6]

The model does not specify that possessing or learning these sorts of social and communication skills and strategies are important; however the interview data suggests that they do seem to aid adjustment, through ensuring appropriate social support and eliciting more satisfactory interactions with other people.

The qualitative themes also shed light on how participants used strategies such as denying, distracting themselves from emotions or repressing emotions in order to appear brave, calm and emotionally robust [*PUTTING ON A BRAVE FACE*]. Putting on a brave face was often intended to protect other people from distress, but could also be for one's own benefit, as a means of gaining strength to keep going.

> Obviously in my head it is quite scary but I find that that strengthens me up a bit. If I sort of a put on a sort of veneer, really. [P17]

Participants also described how they had developed other strategies to deal with negative emotions which they experienced as a result of living with MS (*MANAGING EMOTION).* Some described a process of expressing or releasing negative emotions (e.g. through talking, humour, physical activity).

> I had to do a little bit of catharsis. And I had to write about it. And once I'd written about it and I'd made it funny […] if I made it funny, then I was, I was cleared of it. I didn't have to think about it again. [P6]

The type of coping strategy described above would fall under the concept of 'emotion-focused coping' within the model. The quantitative literature suggests that emotion-focused coping can be associated with poorer adjustment,. However, the coping styles consistently linked to poor adjustment are specifically those which involve avoidance or denial, The MANAGING EMOTION theme suggests that emotion-focused coping strategies which involve expressing emotion appear to be very useful to participants.

The FEELING LUCKY theme mapped somewhat onto the concept of benefit-finding which the model identifies. However, a key aspect of this theme was how participants assessed themselves against standards which led them to evaluate their individual situation as acceptable or even good. Many participants described a process of downwards social comparison; they looked towards less fortunate people and felt better about their own situation. Frequently participants reflected on their own problems compared to people with more advanced or disabling MS, people with other illnesses or problems, or people without the supportive environment they had. Feeling grateful for what they had appeared to improve people's emotional wellbeing but this was not represented in the model.

Sub-themes within the *JOINING OR AVOIDING THE CRIPPLE CLUB* theme (discussed earlier) suggested that there can be beneficial outcomes of attempts to avoid engagement with the MS world. Participants' attempts to distance themselves from the 'cripple club' appeared to serve them well in terms of maintaining self-esteem and avoiding anxiety about their future, perhaps constituting a helpful factor for adjustment, particularly if adjustment is 'precarious'. Whether this distancing and avoidance was adaptive in the longer term could not be determined from the interviews. On the other hand, the participants who did decide to open themselves to accepting a role and label as somebody with MS and engaged in meetings with others with the disease appeared to find this useful.

> It's like any situation. If you can chat to people who are in the same boat as you, you support each other and help each other. [P13]

Engagement with others with MS provided an opportunity for downwards social comparison, as well as providing them with access to other factors which the model prescribes as helpful: increased understanding of the disease, ideas for practical coping strategies, and a unique form of social support and understanding

An interesting theme which was not specified within the model was how priorities, values, goals and standards changed as participants got used to life with MS (*CHANGING PRIORITIES*). Participants reported experiencing transformations in what they considered important in life and where they chose to invest their time and energy. Pleasure in the here and now began to take higher priority as participants realised that the future may not permit their original hopes and plans. Meanwhile participants described becoming less rigid about chores, rules and conventions. They described becoming less hard on themselves and more flexible and these changes appeared to be related to greater satisfaction and wellbeing.

As well as adjusting priorities and standards, maintaining some degree of continuation of 'normal' life also appeared important to many participants *(KEEPING A NORMAL LIFE).* Although there were times when MS posed major problems, most participants reported that they had reached a stage where for the majority of the time their daily life did not revolve around MS. Most of the time they did not consider MS as their defining feature. They considered other things more important and central to life than MS. Related to this attempt to preserve normality, several participants strived to continue to contribute valuably (e.g. by volunteering, taking on new responsibilities) even when their circumstances (e.g. health-related loss of employment) prevented their pre-MS activities and roles *(DOING SOMETHING VALUABLE).* These themes did not appear to map onto the model in a straightforward way but seemed to be complexly related to the concept of acceptance. Retaining 'normal' life and making valuable contributions may be related to the desire to avoid or deny threats to self and identity posed by immersion in illness and disability related experiences and labels *(JOINING OR AVOIDING THE CRIPPLE CLUB).* Alternatively, or additionally, this sense of integration of MS with existing routines, roles and identities could perhaps be mapped onto the positive role that the model specifies for acceptance of MS. Acceptance here seems to involve getting to a stage where MS is

accepted as a fact of life, and no longer considered something to try to overcome, deny, or fight against.

A key feature of the interviews was that notions such as acceptance, denial, fighting spirit and resignation were complex and contradictory. Many participants who appeared to advocate acceptance also described the importance and apparent value of a fighting spirit (*NOT GIVING IN*). A fighting spirit appeared to be useful for participants and led them to take practical action in order to stop MS dominating their existence. This determination to not give in and let MS 'beat' participants or take over their lives might be represented in the model by the concepts of hope, self-efficacy, optimism and problem-focused coping. However, because in reality genuine control over ultimate disease progression is unattainable, *NOT GIVING IN* could also be viewed as relating to the concept of emotion-focused coping due to elements of wishful thinking, avoidance and denial. Such strategies are, according to the model, unhelpful for adjustment, in contradiction to the participants' assertion that this fighting approach is important. Critically though, eliminating or curing MS didn't appear to be a goal of fighting MS. Participants' goals seemed to be more modest and achievable; carrying on with their lives and minimizing disruptions from MS. Trying to fight MS appeared to bring about positive effects in terms of wellbeing and self-esteem. However, some examples suggested that constantly trying to fight against MS could have negative effects on fatigue, symptoms, and lead to participants entering situations where they try to do too much and therefore struggle more physically.

4.3.3. "Factors unhelpful for adjustment"

In line with the model, participants described how ways of responding to MS-related events could hinder achievement of better adjustment. Some themes matched up with concepts identified by the model. Interestingly, though, during the interviews, participants were keen to display their successes in coping and relate to the interviewer factors that they had found helpful. Despite specific prompts, participants mentioned relatively few factors that they had found unhelpful in dealing with MS. Where these were mentioned, they were often described as early experiences and responses that subsequently gave way to more positive and adaptive management of MS. Unhelpful factors described often tended to be things largely beyond the individual's own control and be related to other people or their

environment. Furthermore, most unhelpful factors were simply the polar opposites of resources, behaviours and attitudes that participants identified as helpful (e.g. support vs. lack of support; information vs. ignorance; having money vs. struggling financially).

Themes relating to unhelpful factors elaborate on the model by providing detailed understanding of how concepts such as uncertainty and the unhelpfulness of negative, threatening illness perceptions operate in the context of MS. Understanding of how they appear to produce distress is achieved by examining the themes and stories. Participants' initial distress appeared to be related to extremely threatening perceptions of MS, and uncertainty about what will ultimately happen to them (THE BLACK PICTURE).

> I had this picture of me being in the wheelchair and him buggering off out, you know, and leaving me all the time […] I just had this picture of me being trapped, [P18]

Lack of accurate and balanced information seemed to drive high levels of distress. However, as more information was discovered and scope for management of the disease was understood (ARMING SELF WITH INFORMATION) the acute level of distress dissipated.

> I sort of read about it and realised it might not be that bad and it hasn't been. [P10]

The themes in this study draw attention to how, beyond the individual patients' cognitions and behaviors, the behaviour of health professionals was an important factor that could hinder adjustment. Poor communication of the diagnosis and prognosis and inadequate provision of information contributed to the formation of extremely negative and threatening perceptions of MS and the future (THE BLACK PICTURE).

> I think he [the consultant] could have given me a little bit more information about MS, because like I say, I mean he asked me 'Do I know anything about it?' and I said 'Well, all I… I'm fairly sure it can be quite debilitating' and he said 'Yeah, it can.' But he didn't say, 'But on the other hand, it might not'. all I had was the black picture. [P7]

Furthermore, inadequate provision of support from the health service in the early stages led to feelings of distress (FEELING ABANDONED).

> And then they sort of put me on the system and after that it was absolutely brilliant. They, yeah, I couldn't have asked for better people, but that first initial thing was, yeah, was horrendous. [P9]

Many expressed the need for more support in dealing with the emotional impact of MS, in terms of counselling or psychotherapy for themselves and their families.

Several factors specified as unhelpful within the model were absent from participants' interviews. For example, no themes were identified pertaining to the importance of dysfunctional cognitions, cognitive errors and biases. However, this does not mean these factors are unimportant; participants were not directly asked to comment on these concepts (see interview schedule, appendix G). Indeed, it would be unusual for evidence of these to arise naturally; participants are unlikely to have insight into whether they tend towards these sorts of thinking styles as they are considered automatic and habitual.

An insight that emerged from the qualitative analysis that had not been identified in the model was the potential harm that pressure to be positive could have (BEING POSITIVE). For the most part, positivity, optimism and hope appeared to be useful for emotional adjustment. However some participants viewed negative thinking to be the cause of distress, suggesting that individuals can be responsible (and indeed blamed) for whether they adjust well or not. Thinking positively appeared to be dogmatically advocated by other people, but not necessarily natural or easy for the person with MS to achieve. Some participants felt pressure that they 'should' be thinking and acting in a positive way. This pressure appeared to contribute to distress.

> I know what I should be doing. I know I should be more positive. I know I should be more outgoing and I know I should feel better about myself. [P5]

The qualitative analysis also identified how spending time thinking about and trying to understand other aspects of the MS experience was considered unhelpful (*TRYING TO MAKE SENSE OF IT*). Several participants described how early on following diagnosis they had made attempts at sense-making. They had tried to understand why MS has affected them, what they did to deserve it or bring it on, and occasionally, whether a higher power was punishing or testing them.

> I used to think, 'Why's this happened to me', all the time, you know. And I kept thinking, 'What have I done so wrong that God up there's given me this', you know […].so that played on me mind for a long time. [P18]

The struggle to make sense of illness could be seen as relating to the model as being contradictory to acceptance (a helpful factor). Interestingly though, the model suggests that spirituality is a helpful factor. Potentially spirituality may help people accept and stop trying to find reasons for having been afflicted with MS, however considering MS as a punishment from God appears to promote further distress.

The qualitative analysis also raises some interesting issues regarding acceptance/denial of illness and disability and its potential effects on adaptive coping mechanisms (*AVOIDING OR JOINING THE CRIPPLE CLUB*, discussed earlier). The fear, anxiety and stigma felt when engaging with the MS world could prevent people gaining information, suggestions for problem-focused coping, and emotional support and understanding from others with the disease. Furthermore, a determination not to be considered an ill or disabled person meant that it became difficult to accept assistance and mobility aids that would improve functioning and QoL. For example, participant with increasingly abnormal gait and balance limited her social life, and only went out when she could use her boyfriend to lean on. For her, using a walking stick in public was a declaration of being a disabled person.

> He [her boyfriend] says, 'surely that's, you know, a good thing for you, cos then you won't have to struggle as much'. But I am too proud and too vain to, to do it. [P15]

Finally, the model denotes a role for social and environmental factors in determining adjustment. Participants' discussion of the role of money as a vital resource emerged as a particularly important factor here [*HAVING MONEY*]. Having adequate economic resources was viewed as a resource that made adaptations in the face of MS easier. Lacking such resources, having concerns about money and having to maintain employment to make ends meet, was a major stressor for several participants.

> I work part time and I'm worried that I'm going to have to stop that [crying]……sorry…, I'm worried about money, you know, if that happens, cos being on my own with my son [crying]… yeah, those sort of things are very worrying [P9]

Lack of money also hindered flexibility to manage life with MS in a way that suited them best. For some, energy spent on work meant there was little left for pleasure.

> the only thing I can think of is giving up work, so that I have more energy to do, you know, to do nice things, but how I can do that, I just don't know, moneywise. [P9]

This theme highlights the need to pay attention to more material factors that are out of control of the individual when identifying psychological factors that are conducive to change. Factors such as lacking money can be thought of as critical events and disrupters of emotional equilibrium in themselves, but are also important in influencing whether some adaptive cognitive and behavioural responses (e.g. prioritising pleasure, adequate balance of rest and activity) are actually possible.

4.4. Discussion

4.4.1. Summary: the qualitative findings in the context of the model

4.4.1.1. Overall applicability of the model

The qualitative findings, for the most part, could be readily related to the features of the model. MS-related events were reported to disrupt equilibrium; leading to distress and reduction in satisfaction with life. Participants' stories suggested that the impact of critical events is influenced by pre-MS factors; what they value, do and believe determines how challenging each critical event is for them, and also how they respond to these difficulties. Finally, as is fundamental to the model, all participants described how the way that they responded to MS-related challenges could either help or hinder achievement of better adjustment.

No fundamental revisions to the model appear to be needed in order to accommodate findings from this study although insights gained can fill out areas of the model, adding rich, contextual data, and therefore improving our understanding of the different concepts

and processes. Minor changes that could be made to the model to better represent participants' accounts of experiences of adjusting to MS are discussed below.

4.4.1.2. New insights from the inductive qualitative analysis

A number of themes either deviated from the model or did not map clearly onto the existing helpful and unhelpful factors and therefore constituted new insights

4.4.1.2.1. Critical event/s and disrupted equilibrium

The qualitative findings revealed how adjustment outcomes appeared to be unstable states for some patients and how distinguishing between positive and negative adjustment was too simplistic. The idea of precarious adjustment, whereby adjustment is currently good but constantly under threat from perceived intolerable events in the future emerged as important. The findings also pointed to the issues of identity and self as being critical in adjustment and how encountering the idea of disability and the stigma associated with it was a key critical event, as well as something which could produce both helpful and unhelpful coping strategies.

4.4.1.2.2. Helpful and unhelpful factors

The inductive analysis revealed how participants perceive that an important part of living well with MS is learning to manage other people's responses. The findings suggest the patient has to be proactive in learning behaviours that improve social interactions. The findings also highlighted how downwards social comparison was an important process which seemed to heighten emotional wellbeing. The themes also highlighted how adjusting priorities, goals and standards was helpful, but at the same time maintaining some continuity of lifestyle and valued activities remained important for people. Findings also suggested that emotion-focused coping strategies, including those which the model asserts are associated with worse adjustment, appear to be helpful to some people. Behaviours and thinking styles relating to avoidance and denial of possible deterioration and disability in the future appeared to help to keep distress at bay and maintain self-esteem.

An unhelpful side to the mainstream belief in the importance of being positive, hopeful and optimistic emerged; pressure to be positive and feeling like a failure if it was not achieved. The interviews also showed how sense-making, a demonstration of lack of acceptance, was not constructive, and that turning to religion to answer questions about 'why me?' could potentially be unhelpful. Factors largely outside of the control of the individual, such as having financial pressures, appeared to be critical for adjustment, as they influenced whether some coping strategies were feasible or not. Finally, interviews revealed a tendency to demonstrate successful coping in the interview situation rather than focusing on difficulties and unhelpful actions

4.4.1.3. A revised model

Figure 4 depicts a revised model of adjustment to MS. Here, amendments have been made to the model presented in chapter 3 in order to better accommodate findings from this study. There are three changes:

1. Examples of critical events widened to incorporate self/identity issues.
2. Adjustment outcomes shown as a dynamic continuum within which people can shift, rather than discrete states. This includes successful adjustment, and adjustment difficulties with precarious adjustment in between.
3. Arrows added to better demonstrate that adjustment outcomes are not final and are subject to change in response to future critical events.

It is important to note that the model is chronological rather than causal. Therefore the arrows within the model indicate a process over time, from pre-MS experiences to critical events and disrupted equilibrium, then onto helpful and unhelpful factors that are hypothesised to influence adjustment outcomes. In order to ease interpretability the helpful and unhelpful factors are not all individually listed again here; the intention is to depict the overall process of adjustment. Later chapters will return to examining the detail of the helpful and unhelpful cognitive and behavioural factors.

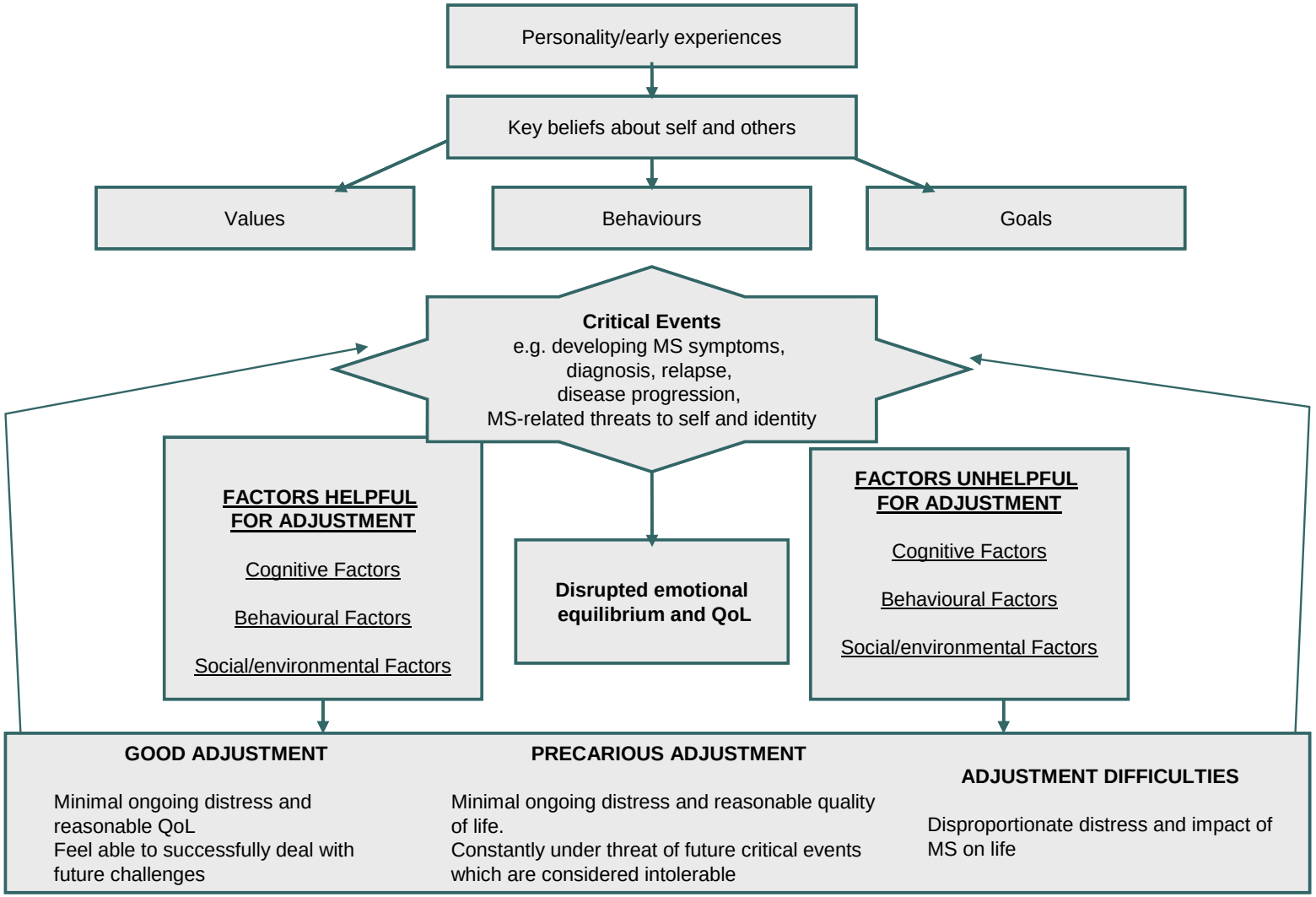

Figure 4: A revised working model of adjustment to MS

4.4.2. Study findings in the context of empirical and theoretical literature

Many of the findings from this research fit with existing research and theoretical models relating to MS, or chronic illness more broadly. These are discussed in four sections below. Firstly, findings regarding difficulties encountered and key factors that help and hinder adjustment are related to previous qualitative research on this population. Secondly, findings are linked to existing models and theories of adjusting to aspects of life with chronic illness, Thirdly, the findings regarding encountering or avoiding the 'cripple club' are related to previous work on experiencing and dealing with threats to self and identity. Finally, findings regarding participants demonstrating a positive outlook and successful, self-initiated coping are considered in light of research from a more discursive perspective.

4.4.2.1. Difficulties encountered and helpful or hindering factors

The findings of this study correspond to previous qualitative investigations into aspects of MS in that they identified varied and weighty psychosocial difficulties, especially following diagnosis, or worsening of disease and impairment. In line with other qualitative work which has considered ways of coping, this study found that people have a large repertoire of coping styles and responses (e.g. Malcomson et al., 2008). The importance of information about, and understanding of MS also emerged strongly in Edward et al.'s (2008) study. Other studies have also identified how perceived abandonment by health professionals can thwart positive adjustment (Edwards et al., 2008; Isaksson & Ahlstrom, 2006; Malcomson et al., 2008).

4.4.2.2. Models of adjusting to chronic illness

Many findings from this study also correspond to existing theoretical models or frameworks for understanding adjustment in chronic illness. For example, themes and their inter-relationships offer support for the Common Sense Model (Leventhal et al., 2003; Nerenz & Leventhal, 1983). Participants revealed both abstract (e.g. MS is serious and usually progressive) and concrete and experiential (e.g. visions of being in a wheelchair,

abandoned by loved ones) illness representations. Furthermore, in line with the proposal that illness representations influence coping responses and therefore emotional adjustment, participants appeared to need information to modify their initial negative, threatening illness perceptions before they developed optimism, problem-focused coping and other seemingly adaptive cognitions and behaviours.

Some aspects of the strategies participants reported using in order to deal with illness-related limitations and intrusions resonated with theories which specify adaptive strategies for dealing with limitations and reduced abilities. Brandstadter, Wentura and Rothermund (1999) hypothesise that ageing results in shifting from assimilation (active adjustment of the situation to meet personal preferences) to accommodation (modifying personal preferences to fit with the situational constraints). This theory appears relevant to dealing with MS; themes demonstrated how active assimilative strategies were used where possible (e.g. keeping a normal life) but where MS made this impossible or increasingly difficult, participants showed flexibility in changing aspects of their lives and lifestyle to accommodate MS (scaling down, replacing and withdrawing from social and leisure activities). As in other studies (e.g. Brandtstadter & Renner, 1990) participants demonstrated both strategies, and appeared to find both useful. However, choice of style appeared contingent on perceived control over the situation and acceptance of the need for accommodation tended to occur only when possibilities of assimilation were exhausted.

Another theory emanating from the field of ageing research also seems relevant to the strategies used by participants for dealing with deteriorating abilities. Baltes and Baltes (1990) suggest that within the context of a shifting ratio of gains and losses, pressure increases for using adaptive strategies. They posit three key strategies; selection, optimisation and compensation, all of which appear to improve functioning and psychological adjustment in older age (Freund & Baltes, 1998). Use of these strategies is evident within themes about various aspects of MS management. For example, adapting social and leisure activities by selecting the most important and enjoyable events rather than doing something every day (selection), planning in order to make outings as simple and hassle-free as possible (optimisation), and using mobility aids or regular rest to compensate for lack of energy (compensation).

Participants' descriptions of changing priorities and values and the apparent beneficial effect of this on adjustment appears to correspond to response shift theory, which asserts

three ways in which the meaning of a target construct such as having an acceptable QoL is evaluated (Sprangers & Schwartz, 1999). Participants appeared to change their internal standards of measurement (e.g. reducing expectations of themselves and their health), their values (e.g. valuing pleasure rather than achievement of professional goals) and their conceptualisations (e.g. QoL as enjoyment of leisure time and close relationships). In line with the response shift theory, these changes appear to be adaptive and buffer the impact of deteriorating health on psychological wellbeing. These findings relating to re-appraisal also map onto other self-regulatory theories (e.g. Carver & Scheier, 1999) in that in that there is a dynamic feedback loop process by which discrepancies (e.g. in QoL or psychological wellbeing) are returned to equilibrium through self-regulatory processes.

The themes identified here suggest that although participants had developed a number of ways of managing day-to-day MS difficulties, where possible they tried not to make MS a focus of their lives. This fits well with the Shifting Perspectives model of illness which holds that people shift between two perspectives, wellness-in-the-foreground or illness-in-the-foreground, but have a preferred or predominant perspective and select encounters and experiences which will not be detrimental to their preferred perspective (Paterson, 2001). Most participants seemed to favour the wellness-in-the-foreground perspective. Many described trying to lead a normal life, continue valued activities and learn and adopt strategies to minimise the influence of MS on day-to-day life. Paterson (2001) argues that holding the burden of the illness in the background appears to sustain a sense of wellbeing and allow people with chronic illness to live as they desire. This model offers an account of why participants described certain ways of responding to MS as unhelpful; for people who prefer to maintain a wellness focus being with other pwMS, seeing reminders of disability, contemplating difficulties, and even accepting help conflict with the wellness perspective and force illness into the foreground.

4.4.2.3. Experiencing and dealing with threats to self and identity

The findings here surrounding avoidance of threatening experiences associated with disability have not been prominent in recent empirical research in MS populations which have tended to emphasise patients' tendency to utilise and benefit from social interaction and support with MS groups and services. However, difficulties experienced around seeing

people with more serious MS, and how becoming involved in MS societies indicates a change of self-identity from "healthy" to "ill" has been described in early studies of adjustment to MS (Miles, 1979; Robinson, 1988). Recent qualitative research in Parkinson's disease found comparable themes regarding the difficulties of meeting others with the disease, seeing reminders of disability and admitting to being "one of them" (Charlton & Barrrow, 2002). Resistance to exposure to and enmeshment in life as an ill or disabled person may be part of the broader experience of adjustment in progressive, disabling diseases.

The current findings suggest that some pwMS avoid thoughts and reminders of present or future disability and dependence in order to protect themselves from thoughts and images they feel unable to cope with. According to understandings of adjustment based in early psychoanalytic thinking (Freud, 1961) and models of dying and grief (Kubler-Ross, 1969) the responses of many participants in our sample would be conceptualised as denial. Strategies involving denial are traditionally considered natural and adaptive in the short term, but unhelpful or pathological in the long term. This thinking has filtered down to health professionals and lay people such that it is taken for granted that acceptance is advantageous and denial is unhelpful. The expectation is that people with a chronic disease should process the difficult emotions associated with their symptoms and their future and then progress towards a goal of acceptance (Telford et al., 2006). However, the accounts of our participants question whether this is always beneficial. There seem to be multiple, independent aspects of acceptance involved in dealing with a chronic illness. Participants' accounts contained many paradoxes regarding their acceptance of MS and in some areas resistance appears to serve people better than acceptance. The consideration of acceptance as a helpful factor within explanations of adjustment may need to be reconsidered. In the context of MS, there is little certainty about the future and therefore little clarity about what it is that people might need to accept. Many pwMS may never progress to the stage where they lose the ability to live independently or need to use a wheelchair. However, some will. Whether an avoidant, resistant, distancing approach to illness and disability is indeed a useful strategy for psychological adjustment in the short and long term cannot be discerned from these interviews. However, it may be that this strategy is characteristic of, and useful for those patients who are 'precariously adjusted' with their wellbeing linked to having a mild and stable disease course.

The findings relating to the 'cripple club' theme show how participants wanted to avoid

association with what they evidently thought of as a stigmatised group and an alien and unwanted identity. Many authors have described the negative impact of chronic illness on self and identity. For example Charmaz (1983) explored how chronic illness can bring about suffering in terms of a "loss of self", or a "diminished self". Scrambler and Hopkins (1986) argue that people with chronic illness attempt to maintain self and avoid acquiring "spoiled identities". However, Adams, Pill & Jones (1997) suggest that damage to sense of self and identity is only experienced if the individual fails to reconcile the new social identity with existing identities, which are irrevocably inter-connected with the person's sense of self. Furthermore, Brownlee, Leventhal and Leventhal (2000) argue that individuals attempt to regulate their self-identity in the light of their understanding of illness by developing "rules" to ensure that their illness representations fit with their sense of self (e.g. maintaining independence in the context of illness by refusing help from others). This may explain the finding of a preference for maintaining continuity of normal roles and valued activities where possible and finding assistance problematic to accept. Many participants accepted their diagnosis of MS but appeared to be managing their self-identity by distancing themselves from stereotypical characteristics associated with ill and disabled people and the unacceptable threat and stigma associated with loss of mobility and independence. Similar processes were observed in a study of people with asthma (Adams, Pill, & Jones, 1997) . Some participants completely refused to accept what they considered to be a stigmatising diagnosis, and therefore avoided using medication and attending clinics. Others accepted the label "asthmatic", but found ways of redefining what it meant in positive, acceptable terms which fit in with their existing identity and did not impact on their sense of self.

Despite many participants reporting significant impairments in functioning most did not appear to consider themselves as disabled, or feel that they fit in with ill or disabled people. Potentially, this may result from the sample being comprised of relatively newly-diagnosed and early stage MS patients. However, other studies have shown that people with congenital or acquired disabilities do not characteristically consider themselves as disabled (e.g. Watson, 2002). Importantly though, whereas Watson's informants did not feel disabled because they viewed their impairments as facts of life and negated the importance of the differences, participants in this study tended to reject the idea that they were similar to others with MS or different disabilities; i.e. people with undesirable, 'discrediting' characteristics (Schneider & Conrad, 1981). It is important to note that although a resistance to "the cripple club" was evident in many accounts, there were individual

differences between participants and a minority of the sample were comfortable with engaging with the world of MS and appeared to gain considerable benefit from it. One possibility is that these differences were related to either older age, longer experience of living with MS, and/or higher severity of disability from MS. Alternatively, they may just reflect individual differences between people and the way in which they choose to adjust. The current research design and sampling strategy is unsuitable for exploring this hypothesis but this would make interesting future research.

4.4.2.4. Positivity and demonstration of laudable attempts at coping

Discursive psychology has raised ideas that may be relevant to the findings that participants were eager to discuss their positivity and successful coping. Specifically, theorising in this area has suggested that participants' talk about being positive can be understood not as a manifestation of an internal state, but as a conversational device with multiple social functions, which leaves us agnostic about the extent to which the individual really thinks positively (Wilkinson & Kitzinger, 2000). These authors, working with data from patients with breast cancer, suggest that the presumed benefits of positive thinking have "leached out into the popular culture" (Wilkinson & Kitzinger, 2000, p801) and that participants' accounts of their coping styles are therefore situated within a context where thinking positive is a commonplace, widely advocated idiom. A similar assumption about positivity is evident within the MS community, in the form that stress and negativity can be responsible for disease exacerbation, as well as psychological distress. Indeed, as the current study noted, there appears to be a psychological, even moral pressure to think positively in order to be good patients (De Raeve, 1997). Fighting spirit talk may also be evidence of this social context where patients feel they have a duty to cope and to fight and that they could be blamed and held responsible if they do not respond in a socially acceptable way. Talk about successful coping despite adversity and factors that have been found to be helpful, rather than unhelpful may be evidence of the "delicate social role that those with chronic illness must occupy" (Yardley & Beech, 1998, p318). Yardley and Beech suggested that accounts of illness management are influenced by participants' need to show commendable effort and position themselves as courageous independent copers but at the same time elicit sympathy and assistance by showing difficulties and evidence of distress. With these insights in mind, findings from this study need to be considered

sensitively and within the context of societal discourses about individual responsibility for health and the perceived duty to cope.

4.4.3. Study strengths and limitations

A number of features of this study give confidence that the results are valid interpretations of participants' reported experiences. The interview schedule was open-ended enough for participants to discuss what was important for them and for leads to be followed and the relatively long average interview length suggests that interviews were not superficial, but truly in-depth accounts. Thematic Analysis is a systematic and rigorous methodology and the steps taken in this study are transparent and described comprehensively.

Both strengths and limitations arise from the fact that the interview schedule and primary analysis was not designed to explore the constructs within the model. Using interview questions that pertained to adjustment, without referring to the model, and then conducting a sensitive and rigorous inductive analysis without the model in mind, gives confidence that themes that were identified were faithful to participant accounts, rather than derived from pre-existing concepts. Negative case analysis strengthens validity of themes and conclusions drawn. The fact that in the relating stage of the analysis, the inductively-derived themes did, for the most part, correspond to the model is more convincing evidence for the usefulness of the model than if the analysis had been deductive, with the model as the guiding framework, from the outset. On the negative side, because participants were not prompted to discuss material related to the model, not all elements of the model could be explored and extended using the qualitative data. For example, participants did not typically talk about pre-MS personality, beliefs and values so these aspects of the model cannot be substantially enhanced from this study.

The relatively large and varied sample allowed for the exploration of a range of views and the achievement of saturation of data. However, given the qualitative nature of the study and sampling method it cannot be claimed that the views of these thirty participants represent those of pwMS in general. Furthermore, one must remember that data from qualitative research can be understood and interpreted in more than one way. Analysis of participants' talk does not offer a foolproof and unproblematic insight into their psyche. Inevitably, the analysis presented here is shaped by the characteristics and perspectives of

the analyst and the interviewer, as well as the participants and the social context. With this in mind, the findings should be taken as suggestive, thought-provoking themes that may be useful for broadening our understanding rather than definitive facts. Additionally, this study can only suggest that some things appear helpful or unhelpful for adjustment given how participants describe their experiences; it does not constitute evidence that these factors, strategies, and processes are actually implicated in better or worse adjustment. Participants may not always have accurate insight into what is most helpful and causal links cannot be determined from this type of study.

Another limitation of the study is that only limited data were collected on cognitive and behavioural factors that hindered adjustment. It may be that within the interview situation participants were concerned with pleasing the researchers by being 'good patients', for example, demonstrating successful coping and positive thinking as discussed earlier. Alternatively, participants may have lacked insight into their own unhelpful thoughts and actions, some of which are automatic and perhaps outside of awareness. An alternative methodology may be needed to access information about unhelpful responses. A study nested within a psychological intervention, such as a qualitative analysis of transcripts from therapy sessions, may provide some insights, although these would inevitably be shaped by the type of therapy and the therapist's focus.

The study participants are likely to possess certain characteristics that may not be present in the broader population of pwMS. Firstly, by using volunteers, the sample is bound to contain people who are interested in discussing their life with MS and helping advance research on MS. One would expect such volunteers to have reconciled themselves to the diagnosis of MS and to have started to develop ways of coping with MS. It is interesting to consider what differences would have been found had the sample comprised pwMS who do not access either the MS Society or have regular contact with NHS services. Secondly, although no objective information about mental health status was collected, it does seem the majority of the participants who volunteered for this study were particularly well adjusted and not currently experiencing significant depression or anxiety. Therefore the account presented here comes from a sample of people with relatively successful stories of adjustment. Finally, by deliberately sampling in order to explore early stage adjustment, the sample comprised mainly (but not wholly) those with mild to moderate disease severity. Participants were, for the most part, able to live independently and continue with important work and/or social roles, albeit using symptom management strategies and practical

adaptations. An interesting question would be if and how things change for these participants over time, given potential deterioration of health and abilities.

4.4.4. Clinical implications

This study suggests that although there are huge ongoing challenges, adjustment to MS and leading a full and satisfying life is achievable for many patients in the early stages of MS. Time appears to be one of the most important factors in emotional adjustment; early intense negative emotional responses seem inevitable, even natural, although typically these later ease and are replaced by focused coping behaviours and more subdued emotional responses. Whilst expectations of a rapid and smooth course towards positive adjustment may not be realistic or helpful, there is cause for optimism about adjusting to MS which should be communicated to patients in the early stages following diagnosis. It appears that it would be useful to offer reassurance that people do naturally cope and emphasise the existence of ways of managing MS, rather than overwhelming people with too many negative details about the disease and its prognosis. On a similar note, themes from this study point towards the crucial nature of adequate communication and support from health professionals involved in the diagnosis of MS, as well as the need for substantial emotional support early on, from health professionals as well as family and friends. Perceived deficiencies in information and support post-diagnosis was consistently recounted as being unhelpful, whereas finding out more about MS, and getting a more balanced view seemed critical for moving forwards. This highlights the importance of health professionals providing balanced early messages and stressing the existence of a support system of MS specialist nurses and patient organisations.

Themes in this study suggests that many people feel abandoned and unsupported in dealing with MS after their diagnosis, and desire formal psychological interventions in the early stages of MS. Themes from this study regarding factors that hinder the adjustment process may be useful in deciding who should be screened for adjustment problems and referred to psychological interventions. Participants appeared to struggle with emotional adjustment more when they lacked support from family and health professionals, had less economic resources, had MS that interfered with critical and valued activities (e.g. work, driving) and were predisposed to have less robust personalities and optimistic attitudes. These patients may be particularly in need of extra support and intervention.

The findings offer broad support for the relevance of interventions based on cognitive-behavioural therapy: many of the factors that were identified as helpful or unhelpful could be modified through such interventions. For example, CBT is well placed to reduce uncertainty and extreme, negative thoughts about MS and its consequences, help the development of an adaptive understanding of MS and its controllability, assist with the development of symptom management strategies that hit the right balance between providing rest and interference with valuable or pleasurable pursuits. The themes identified here also draw attention to patients' preference for positive, proactive approaches and suggests that these would be more acceptable than approaches that focus on discussing difficulties, processing negative emotion, and making sense of adverse experiences. Nonetheless, pressure to be positive, heroic copers may be unhelpful to some, and should not be imposed upon patients. Themes relating to the importance of good interactions with significant others also imply that interventions which involve family members and consider relationships and social support would be beneficial. Developing assertiveness and good communication skills should also be considered as part of psychological interventions. In order to attempt to deal with feelings of precarious adjustment contingent on good health, interventions should raise confidence and self-efficacy for managing future crises and give patients opportunities to master skills and consider how they could use them in the face of future MS progression, relapse or other stressors. The continuous nature of adjustment to MS in the face of new challenges and the fluctuations in sense of wellbeing experienced by patients suggests that follow-up booster sessions of an intervention, and easy access to support services in the future may be important.

The findings regarding avoidance of threats of illness and disability shed light why people in the early stages of MS may not take up services available from NHS MS services such as information and advice events which are typically available soon after diagnosis. Professionals who are providing information, advice and support to people in the early stages of MS need to consider whether services provided fit in with people's natural ways of adjusting to the disease or whether they may actually be alienating them. For example, discussion of mobility aids and longer-term adaptations and care may be unhelpful to people who find this future too threatening. In order to ensure that people do not miss out on important formal help and support health professionals must provide sensitive services which fit with accounts of how people choose to manage their illness. As well as offering advice and support soon after diagnosis, continuing to offer this support to people when

patients are further on in their illness experience seems sensible, as their approach to engaging with such services may change over time. MS clubs and societies may also benefit from considering whether some of the valuable services they provide could be made more acceptable and less threatening to those in early stages of adjusting to MS.

The concept of acceptance, and particularly using it as a marker of successful adaptation, requires consideration and caution. If health professionals expect their patients to accept their illness and potential future disability, patients may become aware of this. If patients' coping strategies are implicitly criticised and labels of being 'in denial' or 'failing to accept' their illness are articulated, this may be damaging to patients' self-esteem (Telford et al., 2006). Seeking to understand individual patients' experiences, feelings and reasoning without imposing expectations and obligations about how they should be dealing with the prospect of current and future impairment, may be helpful to some patients. However, there may be situations where health professionals could gently intervene to explore and address some of the beliefs underlying difficulties in acceptance of illness and/or disability. This might include situations where perceived unacceptability of being ill or disabled, and the stigma of accepting help and using aids is related to unhelpful outcomes such as excessive fatigue and unnecessary restrictions on valued activities and independence.

Finally, the finding that lacking money is a major stressor as well as a factor that can hinder adaptive coping strategies suggests that some pwMS may benefit from professional assistance with arranging their finances, weighing up pros and cons of continued employment and how to manage their time and energy if they want or need to continue full time employment, or applying for disability benefits or retirement on health grounds. In addition to psychological interventions that tackle personal responses, approaches that aim to improve the social and environmental context in which the patient is experiencing MS should not be neglected.

4.4.5. Research implications

In terms of future research, it would be useful to conduct longitudinal qualitative studies that track the obviously unstable adjustment process over time, in order to establish changes in ways of dealing with life with MS, adjustment outcomes, and how adjustment

(in particular, precarious adjustment) unfolds in the context of relapses, disease progression, and increasing disability.

Well designed quantitative studies are needed in order to confirm whether factors and strategies reported by participants are indeed important in influencing adjustment outcomes. Prospective studies could examine some of the potentially important strategies, resources, and attitudes at one time point and measure indices of positive or negative emotional adjustment (distress, social adjustment, QoL) several months or years subsequently. The social skills and interpersonal strategies described in this study and strategies for accommodation, assimilation and adjustment of goals and priorities require further exploration in terms of their pervasiveness and utility for promotion of positive adjustment outcomes. Issues relating to engagement with and avoidance of other MS patients, and disability-related stimuli should be followed up in larger, more diverse samples using designs where relationships between engagement/avoidance and short and long term adjustment outcomes can be determined. The importance of acceptance also needs more research, in particularly delineation of different domains of acceptance and their (perhaps differential) relationship to adjustment outcomes. Clearly acceptance is not a simple, unified construct which is easily defined or measured, and these qualitative results suggest that questionnaire-based measures need to be considered carefully to determine exactly what aspects of acceptance are being tapped so that conclusions about the helpfulness of acceptance are accurate.

Intervention studies that successfully modify important factors elicited from this study (e.g. information seeking, practical management strategies, development social skills to manage others' responses) and demonstrate an accompanying improvement in adjustment outcomes would provide even stronger evidence for their importance in the adjustment process.

4.4.6. Conclusion

Themes derived from an inductive analysis of the adjustment experiences of people with early stage MS largely supported the key tenets of the cognitive-behavioural model of adjustment suggested following a review of the quantitative literature in chapter 3. The qualitative findings added depth and detail to several elements of the model and provided insights which led to some changes and developments of the model which make it a better

fit with participants' accounts of their adjustment experiences. The following two empirical chapters use quantitative methodologies to test some specific elements of the cognitive-behavioural model; namely assessing a set of cognitive and behavioural variables emanating from health psychology and clinical psychology theories as possible correlates (chapter 5), and mechanisms (chapter 6) of successful adjustment outcomes.

Chapter Five: A Cross Sectional Study of Cognitive and Behavioural Correlates of Adjustment

5.1. Introduction

In chapter 3, empirical evidence from studies of possible psychological correlates and predictors of adjustment outcomes was systematically reviewed. It was shown that a range of cognitive and behavioural (CB) factors are important in predicting and explaining individual differences in adjustment. A working model of adjustment was suggested whereby MS-related stressors disrupt emotional equilibrium and QoL, but that CB variables can either promote or hinder longer-term positive adjustment outcomes. Importantly, it may be possible to address these CB factors in psychological interventions in order to improve adjustment.

The review identified CB factors for which existing research had clearly established links to adjustment (e.g. coping strategies, perceived social support). However, it also suggested a number of CB variables which warrant further investigation. Some of these were derived from theoretical frameworks from health psychology, whereas others were more typical of models within clinical psychology. The inductive qualitative study reported in chapter 4 provided overall support for a cognitive-behavioural model of adjustment to MS, and also highlighted psychological variables that have not received research attention so far in the quantitative literature, but may be fruitful avenues for future research.

The study reported in the current chapter is a cross-sectional quantitative analysis which investigates a selection of variables highlighted by earlier chapters as potential important for adjustment. The current study also addresses some of the methodological weaknesses of research examined in the systematic review.

5.1.1. Psychological variables requiring further investigation.

The systematic review concluded that variables derived from health psychology frameworks such as the CSM (Leventhal et al., 2003) require further research. The available evidence suggested that participants' beliefs about the nature of their MS are related to a broad range of adjustment outcomes (Jopson & Moss-Morris, 2003). Since the current study began, two additional cross-sectional studies of MS illness representations

have been published, both using the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996). Neter et al. (2009) found that illness perceptions explained depression, anxiety, illness intrusiveness and purpose in life (20-35% of the variance) even after controlling for EDSS and goal engagement and reengagement. Illness identity and consequences were key predictors. Results from the other recent study do not provide clear information about the importance of illness perceptions. Correlations between illness perceptions and adjustment outcomes are not reported. However, they were entered on the same step of regression models as anxiety, depression, pain and fatigue in order to predict various different domains of QoL. The step as a whole explained significant variance in the QoL domains. However, the illness perceptions were, on the whole, not unique predictors because the other variables were very strong predictors of QoL and, arguably measured overlapping concepts (Spain et al., 2007).

The systematic review also identified some encouraging preliminary work on how people interpret and respond to MS symptoms (Skerrett & Moss-Morris, 2006). Since the current study began, further research has found responses to symptoms to be associated with adjustment outcomes, this time specifically identifying a range of maladaptive beliefs about and reactions to MS pain (Douglas et al., 2008). Despite appearing to be promising predictors of adjustment, with only a handful of studies available which examine illness and symptom-related cognitions, it is unclear to what extent these variables are important for outcomes such as emotional distress compared to other outcomes such as functional impairment. Furthermore, it is still to be determined whether there are specific types of beliefs about MS and its symptoms that are consistently related to good or poor outcomes.

The systematic review also suggested the role of acceptance of MS requires further investigation. Only two studies identified in the review examined acceptance. Both explored its relationship to marital adjustment and the findings were inconsistent (Dupont, 1996; Harrison et al., 2004) with one study finding a positive association and the other finding no relationship. A large longitudinal study, published since the current study was completed, suggests that acceptance is indeed related to a range of positive adjustment outcomes and predicts distress and positive affect over time (Pakenham & Fleming, 2011). Findings from the qualitative study in chapter 4, however, raise interesting questions about acceptance and its supposed links to positive outcomes. The qualitative results suggest that acceptance may not always be useful for patients' emotional wellbeing and may have complex relationships with adjustment outcomes. Findings of a relationship between

acceptance and distress needs to be replicated, and its relationship to functional impairment has not been investigated at all to date.

The systematic review also indicated that variables derived from cognitive models of psychopathology may be important for understanding and predicting depression in PwMS. These include cognitive biases towards negative information and attributions and unhelpful or negative beliefs about oneself, the world and the future. However, only a handful of studies have been conducted in MS so far (Bruce et al., 2007; Kneebone et al., 2003; Kneebone & Dunmore, 2004; Shnek et al., 1995; Shnek et al., 1997) and these factors have not been studied in relation to broader adjustment outcomes such as social and role functioning and QoL.

Another variable deemed worthy of exploration is people's beliefs about experiencing and expressing negative emotions. Although no existing quantitative studies have explored this area, the qualitative study reported in chapter 4 suggested beliefs about emotions are important. Participants described how strong negative emotions are almost inevitable in response to MS-related challenges such as diagnosis and relapse. Some also expressed feeling that ongoing negative emotions should not be tolerated and that demonstrating positivity and 'putting on a brave face' is desirable. As discussed in Chapter 2, ways that individuals regulate their emotions has been investigated as an important factor in adjustment to other chronic health conditions. Research has generally found that suppressing and denying emotions is linked to increased distress and social adjustment difficulties, whereas acknowledging, processing and expressing emotions appears to promote good adjustment (e.g. de Ridder et al., 2008). Similar beliefs to those observed in the qualitative study about the unacceptability of negative emotions have been noted in populations with other mental and physical health problems (Ali et al., 2000; Cramer & Langlois, 2005; Jack, 1991; Surawy, Hackmann, Hawton, & Sharpe, 1995). Such beliefs are thought to play a role in the development and maintenance of clinical problems through a number of pathways (Cramer & Langlois, 2005; Jack, 1991; Rimes & Chalder, 2010).

5.1.2. Study aims

The current study sought to extend promising areas of research highlighted above. The aim was to identify the types of variables which are related to adjustment in order to better understand factors involved in adjustment to MS and to pinpoint factors which may be important to target in interventions which seek to improve adjustment outcomes.

As discussed in chapter 2, adjustment is multifaceted, comprising various outcomes such as psychological distress, functional impairment and QoL. Therefore, the current study explored how different factors might contribute to different adjustment outcomes. It examined functional impairment (the impact of MS on ability to perform key roles such as work and social activities) and psychological distress. These outcomes capture two key aspects of adjustment. Although potentially related, these are in fact distinct dimensions with one representing a more emotional outcome, and the other representing how much MS is perceived to limit the persons life.

The current study also addressed some important methodological limitations of previous studies which were highlighted by the review in chapter 3. Most existing studies fail to measure or account for the influence of illness-related factors such as MS type and disability status. They cannot therefore conclude that the psychological factors which explain variance in adjustment outcomes are not simply a response to more severe and advanced disease. The current study examined the influence of CB variables over and above MS type and severity factors. It also addressed sampling problems inherent in existing research. Many studies do not distinguish between patients at different points in their disease trajectories where adjustment issues may differ. Very few studies have examined adjustment in people relatively early on in their disease course despite research suggesting that distress is apparent early on and that patients desire psychological support at this stage (Dennison, Yardley, Devereux, & Moss-Morris, 2010; Janssens et al., 2003). This study, therefore, specifically sampled patients early on in their disease trajectory. Furthermore, previous studies have typically drawn participants from voluntary patient organisations who represent only a percentage of all PwMS. Those who join such support groups may have different ways of dealing with the illness than those who do not. This study recruited through hospital and community based MS services, therefore capturing a broader group of MS patients.

5.1.3. Hypotheses

It was expected that CB factors would explain significant variance in functional impairment and distress in early stage MS over and above illness severity variables.

5.1.3.1. Variables important for explaining functional impairment

It was hypothesised that MS-specific illness and symptom beliefs and behaviours would be particularly important for explaining functional impairment This is in line with initial research findings in MS (Jopson & Moss-Morris, 2003; Skerrett & Moss-Morris, 2006). It was hypothesised that fearful and negative beliefs about MS (such as that MS is associated with lots of symptoms, does not make sense, and cannot be controlled) and strong emotional representations will be most strongly associated with functional impairment. Regardless of whether these beliefs are objectively accurate the CSM proposes that they influence how people cope with an illness (Leventhal et al., 1984; Leventhal et al., 2003). Highly threatening perceptions of MS may lead to less adaptive ways of coping and may mean that people behave in ways and make choices which themselves contribute to restricted social, leisure and vocational activities. People who hold strong negative illness perceptions may also be more likely to appraise and report MS as interfering with life roles than those who have less extreme beliefs about its threatening nature. The way that people respond to their symptoms is also predicted to be an important correlate of functional impairment. In line with previous research, cognitive pre-occupation with symptoms and exaggerated fears and concerns about symptoms are expected to be linked to higher levels of functional impairment (Skerrett & Moss-Morris, 2006). Specific behaviours have also been reported as being unhelpful to managing physical health problems and contributing to increased impairment. Two important behaviour patterns have been identified. One is all-or-nothing behaviour, where the patient switches between trying to do too much and then becoming extremely fatigued and needing complete rest to recover from their exertions. The other is avoidance and resting behaviour, where the patient rests excessively in the hope of avoiding symptoms (Moss-Morris, Chalder, Skerrett, & Baldwin, 2011; Skerrett & Moss-Morris, 2006; Spence, Moss-Morris, & Chalder, 2004). Both of these behaviour patterns are understandable responses to MS but would ultimately be unhelpful for consistent good functioning in terms of work and social activities.

5.1.3.2. Variables important for explaining distress

For distress, it was hypothesised that although the MS-specific illness and symptom beliefs and behaviours mentioned above may contribute to distress, more general maladaptive beliefs about the self would be of key importance. Cognitive models of psychopathology

specify that unhelpful ways of thinking about the self and the world contribute to depression and anxiety (Beck, 1976). It was expected that as in the limited number of previous MS studies (e.g. Kneebone et al., 2003) unhelpful beliefs about the self such as feeling inadequate and needing approval from others would be one of the key determinants of distress. These thinking styles may have existed prior to the development of MS, but may be particularly unhelpful to people when dealing with the severe stressor of having a chronic, unpredictable and potentially disabling disease.

It was also expected that unhelpful beliefs about ones' emotions would be associated with distress. In line with emotional regulation theoretical frameworks, patients who feel that negative emotions are unacceptable and should not be expressed or tolerated become more distressed by trying to suppress negative emotion and hide emotion from others. Suppressing emotions tends to be counterproductive, leading to increased distress. Furthermore, trying to block negative emotion, and not sharing emotion with others is likely to influence quality of interpersonal relationships, reduce social interaction, and lead to feeling ignored, unsupported and emotionally numb (Corstorphine, 2006; Kennedy-Moore & Watson, 2001; Wenzlaff & Wegner, 2000).

Finally, acceptance was expected to be negatively related to distress. Since MS is a chronic, incurable disease, continued resistance to the idea of living with this could increase the focus on MS but prevent people from adopting useful emotional and practical strategies to adapt and cope with the demands of the illness.

5.2. Method

This cross-sectional study was nested within the saMS trial, a RCT testing psychological interventions for adjustment to early stage MS (Moss-Morris et al., 2009). The data presented here is from the baseline questionnaires completed prior to randomisation to a treatment group. The study was approved by NHS and University ethics committees and research governance departments.

5.2.1. Participants

Participants were recruited from two NHS MS Services: the Wessex Neurological Centre in Southampton and King's College Hospital in South London. During clinical consultations, nurse specialists and neurologists informed patients who met eligibility

criteria about the study and issued information sheets (appendix J). Potential participants then had the opportunity to discuss the study with the trial co-ordinator before deciding whether to take part. Eligibility was confirmed by a telephone screening interview (appendix K) after written consent was given (appendix L).

To be eligible for inclusion in the trial patients had to have a definite diagnosis of MS within the last ten years. They had to be able to walk a distance of at least 20m with bilateral support which was indicated by an EDSS of 6.5 or less (Kurtzke, 1983). Patients were excluded if they had severe cognitive impairment as this would have made participation in the therapy trial and completion of questionnaires problematic. Presence of severe cognitive impairment was determined using the Telephone Interview for Cognitive Status Modified (TICS-M; Brandt et al., 1993) and a score of 20 or more was required. The TICS-M is an English modification of the original TICS (Brandt et al., 1993) which was designed to assess cognitive status over the telephone. Broadly modelled on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), the test covers various cognitive domains such as orientation, memory and repetition. It takes around five minutes to complete and produces scores that are highly correlated with the MMSE in clinical samples (Brandt et al., 1993). It has been shown to be a useful tool for identifying people with and without cognitive impairment in studies where other testing methods are too impractical or expensive (Crooks, Clark, Petitti, Chui, & Chiu, 2005). Patients with other serious physical health problems or severe mental health problems (e.g. psychosis) were excluded. Participants did not have to be currently experiencing adjustment difficulties.

161 patients contacted the researchers to express interest in the study and 112 (69.6%) consented to participate. Eight of these were not eligible at screening, six changed their mind and four were not contactable. This resulted in a sample of 94 participants who completed a baseline questionnaire assessment by post.

5.2.2. Measures

5.2.2.1. Demographic and illness measures

Participants completed a demographic data questionnaire and self-reported information about their MS. To measure neurological disability participants completed a self-report EDSS (Bowen, Gibbons, Gianas, & Kraft, 2001). This is a relatively new instrument which allows MS patients to self-report their current disease status, rather than this being assessed

by a neurologist during a clinical examination. The questionnaire includes items which relate to mobility, strength, co-ordination, sensation, bladder, vision, speech, swallowing, and cognition. Using the responses from these items, functional system scores are computed and an overall score is assigned to the participant ranging from 0 (no neurological impairment) to 10 (death from MS). The self-report EDSS has been shown to correlate well with physician rated EDSS (Bowen et al., 2001). EDSS questionnaires were scored by myself and later co-rated by a neurologist experienced in EDSS assessment in order to ensure reliability of scoring. Kappas for all items were >.70 (substantial agreement), with most >.80 (excellent agreement) (Landis & Koch, 1977). Any discrepancies between total scores assigned were reviewed by myself and the neurologist and a consensus was reached.

5.2.2.2. Adjustment outcomes

The Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002) measures how much an identified illness (in this case MS) interferes with the person's work, home management, social and leisure activities and relationships. Higher scores indicate greater functional impairment. The WSAS has excellent psychometric properties and has been previously used in MS research (van Kessel et al., 2008; Skerrett & Moss-Morris, 2006). Cronbach's alpha (α) in this sample was excellent (.84).

The General Health Questionnaire-12 (GHQ; Goldberg, 1992) measures psychological distress in people in community and medical settings. Higher scores indicate greater distress. The measure has good psychometric properties and a recent study found it to be the most treatment-responsive measure of distress in MS (Hobart, Riazi, Lamping, Fitzpatrick, & Thompson, 2006). A Cronbach's alpha of .91 indicated excellent internal reliability.

5.2.2.3. Potential predictors of adjustment

5.2.2.3.1. Hypothesised predictors of functional impairment

The Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) assesses cognitive and emotional illness representations through eight items, each of which corresponds to a specific type of belief about the illness (in this case MS). The

Consequences item measures the extent to which the respondent thinks that MS affects their life. The *Timeline* item taps how long the respondent thinks their MS will continue. The *Personal Control* measures the extent to which the participant considers that they themselves can control their MS. The *Treatment Control* item measures the extent to which the participant perceives that treatment will help MS. The *Illness Identity* item taps whether the participant attributes many symptoms to their MS. The *Concern* item measures concern about their MS. The *Coherence* item measures the extent to which the respondent understands their MS. The *Emotional Representations* item taps how much MS has an emotional impact on the respondent. High scores reflect negative perceptions of aspects of the individual's MS. Internal reliability for the BIPQ total score was poor (α=.57) so individual item scores were used in analyses. Since two BIPQ items were somewhat confounded with the outcomes (*Emotional Representations* overlapped with the GHQ and *Consequences* overlapped with the WSAS) these items were omitted from the applicable analyses.

The Cognitive and Behavioural Responses to Symptoms Questionnaire (CBRSQ; Moss-Morris et al., 2011) is a newly-devised scale which assesses patients' responses to their symptoms. To reduce questionnaire burden for the saMS trial, a shortened version was used. This omitted the illness identity section (a checklist of symptoms experienced and their attributions) and reduced the items from 42 to 34. Items with the highest factor loadings for each subscale were retained. The five subscales dealing with cognitive responses are *symptom-focusing* (e.g. "I think a great deal about my symptoms"), *catastrophising* (e.g. "I will never feel right again"), *damage* (e.g. "Symptoms are a signal that I am damaging myself "), *fear/avoidance*, (e.g. "I should avoid exercise when I have symptoms ") and *embarrassment* (e.g. "The embarrassing nature of my symptoms prevents me from doing things"). The two behavioural subscales measure *all-or-nothing* behaviour (e.g. "I find myself rushing to get things done before I crash") and *avoidance/resting* (e.g. "I stay in bed to control my symptoms"). High scores indicate more unhelpful responses. It is possible to create total scores for the cognitive and behavioural subscales. However, in this study the subscales were examined individually. Alphas ranged from .66 for *fear/avoidance* to .88 for *embarrassment*, with most >.75

5.2.2.3.2. Hypothesised predictors of distress

The Psychological Vulnerability Scale (PVS; Sinclair & Wallston, 1999) measures unhelpful beliefs about the self. It assesses maladaptive cognitive responses (e.g. perfectionism, need for approval) which are proposed to promote unhelpful responses to stressors. High scores indicate more maladaptive thinking. Good internal reliability was demonstrated in this sample (α=.76).

The Beliefs about Emotions Scale (BES: Rimes & Chalder, 2010) measures unhelpful beliefs about emotions. It measures the extent to which the person holds beliefs that it is intolerable and unacceptable to experience negative emotions, express emotion or weakness to others, and that negative emotions should be carefully controlled. High scores indicate more unhelpful beliefs about emotions. Reliability was excellent (α = .84) .

The Acceptance of Chronic Health Conditions scale (ACHC; Stuifbergen, 2008) assesses acceptance of, and adjustment to, change in one's life due to a chronic health condition. High scores indicate greater acceptance of MS. Reliability in this sample was excellent (α =.83).

5.2.3. Data analysis

5.2.3.1. Data checking and screening

All adjustment outcome data, and 10% of the remaining data was double entered. Any discrepancies were checked and corrected. SPSS frequency reports were used to check that all data was within the expected ranges. Histograms and box plots were checked for outliers. All identified outliers were genuine scores rather than inputting errors and were left in the data set

Inspection of the data revealed that two cases were missing at least one item on the GHQ, four cases were missing at least one item on the WSAS, and for all other CB scales between zero and six participants had missing data for an item. Therefore, when at least 70% of data for each scale was provided the mean for the other items in the scale was used in order to substitute a total score. Where more than 30% of data items was missing from any one subscale, a score was not computed and that participant was excluded from analyses involving that variable.

Histograms, kurtosis and skew statistics, and Kolmogorov-Smirnov tests were consulted to check the distribution of all data measured on continuous scales. The only measure with a distribution of concern was the BIPQ timeline item (very negatively skewed since the 76% of participants believed their MS would last forever). This scale was dichotomised into those who believed their MS would last forever and those who did not.

5.2.3.2. Statistical analysis

Analyses were conducted using SPSS version 17. The analyses assessed the presence and degree of relationships between demographic, MS severity, CB variables, and the two adjustment outcomes. Pearson's correlations were performed for continuous variables. Independent samples *t*-tests or one way ANOVAs were used for categorical data.

Two separate hierarchical multiple regressions were conducted with GHQ and WSAS as the dependent variables (DV) in order to determine whether the CB factors accounted for variance in distress and functional impairment over and above illness severity and demographic variables. A number of diagnostic checks were carried out to confirm the validity of the regression models.

A significance level of $p<0.05$ was adopted when reporting results. However, results significant at both $p<.05$ and $p<.01$ are highlighted in the tables for interest.

Table 4: Participant characteristics (N=94)

	N (%) or *M* (SD)
Demographic variables	
Age (years)	41.7 (9.6)
Gender (female)	65 (69.1%)
Ethnicity	
White British	71 (75.5%)
Other White	10 (10.6%)
Other	13 (13.9%)
Education	
No formal	1 (1.1%)
GCSEs or A levels (or equivalent)	45 (47.9%)
Degree or postgraduate	41 (43.6%)
Other (e.g. vocational qualification)	7 (7.4%)
Marital status	
Married or co-habiting	54 (57.4%)
Single	28 (29.8%)
Divorced or separated	12 (12.8%)
Illness variables	
Time since diagnosis (years)	3.8 (2.8)
Type of MS	
RRMS	73 (77.7%)
PPMS	12 (12.8%)
SPMS	9 (9.6%)
EDSS	5.0 (1.2%)
Relapses in last 12 months [1]	
None	27 (32.9%)
1 to 3	44 (53.7%)
More than 3	44 (53.7%)
Missing	1 (1.2%)
Current relapse[1]	
Yes	7 (8.5%)
No	74 (90.2%)
Missing	1 (1.2%)
Cognitive Impairment (TICS-M score)	26.5 (3.5)

[1] *n*=82 because patients with PPMS do not experience relapses

5.3. Results

5.3.1. Participants

The demographic and illness profiles of the participants are depicted in Table 4. The sample was 69.1% female, 75.5% White British with a mean age of 41.7. Most participants were married and highly educated. Participants had been diagnosed with MS for a mean of 3.8 years, therefore the sample was relatively early in their disease trajectory. Most had RRMS. As a result of exclusion criteria of a TICS-M score of <20, no participants were considered to have substantial cognitive impairment (range=20-35, M= 26.5, *SD*=3.5). The mean EDSS was 4.85 indicating a combination of disability in a number of functional systems (e.g. problems with vision, co-ordination) and/or difficulty walking distances less than 500 metres.

5.3.2. Preliminary analyses

Preliminary analyses explored whether demographic and illness characteristics were related to the two adjustment outcomes (table 5). Gender, marital status, education and ethnicity were unrelated to either WSAS or GHQ scores. Time since diagnosis, current and recent relapse status, and cognitive impairment were also unrelated to either adjustment outcome. Age, MS type (progressive or relapsing-remitting) and EDSS were unrelated to GHQ scores. However age was positively correlated with WSAS, suggesting that older age was related to worse functional impairment. People with progressive forms of MS also had higher WSAS scores than those with relapsing-remitting MS, indicating that progressive disease was associated with more functional impairment. WSAS had a medium strength positive relationship with EDSS, suggesting that increasing neurological disability was related to worse functional impairment. Since age, MS type and EDSS were related to the WSAS, these were controlled for in later regression analysis where WSAS was the DV.

Table 5: Relationships between demographic and MS factors and adjustment outcomes

	Functional impairment (WSAS)	Distress (GHQ)
Demographic variables		
Gender	*t* (1,91) = -.073, *p*=.942	*t* (1,92) = 1.163, *p*=.248
Age	*r*=.220*	*r*=.015
Marital status	*F* (3,89)=.062, *p*=.980	*F* (3,90)= .573, *p*=.634
Education	*F* (5,87) =1.362, *p*=.246	*F* (5,88)= .857, *p*=.513
Ethnicity	*F* (10,82) =.745, *p*=.680	*F* (10,83)=1.042, *p*=.417
Illness variables		
Time since diagnosis	*r*=.123	*r*=-.080
EDSS	*r*=.475**	*r*= .054
Cognitive impairment	*r*=.059	*r*=-.089
Type of MS	*t* (1,91)=-2.710, *p*=.008**	*t* (1,92) =-1.428, *p*=.157
Current relapse	*t (1,91)* = 1.639, *p*=.105	*t* (1,91) = .181, *p*=.857
Recent relapses	*F* (4,87) = .295, *p*=.880	*F* (4,88)= .689, *p*=.601

*p<.05, **p<.01

5.3.3. Correlates of adjustment

Table 6 depicts the correlations between the CB factors and the adjustment outcomes. WSAS scores were only associated with MS-specific psychological factors; CBRSQ items and some of the BIPQ items. Significant positive correlations were found between WSAS and CBRSQ fear/avoidance, embarrassment, all-or-nothing behaviour and avoidance/resting,. WSAS scores were also positively correlated with the BIPQ Illness Identity and Emotional Representations items. Thus, participants who endorsed unhelpful cognitive and behavioural responses to their symptoms and who held negative cognitive and emotional representations of their MS had higher functional impairment.

Table 6: Correlations between CB variables and adjustment outcomes

	Functional Impairment (WSAS)	Distress (GHQ)
Unhelpful beliefs about self (PVS)	.10	.51**
Unhelpful beliefs about emotions (BES)	.03	.33**
Acceptance of MS (ACHC)	-.17	-.40**
Illness perceptions (BIPQ)		
Consequences	n/a [1]	.25*
Timeline	-.16	.16
Personal control	.07	.20
Treatment control	.06	-.00
Illness identity	.48**	-.08
Concern	.20	.37**
Coherence	-.12	.28**
Emotional representations	.31**	n/a [1]
Cognitive and Behavioural Responses to Symptoms (CBRSQ)		
Fear/avoidance	.23*	.11
Catastrophising	.19	.38**
Damage	.17	.21*
Embarrassment	.21*	.44**
Symptom-focusing	.09	.38**
All-or-nothing	.32**	.16
Avoidance/rest	.42**	.02

*p<.05, **p<.01
[1] result not of interest due to overlap between constructs

GHQ scores were correlated with both the MS-specific and the broader personal beliefs measured in this study. Significant positive relationships were found between the GHQ and both unhelpful beliefs about the self and unhelpful beliefs about emotions. GHQ scores were also positively related to a number of cognitive responses to symptoms; CBRSQ Catastrophising, Damage, Embarrassment and Symptom-focusing subscales. GHQ scores also correlated positively with BIPQ Consequences, Concern and Coherence. Thus, participants who endorsed more statements on these measures of maladaptive MS-related beliefs and behaviours had higher distress. GHQ was also significantly negatively related to acceptance showing that acceptance of MS was associated with less distress.

Bivariate correlation of WSAS and GHQ scores revealed that they were positively correlated but the effect size was small (r= .215, p<0.05). Thus, as expected they appeared to measure somewhat independent aspects of adjustment. Appendix M contains a table showing the correlations between the CB factors.

5.3.4. Hierarchical multiple regressions

Two separate hierarchical multiple regressions were conducted with GHQ and WSAS as the DVs, in order to determine the most important psychological predictors of the adjustment outcomes and whether these factors accounted for variance after the contribution of the relevant demographic and illness-related factors. Age, type of MS (relapsing-remitting vs. progressive forms) and EDSS were entered onto the first step for the analysis of predictors of WSAS (see above). The second step included the CB factors that were significantly correlated with the particular adjustment outcome at p<.05.

The results for WSAS are shown in Table 7. Age, EDSS and MS type accounted for a significant 24.4% of the variance, with EDSS emerging as the significant correlate on step 1. On step 2, patients' symptom responses and illness perceptions accounted for a further 23.3% of the variance in WSAS. Examination of the beta weights showed that the significant correlates were CBRSQ avoidance/resting, and the BIPQ illness identity item (perceiving that they experience lots of symptoms due to MS). Overall the model accounted for 47.7% of the variance in WSAS scores.

Table 8 shows the hierarchical multiple regression results for GHQ scores. The CB factors accounted for a significant 44.2% of the variance. Examination of the beta weights

suggested that the strongest correlate of GHQ score was unhelpful beliefs about the self (e.g. need for approval, perfectionism). Unhelpful beliefs about emotions was also an important predictor as were the BIPQ consequences (perceiving extreme negative consequences of MS) and coherence (lacking a clear understanding of MS) items.

Inspection of histograms and P-P plots confirmed that the residuals were normally distributed. Partial plots of residuals of the outcome variables and each of the predictors indicated linear relationships and homoscedasticity. Inspection of correlation co-efficents of the psychological correlates, variance inflation ratios, tolerance statistics and eigenvalues suggested that multi-collinearity was not a problem in this data set. The Durbin-Watson statistic for each regression model was between 1 and 3, confirming that the assumption of independent errors had been met. To check the data for cases that might have unduly influenced the regression models, cases with a standardised residual of less than -2 or greater than 2 were inspected (n=3 for WSAS, n=3 for GHQ). Examination of Cooks distance, leverage, mahalanobis distance, DFBeta and covariance ratio did not show any cause for concern. These checks suggest that the regression models appear to be valid and generalisable to outside of this sample.

Table 7: Hierarchical multiple regression of demographic, illness and CB variables on functional impairment (WSAS)

		B	*SE B*	β	*p*
Step 1	Constant	-4.284	4.567	-	.315
Control	Age	1.079	.084	.094	.351
variables	EDSS	1.911	.709	.422	.000**
	MS type	1.543	2.107	.078	.466
R^2=.244, *F*=9.367 (3,87) *p*<.001					
Step 2	Constant	13.735	4.637	-	.004**
CB	Age	.084	.075	.100	.263
variables	EDSS	1.436	.677	.208	.037*
	MS type	2.537	1.890	.128	.183
	BIPQ illness identity	1.016	.358	.263	.006**
	BIPQ emotional reps.	.456	.355	.125	.202
	CBRSQ fear/avoidance	.112	.194	.055	.566
	CBRSQ embarrassment	.185	.194	.090	.343
	CBRSQ all-or-nothing	.177	.224	.079	.431
	CBRSQ avoidance/rest	.374	.158	.237	.020*
R^2 change=.233, *F*=8.219 (9,81) *p*<.001.					
Total R^2=.477, Adjusted R^2= .419					

*p<.05, **p<.01

Table 8: Hierarchical multiple regression of CB variables on distress (GHQ)

		B	*SE B*	β	*p*
Step 1	Constant	.355	5.854	-	.952
CB	PVS	.363	.132	.299	.007**
variables	BES	.158	.079	.181	.049*
	ACHC	-.064	.106	-.078	.545
	CBRSQ catastrophising	-.310	.243	.169	.205
	CBRSQ damage	-.055	.186	-.028	.767
	CBRSQ embarrassment	.293	.157	.186	.066
	CBRSQ symp. focus.	.243	.206	.129	.242
	BIPQ consequences	.584	.261	.206	.028*
	BIPQ concern	.197	.325	.074	.546
	BIPQ coherence	.569	.258	.202	.030*
R^2=.442, F=6.349, (10,80) p<.001					
Adjusted R^2= .373					

*p<.05, **p<.01

5.4. Discussion

5.4.1. Summary and interpretation of results

The results of this study were broadly in line with hypotheses. Distress was associated with both broad personal beliefs and illness-specific unhelpful beliefs and behaviours. However, functional impairment was only related to illness-specific thoughts and behaviours. The results demonstrate the importance of recognising multiple domains of adjustment in MS and considering different CB formulations for explaining different aspects.

5.4.1.1. Explaining functional impairment

For functional impairment, behavioural responses to symptoms were important, with excessive rest and avoidance emerging as a key predictor. The importance of behavioural responses corresponds to findings in the wider literature on functional impairment in populations with chronic diseases or symptoms, for example on chronic pain and chronic fatigue which has highlighted the relevance of unhelpful patterns of rest and avoidance in response to symptoms (Deale, Chalder, & Wessely, 1998; Pfingsten et al., 2001; Surawy et al., 1995). The importance of behavioural responses also concurs with the only existing study of pwMS that considered this variable (Skerrett & Moss-Morris, 2006). That study found that avoidance and resting in response to symptoms was the key predictor of poorer functional impairment, using regression analysis with the same outcome measure as the current study. However, in addition, their results suggested that all symptom responses subscales correlated significantly with functional impairment, whereas this study did not find significant relationships for some of the cognitive response subscales (damage, catastrophising, symptom-focusing). It is unclear why these differences have arisen, although minor differences in the CBRSQ measures may have contributed to discrepancies in results; the CBRSQ measure used within this study was a reduced version of the one used by Skerret & Moss-Morris (see method section). It is noteworthy, however, that in the current study the symptom cognitions that were significantly related to functional impairment were those that were tapping beliefs in the need for avoidance of situations to cope with symptoms (i.e. fear/avoidance and embarrassment) compared to those which

tapped other concerns or beliefs . It makes sense that these beliefs would be most strongly related to functional impairment as thinking that avoiding physical exertion or avoiding other people is necessary may prompt avoidant behaviours which ultimately prevent normal, or desired functioning at home, work and in social and leisure activities.

The current study found that out of the range of illness perceptions items only illness identity (perceiving that lots of symptoms were associated with MS) was a strong predictor of functional impairment. A theoretical explanation for why illness identity influences functional impairment above and beyond an objective measure of MS severity can be found within Leventhal et al's (1997) discussion of symmetry in symptom perception and illness labelling. According to this theory patients search for a label for symptoms they experience, but also look out for symptoms when they have been given a label. It may be that given the unpredictable, idiosyncratic nature of MS, some patients may tend to attribute non-MS symptoms, including those due to stress, fatigue, anxiety, and ageing, to MS. This could influence their ways of coping; with people who perceive many symptoms modifying their behaviour in ways that disrupt functioning. Inspection of the correlations (Appendix M) between the illness identity BIPQ item and the behavioural responses to symptoms subscales (avoidance/resting, and all-or-nothing) suggested that these factors are associated, with people scoring high on illness identity also engaging in more unhelpful behavioural responses to symptoms, particularly avoidance and resting.

Current findings regarding illness perceptions and functional impairment differ from an earlier study (Jopson & Moss-Morris, 2003). In that study, perceiving severe consequences of MS was the only illness perception item to predict role dysfunction, a similar concept to functional impairment (Jopson & Moss-Morris, 2003). However, in the current study, the *consequences* BIPQ dimension was excluded from analyses of predictors of functional impairment because there was deemed to be a considerable overlap in the concepts they were measuring. In a more recent study, illness identity and consequences both emerged as unique predictors of a similar outcome, illness intrusiveness (Neter et al., 2009). Differences in findings across illness perceptions studies may have several explanations, including use of different measures. Jopson and Moss-Morris used the IPQ-R (Moss-Morris et al., 2002), Neter et al. (2009) used the IPQ (Weinman et al., 1996) and this study used the BIPQ (Broadbent et al., 2006).

This is the first study to examine unhelpful beliefs about the self, beliefs about emotions, and acceptance in relation to impact of MS on functional impairment. The findings that these factors were unrelated to functional impairment corresponded to this study's hypotheses. Presumably, whilst people's unhelpful beliefs that are not specific to MS are important in determining how they feel, it is ultimately what people do in response to MS symptoms (e.g. how much they avoid activity, rest excessively) that contributes to how much impact MS has on aspects of life such as work, leisure and social activities.

5.4.1.2. Explaining distress

In contrast to the results for functional impairment, in the prediction of distress unhelpful beliefs about the self (such as feeling inferior, needing others' approval, and feeling like a failure if goals are not achieved) emerged as the strongest correlate. Unhelpful beliefs about emotions were also a unique predictor within the regression analysis. These findings are in line with this study's hypothesis that broad unhelpful self beliefs, rather than illness-specific cognitions and behaviours, are particularly relevant for explaining distress. This also concurs with previous research which links maladaptive thinking styles to depression in MS (Kneebone et al., 2003; Shnek et al., 1995; Shnek et al., 1997). One explanation of this finding is that these unhelpful thinking styles develop through early experiences and are present prior to MS development. However, these prove particularly unhelpful in the context of the major stressors that MS produces and promote poor adjustment. For example, somebody who believes that they must meet very high standards in order to be acceptable is likely to encounter difficulties when MS prevents achievement of these high standards. Similarly an individual who believes that anger, fear or sadness should not be expressed or shared may struggle when these emotions occur and may find it harder to discharge emotions or to seek support from others The finding that lack of acceptance of MS was correlated with distress is also in line with expectations and the some of the limited existing literature which has linked acceptance to better adjustment outcomes (Harrison et al., 2004; Pakenham & Fleming, 2011). Interestingly acceptance of MS was not an important predictor of distress in the regression analysis when considered alongside unhelpful beliefs about the self and unhelpful beliefs about emotions. This suggests that addressing dysfunctional assumptions about the self and changing attitudes regarding experiencing and expressing negative emotions may be key to moderating levels of distress

in MS. Specific efforts to try to encourage patients' acceptance of MS may also lessen distress but appears to be less important.

Some of the illness perceptions items also emerged as important for understanding distress. Perceiving severe consequences and lacking a coherent understanding of MS were significant unique predictors within the regression analysis. Previous studies of illness perceptions in adjustment to MS (Jopson & Moss-Morris, 2003; Neter et al., 2009) also found that negative, threatening beliefs about MS were correlated with and predicted emotional adjustment outcomes within a regression analysis. However, slightly different patterns of specific findings occurred. Jopson and Moss-Morris's findings suggested a broader range of illness perceptions were important in explaining variance in emotional adjustment outcomes, including illness identity, personal control, cyclical timeline and psychological causes (the latter two are not tapped by the BIPQ measure used in the current study). Neter et al., however, reported illness identity and consequences as the important predictors. Differences in results between studies could potentially be influenced the inclusion of other strong cognitive and behavioural correlates of adjustment in the current study. Alternatively, differences in the illness perceptions measures (discussed above) or differences in the outcome measures or sample characteristics.

5.4.1.3. The influence of disease factors

As predicted, this study demonstrated that CB factors were important above and beyond the contribution of demographic and illness factors which played a relatively small role in adjustment. Disease factors were unrelated to distress, although neurological-related disability (EDSS) was a significant correlate of functional impairment and accounted for a significant proportion of the variance within the regression model. This pattern largely corresponds to existing literature on the relative contribution of disease variables and psychological variables to adjustment outcomes (e.g. Jopson & Moss-Morris, 2003; McIvor, 1984). These findings also fit well with a cognitive behavioural model of adjustment to MS proposed in chapter 3. Thus, whilst disease factors are important triggers for adjustment difficulties, an individual's cognitions and behaviours contribute significantly to psychological adjustment above and beyond this, indicating scope for improving adjustment through psychological interventions to modify cognitions and behaviours. It appears that patients' beliefs are vital for understanding (and perhaps

reducing) levels of distress. However, functional impairment may be more difficult to change through addressing cognitions and behaviours (e.g. within psychological interventions) because it appears to be, at least in part, determined by objective disease severity. Nonetheless, there is scope for modifying the disease-specific cognitions and behaviours that appear relevant to increased functional impairment.

In this study the importance of CB factors for explaining distress and functional impairment was substantial. However, the combinations of variables investigated in this study explained only 23.3% and 44.2% of the variance in functional impairment and distress respectively. Therefore, other variables are also likely to be relevant to understanding adjustment.

5.4.2. Implications for improving adjustment in people with MS

Knowledge about the correlates of adjustment is important for identifying who may be vulnerable to adjustment difficulties in the future. For example, it may be possible to target adjustment-related interventions at patients who are starting to develop avoidant responses to their MS symptoms (e.g. resting excessively in the hope of reducing symptoms) to limit future functional impairment.

The relevance of CB variables in adjustment above and beyond MS severity variables gives cause for hope for interventions to assist adjustment, especially when conceptualised in terms of distress. Whereas the scope for modifying the course and severity of MS remains modest for many PwMS, cognitions and behaviours are potentially modifiable. This study provides some preliminary suggestion as to potential areas of focus within adjustment interventions. Depending on the aim of the intervention - reducing distress, improving functioning, or both- clinicians may opt to select the strongest correlates of that adjustment outcome as a focus for change. For example, an intervention primarily aiming to reduce distress in clients may usefully tackle unhelpful cognitions (e.g. around perfectionism and need for approval) by using thought diaries, and training in developing alternative and more helpful thoughts. On the other hand, an intervention aiming to help people engage in a more active social life and contribution to home life may concentrate on symptom-related behaviours and thoughts by helping the client to develop more consistent patterns of activity and rest through planning, monitoring and graded activity, and to identify and modify unhelpful and inaccurate beliefs about MS and symptoms.

5.4.3. Limitations of this study

Because the study was nested within a therapy trial, with strict eligibility criteria and substantial time commitment required to participate, the sample may not be representative of PwMS. Furthermore, whilst this study sampled people in the early stages of MS, replication in a larger, broader sample, including patients with higher levels of disability and longer illness duration would be valuable.

Another limitation of the study is that the sample size is somewhat small compared to the number of predictor variables examined. This limitation arose due to the current study making use of data from a therapy trial for which sample size was based on power calculations for the primary efficacy analyses (Moss-Morris et al., 2009). Various guidelines are available for the sample size required to test different numbers of predictors within multiple regression analysis (Field, 2005). A common rule of thumb is to multiply the number of predictor variables by 10 in order to get the required sample size. In this study this would mean that to test the variables in the WSAS regression model 90 cases are required and to test the GHQ regression model a sample size of 100 is needed. With a sample size of 94 this study meets these guidelines for the WSAS regression and narrowly misses it for the GHQ regression analysis. However, some other researchers have advocated larger sample sizes. Green (1991) suggests that the equations of $50+8k$ or $104+k$ should be used depending on whether the researcher is interested in the overall model or the individual predictors. Using the latter equation (since the influence of individual CB variables was of interest), the sample size should ideally have been 113 for the WSAS analysis and 114 for the GHQ analysis (i.e. 19 and 20 cases too few for the respective analyses). Whichever method is used to calculate required sample size, it appears that the numbers in this study may be inadequate, potentially leading to overestimation of effects (Field, 2005). For this reason, the results should be treated with caution and replicated in other, larger samples.

The lack of influence of MS type, relapse status, and severity on adjustment could potentially be related to the use of self-report questions for determining these factors. A more thorough examination of these factors, by conducting neurologist examinations on entry to the trial may have revealed more but was beyond the scope of the study.

A major limitation of this study is that due to its cross-sectional design causal relationships cannot be inferred. Longitudinal studies are required to explore relationships further. Intervention studies examining changes in these CB factors as mechanisms of any treatment effects would add weight to the argument that these play a causal role in adjustment outcomes.

5.4.4. Conclusions

The empirical study in this chapter used a sample of early-stage MS patients to explore the relevance of a number of cognitions and behaviours which the systematic review in chapter 3 suggested were promising, but under-researched correlates of adjustment outcomes. As predicted, different factors emerged as important to the two different adjustment domains. Functional impairment was related to unhelpful illness perceptions and symptom responses, especially avoidance and rest. However, distress was better predicted by cognitive factors that were not illness-specific, especially unhelpful beliefs about the self. An interesting, and clinically-relevant next step is to extend these cross-sectional findings to explore whether change in the key predictors influence change in adjustment outcomes. Such a study is reported in chapter 6

Chapter Six: An Investigation of Change Processes in MS Adjustment Interventions

6.1. Introduction

6.1.1. Overview

The previous chapter reported a study of cross-sectional associations between cognitive and behavioural (CB) variables and adjustment outcomes in pwMS. Although the findings suggested that a number of CB variables were important for explaining adjustment outcomes, the research design could not address causal hypotheses, or determine whether a change in these variables would influence adjustment outcomes. This was also a limitation of many of the studies that were included in the systematic review (chapter 3). One recommendation from that review was that more longitudinal research and investigations of change within interventions was needed. The empirical study reported in this chapter continues to investigate CB variables involved in adjustment, but this time explores change within a treatment trial. Analyses of mechanisms of change (mediators) and interactions between treatment and patient characteristics (moderators) are conducted.

6.1.2. Psychological interventions for adjustment to MS

As described in chapter 1 research has established that many pwMS experience negative psychosocial consequences including depression, anxiety, relationship difficulties, poor health-related QoL and interference with work and social activities. It is therefore not surprising that a number of research trials have investigated the effectiveness of psychosocial interventions to improve these outcomes. Various psychological interventions have been investigated including insight-oriented group psychotherapy (Crawford & McIvor, 1985), relaxation and imagery (Maguire, 1996), manualised CBT (Mohr et al., 2001; Mohr et al., 2000; Mohr, Cox, & Merluzzi, 2005), coping or stress management interventions containing CBT elements (Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987; Rigby, Thornton, & Young, 2008; Schwartz, 1999), a self-efficacy based intervention (Wassem & Dudley, 2003), supportive-expressive group therapy (Mohr et al., 2001), a health promotion intervention (Stuifbergen, Becker, Blozis, Timmerman, & Kullberg, 2003) and peer support (Schwartz, 1999). A number of these studies have reported positive effects on outcomes such as depression (Foley 1987, Mohr 2001, 2003),

anxiety (Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987), injection-related anxiety (Mohr et al., 2005), self-efficacy (Stuifbergen et al., 2003) health-related QoL (Stuifbergen et al., 2003) and medication adherence (Mohr 2000).

A recent Cochrane review of this growing body of intervention literature tentatively concluded cognitive-behavioural approaches are beneficial in the treatment of depression, and helping people adjust to having MS but highlighted methodological weaknesses of the evidence base such as inadequate reporting and small sample size. (Thomas, Thomas, Hiller, Galvin, & Baker, 2006). Another review reached similar conclusions: interventions with elements of CBT such as goal setting, homework, education and information appeared to be most effective for improving wellbeing and QoL in pwMS (Malcomson, Dunwoody, & Lowe-Strong, 2007). A more recent clinical expert review concluded that CBT appears to be a valuable approach to improving various psychosocial outcomes in pwMS (Dennison & Moss-Morris, 2010).

6.1.2.1. The saMS trial

The data in this chapter was collected within the saMS trial (Moss-Morris et al., 2009). This RCT compared the efficacy of two psychological interventions for adjustment to MS: CBT and Supportive Listening (SL) (these interventions are outlined in the method section of this chapter). The trial considered two primary outcomes as indicators of adjustment: distress and functional impairment. CBT was hypothesised to be an effective intervention for improving both adjustment outcomes, whereas the SL arm was included as a comparison intervention to control for participant expectations and non-specific treatment factors such as therapist time and empathy. SL was expected to have minimal effects on both outcomes.

The main trial results regarding treatment efficacy are reported elsewhere (Moss-Morris et al., 2011) and are not a component of this thesis. However, to summarise, distress reduced in both treatment arms but CBT was a superior treatment for distress. At post-therapy the effect size was medium (estimated group difference -3.23, p=.004, d=-0.52). By long-term follow-up at 12 months the difference between the CBT and the SL group was just

significant and the effect size was small (estimated group difference=-2.22, p=0.049, d=-0.36). Although there were some improvements in functional impairment in the CBT group at post-therapy and long term follow-up, the differences between groups were small and not statistically significant (estimated group difference=-1.76, p=0.19, d=-.22 at post-therapy and .163, p=.19, d=.20 at 12 months).

The saMS trial was powered for detecting change in the primary outcomes, rather than mediation or moderation analysis. The analyses reported in this chapter are therefore exploratory. Because the current research aims were specifically concerned with understanding factors involved in change, data from the post-therapy trial assessment point, where the strongest treatment effects were obtained, are used as the outcome measure.

6.1.3. Investigating change within interventions

Investigating factors that are implicated in the change process highlights important components of interventions. This increases theoretical understanding of the phenomenon being studied; in this case, psychological adjustment to MS. Investigating mechanisms can also guide the process of developing and refining interventions to focus on the elements with proven efficacy (i.e. active ingredients). Knowledge of important change processes involved in adjustment also provides information that could be useful to pwMS seeking guidance in how to best live with the disease. For example, if reducing excessive rest and avoidance behaviour emerged as a key mechanism for reducing functional impairment, pwMS could be advised and supported by their health professionals and patient organisations to appropriately balance rest and activity.

Despite the usefulness of understanding change processes, there have been few formal assessments of mechanisms responsible for improvement during psychosocial interventions for pwMS. Little is known, therefore about what drives the change or improvement in adjustment seen in some interventions. Lack of understanding of mechanisms through which interventions exert their influence is also a problem in the broader psychological intervention literature. Whilst there is good evidence that certain interventions work, we often have little knowledge of why and how (Hodgetts & Wright, 2007; Kazdin, 2007). This situation appears to be improving and in recent years

researchers who run psychological intervention trials are explicitly testing mechanisms using statistical techniques (most appropriately, mediation analysis). The usual approach here is to specify a priori, the mechanism/s through which the intervention is theoretically proposed to work. Measures of the proposed mediator/s would then be assessed within the trial and statistical analysis would be used to determine whether the proposed mediation model was plausible.

So far, research has only provided a limited understanding of the processes within interventions which improve adjustment in pwMS. A number of secondary analyses of CBT trials conducted by Mohr and colleagues have been published. One study found that reduced fatigue was related to improved mood (Mohr, Hart, & Goldbert, 2003). In another, improved disability status was related to reductions in fatigue (Mohr, Hart, & Vella, 2007). A third found that improved depression was related to improved QoL and wellbeing (Hart, Fonarevan, Merluzzi, & Mohr, 2005). However, these studies simply examined relationships between change in different variables without conducting a mediation analysis. The one study that formally tested mediation found reductions in depression and increases in positive affect mediated the relationship between CBT and improved QoL (Cosio, Jin, Siddique, & Mohr, 2011). Whilst these findings suggest that improving one domain of adjustment (e.g. mental health, fatigue) is associated with, or may be responsible for, improvement in another (e.g. QoL, physical functioning), they provide little insight into how the intervention worked and what components were effective in producing desired change in outcome. It is particularly surprising that these studies of CBT have not tested whether changes in unhelpful cognitions and behaviours are mechanisms through which the intervention produces positive change. Only two studies of psychosocial interventions in MS have focused on mediating variables that are theoretically proposed to be responsible for change within the intervention under study. Both have been published since the current study was carried out. Cosio et al. (2011) investigated change in social support and coping skills as potential mediators of QoL improvements in CBT for pwMS but found no evidence for these variables as mechanisms. However a recent study of an MS fatigue trial tested a cognitive-behavioural model of MS fatigue by testing illness perceptions and symptom responses as potential mediators. The superior reduction of fatigue in CBT participants compared to participants in a relaxation skills condition was mediated by change in negative perceptions about fatigue (Knoop, van Kessel, & Moss-Morris, 2011).

In addition to understanding change processes it is of interest to explore factors that predict treatment outcome. Regardless of treatment received participants with certain characteristics (e.g. MS-related, demographic or psychological) may have better or worse outcomes than others. Identifying these patterns may increase theoretical understanding of the phenomenon under study, guide decisions about where best to focus limited clinical resources and identify situations where a different intervention may be required. It is also important to examine moderators of treatment outcome; factors that interact with treatment to change the presence, direction or strength of the relationship between intervention and outcome. Again, these analyses may allow a deeper theoretical understanding of change processes, and conditions under which they operate. They may also influence clinical decision-making by providing information about the conditions under which an intervention is most effective. Indeed the Cochrane review (Thomas et al., 2006) suggested that future research should identify subgroups of pwMS who benefit most, and when it is most timely to receive adjustment-based interventions.

Despite the importance of understanding factors related to intervention success there has been surprisingly little research identifying factors that predict or moderate response to psychosocial interventions for pwMS. Two studies (again, secondary analyses of Mohr et al.'s CBT trials) found that high levels of therapeutic alliance (Beckner, Vella, Howard, & Mohr, 2007) and social support (Beckner, Howard, Vella, & Mohr, 2010) predicted better depression outcomes in CBT participants, but not people assigned to the supportive emotion-focused comparison treatment.

In addition to the lack of existing research on predictors and mechanisms of change in MS interventions, it is of particular interest to seek to understand change within the saMS trial. Unlike most previous MS intervention studies, the saMS trial specifically sought to improve psychological adjustment in a broad population of patients with early stage MS rather than targeting the intervention at people with psychiatric symptoms or a specific MS symptom such as fatigue. The CBT within this trial was newly developed with reference to the systematic review, model and qualitative study from this thesis (chapter 3 and 4). Therefore, understanding factors that led to improvements in adjustment within this intervention is an important step forward, not only in understanding how the specific interventions tested within this trial exerted their influence, but in exploring further the validity and value of a cognitive-behavioural model of adjustment to MS.

6.1.4. Aims

The aims for this study were to explore mechanisms, predictors and moderators of improvement in distress and functional impairment within psychological adjustment interventions. The study investigated the set of CB variables analysed in the previous chapter (beliefs about the self, beliefs about emotions, acceptance of MS, illness perceptions and cognitive and behavioural responses to symptoms) as mechanisms of change. The study also explored whether participants' status on these CB variables, MS variables or demographic characteristics predicted or moderated improvement in distress and functional impairment.

6.1.5. Hypotheses

6.1.5.1. Mechanisms of change

In line with a cognitive-behavioural model of adjustment to MS (as described in chapter 3) both illness-specific and more general cognitions and behaviours are purported to contribute to adjustment outcomes. It was hypothesised that some of the beliefs and behaviours examined in the previous chapter would function as mechanisms of change, improving particularly during CBT treatment, and in turn reducing distress and functional impairment.

6.1.5.2. Hypothesised mechanisms of change in distress

6.1.5.2.1. Reductions in unhelpful beliefs about the self

It was expected that changes in unhelpful beliefs about the self would emerge as a mechanism of change in distress. This variable was a unique predictor of distress within chapter 5's cross-sectional multiple regression analyses. Cognitive models of psychopathology centre around the role of negative or biased thought processes (Beck, 1976). Several previous studies reviewed in chapter 3 have found that measures of negative cognitive styles and biases were associated with depression in pwMS (Shnek, Foley,

LaRocca, Smith, & Halper, 1995; Shnek et al., 1997; Kneebone & Dunmore, 2004; Bruce, Polen, & Arnett, 2007). These include one study which considered the measure of unhelpful beliefs about the self used within this thesis (Kneebone, Dunmore, & Evans, 2003).

6.1.5.2.2. Reductions in unhelpful beliefs about emotions

Beliefs about emotions were also hypothesised to mediate reductions in distress. These beliefs have not been investigated in pwMS prior to this thesis. However, the qualitative study in chapter 4 suggested that some pwMS consider experiencing and sharing negative emotions unacceptable and chapter 5 showed that these beliefs were key correlates of distress. Furthermore, as described in chapter 2, research into other chronic diseases has suggested that emotional regulation is an important part of adjustment to chronic illness (de Ridder et al., 2008). Cognitive behavioural theory suggests that unhelpful beliefs about emotion may be important for understanding the development and maintenance of psychological distress through a number of pathways (Cramer & Langlois, 2005; Jack, 1991; Rimes & Chalder, 2010). Suppressing emotions tends to be counterproductive, leading to increased distress. Furthermore, trying to block negative emotion, and not sharing emotion with others is likely to influence quality of interpersonal relationships, reduce social interaction, and lead to feeling ignored, unsupported and emotionally numb (Corstorphine, 2006; Kennedy-Moore & Watson, 2001; Wenzlaff & Wegner, 2000).

Both beliefs about the self and beliefs about emotions would be expected to be modifiable. A core component of all CBT is enabling clients to identify and modify unhelpful cognitive styles and biases that either cause or maintain their difficulties (Beck, 1976; Young, Rygh, Weinberger, & Beck, 2008; Rupke, Blecke, & Renfrow, 2006; Clark, Beck, & Alford, 1999). Within the saMS trial, unhelpful thinking relating both to MS (e.g. ‘his symptom means I’m about to go blind’) and to more general beliefs (‘I need to do things perfectly to be acceptable’, ‘Crying means I’m weak’) was identified and challenged through cognitive restructuring. It was also considered probable that beliefs about emotions would change as a result of positive experiences of expressing emotion within the context of the therapy. Participating in research which validates and legitimises the experience of distress as a consequences of living with MS, and experiencing the safe environment, empathy and unconditional positive regard common to both CBT and SL were also

considered likely to modify participants' beliefs about the acceptability of feeling and expressing anxiety, fear, depression and sadness.

6.1.5.2.3. Increases in acceptance

It was also considered possible that increased acceptance may be another mechanism of distress reduction. The qualitative study (chapter 4) suggested that acceptance of MS and its implications for the self and the future was an important aspect of adjustment but that it might have a complex relationship with outcomes such as distress. Although it did not emerge as a key predictor in the cross-sectional regression analysis in chapter 5 it was moderately negatively correlated with distress. Recent research in people with MS also suggests that acceptance predicts later emotional adjustment (Pakenham & Fleming, 2011) Acceptance is theoretically considered changeable (Hayes et al., 2006). The saMS trial CBT included some basic elements of Acceptance and Commitment Therapy (Hayes et al., 2006; Hayes et al., 2006) to foster acceptance of elements of MS that cannot be realistically changed or controlled (Moss-Morris et al., 2009).

6.1.5.2.4. Reductions in unhelpful perceptions of MS and symptom responses

Changes in illness perceptions and responses to symptoms were also expected to mediate reductions in distress. Some measures of these variables were associated with distress in the cross-sectional correlation analyses in chapter 5 and the consequences and coherence items from the BIPQ emerged as unique predictors within the multiple regression analysis. Furthermore, previous studies have found that negative, threatening perceptions of MS and MS symptoms were associated with distress (Jopson & Moss-Morris, 2003; Osborne, Jensen, Ehde, Hanley, & Kraft, 2007). The CSM prescribes that illness-related beliefs and responses to health problems are not fixed and are modified by experience (e.g. Leventhal et al., 1984). There was also reason to expect unhelpful MS-related beliefs and behaviours would change as a result of the CBT intervention. The CBT within the saMS trial included a psychoeducational component which was expected to have increased understanding of MS (BIPQ coherence). Learning strategies to problem solve, set goals and manage stress, symptoms and sleep were considered likely to alter control perceptions (e.g. BIPQ personal control, treatment control). CBT also covered cognitive strategies to reduce preoccupation

with symptoms (CBRSQ symptom-focusing) and the tendency to perceive everyday symptoms as being MS-related (BIPQ illness identity) and highly threatening (CBRSQ catastrophising, embarrassment, damage, fear/avoidance). Change in these types of beliefs, and changes to behavioural patterns (e.g. avoidance/resting, all-or-nothing) through activity and rest scheduling and goal setting were expected to reduce the distress that had resulted from symptom-based worries and preoccupation and from undesired disruptions to valued activities. It was considered plausible that sharing MS-specific worries, losses, fears and concerns and finding these either validated (where realistic) or challenged (where unrealistic or unhelpful) would reduce emotional representations and concern perceptions, as well as potentially negative perceptions of MS consequences.

6.1.5.3. Hypothesised mechanisms of change in functional impairment

Given the results from chapter 5 it was not expected that changing beliefs about emotions, beliefs about the self, and acceptance would be particularly important in modifying functional impairment. Instead, it was hypothesised that participants' negative and threatening beliefs about MS and unhelpful cognitive and behavioural responses to symptoms would reduce during CBT and that some of these reductions might lead to reductions in functional impairment.

6.1.5.3.1. Reductions in unhelpful perceptions of MS and symptom responses

A selection of illness and symptom cognitions were related to impairment in chapter 5's cross-sectional analyses and in previous studies (Jopson & Moss-Morris, 2003; Osborne et al., 2007; Skerrett & Moss-Morris, 2006 ;Douglas et al., 2008; Neter et al., 2009; Spain et al., 2007; Neter et al., 2009; Pakenham & Fleming, 2011; Spain et al., 2007). Psychological interventions have been shown to modify illness perceptions and symptom beliefs and behaviours in various chronic illness groups including pwMS (Petrie, Cameron, Ellis, Buick, & Weinman, 2002; Moss-Morris, Humphrey, Johnson, & Petrie, 2007; Deale, Chalder, & Wessely, 1998; Knoop et al., 2011). Furthermore, symptom-related cognitions appear to mediate the effect of CBT on various outcomes including MS fatigue (Knoop et al., 2011) functional impairment in patients with chronic fatigue syndrome (Wiborg,

Knoop, Prins, & Bleijenberg, 2011) and functional impairment in chronic pain patients (Turner, Holtzman, & Mancl, 2007). As described above, CBT within the saMS trial included many features that were considered likely to reduce unhelpful thinking about MS and its symptoms. It was hypothesised that increases in control and coherence beliefs and reductions in catastrophising about symptoms, focusing on symptoms, believing that symptoms are causing physical damage and social embarrassment would lead participants to change their views on how much MS limits and restricts them when they are asked to consider how much MS affects their lives. Reduction in these sorts of fearful and threatening beliefs may themselves influence behavioural changes.

It was expected that behavioural responses to symptoms would be the key drivers of change in functional impairment. These limiting responses are not necessarily dictated by the disease severity itself (e.g. ambulation difficulties) and are often disproportionate to the behavioural changes a person will need to make in response to their MS. Chapter 5 indicated that excessive avoidance and resting in response to symptoms predicted functional impairment, even after considering disease severity. Similar results were found in the other study which has investigated this construct in MS (Skerrett & Moss-Morris, 2006). Within CBT, these behaviours were expected to be modified as part of goal-setting and activity/rest scheduling. It was also considered plausible that these behaviours might change as a result of cognitive changes such as reductions in threatening thoughts related to MS and MS symptoms. It was expected that as participants reduced avoidance of situations that they believed would worsen symptoms, reduced excessive resting, and adopted more consistent levels and patterns of activity, they would experience less disruption to activities such as socialising, home management, leisure activities and work. They were therefore expected to report lower functional impairment.

Despite expecting certain variables to be particularly important in understanding change in distress and functional impairment it is important to note that it was not expected that any single variable would be responsible for all change. It was hypothesised that there are multiple contributors to adjustment outcomes, including both variables measured and variables not measured within this study.

6.1.5.4. Predictors and moderators of change

6.1.5.4.1. Baseline status on cognitive and behavioural (CB) variables

In addition to being important mechanisms of change, participants' pre-therapy CB characteristics were also considered as predictors of adjustment outcomes. However, given that multiple factors (including the interventions themselves, and pre to post-therapy change in the variables) would influence post-therapy adjustment outcomes, they were not expected to explain much of the variance. Instead, it was hypothesised that there would be an interaction between treatment arm and pre-therapy scores on CB variables such that participants who showed more evidence of maladaptive beliefs or behaviours would have better post-therapy outcomes in CBT compared to SL. This is because the hypothesised mechanism of action of CBT is through altering unhelpful responses which influence adjustment outcomes. In line with the hypotheses regarding change mechanisms, it was expected that unhelpful thoughts about the self and emotions would be most important for moderating reductions in distress whilst illness perceptions and symptom responses would be most relevant for moderating reductions in functional impairment.

6.1.5.4.2. MS Status

It was expected that worse pre-treatment illness status would predict worse outcome at post-therapy. In other words, regardless of which therapy a participant was assigned to, if their MS was severe and active at the beginning of the trial, they would show worse adjustment than those who had less severe and active MS. Previous research, including the cross-sectional study in chapter 5 suggest that illness variables are more consistently related to adjustment outcomes that capture physical and role functioning as opposed to emotional or mental health outcomes (Nortvedt, Riise, Myhr, & Nyland, 1999; Rudick, Miller, Clough, Gragg, & Farmer, 1992; Turpin, Carroll, Cassidy, & Hader, 2007; Pittock et al., 2004). Therefore, it was expected that the relationship between illness factors and post-therapy adjustment outcomes would only be strong for functional impairment. It was unclear what relationship time since diagnosis would have with adjustment outcomes since, as discussed in chapter 1, previous research has yielded very inconsistent results. It was expected that disease course and severity of MS may be more important than length of time since the diagnosis.

Although MS severity variables were considered as non-specific predictors of poorer adjustment outcomes at post-therapy (i.e. important regardless of therapy arm), an interaction with therapy arm was hypothesised to be more likely. It was predicted that participants with worse illness status would be particularly well suited to CBT as they may have more current difficulties on which to draw and apply newly acquired self-management techniques (e.g. goal setting, activity scheduling, recognising unhelpful thought processes, reducing unnecessary worry about symptoms and the perceived need to rest excessively or avoid situations or activities). Conversely, participants with worse illness status were expected to find SL less effective or potentially slightly unhelpful as it offers no practical suggestions or coping techniques and may draw attention to their difficulties without resolving them.

6.1.5.4.3. Demographic factors

Age, gender and marital status (married or cohabiting versus single, divorced or widowed) were explored as potential predictors or moderators of change. Theory and previous research did not indicate any specific hypotheses about the relationships these variables would have on post-therapy adjustment outcomes.

6.2. Method

6.2.1. Procedure

Data collection for this longitudinal study was nested within the saMS trial. Full details of the trial procedures and hypotheses are published elsewhere (Moss-Morris et al., 2009).

Recruitment procedures and inclusion criteria for this study have already been detailed in chapter 5 (section 5.2.1). Participants completed baseline self-report questionnaires before being randomised to either CBT (n=48) or SL (n=46). They took part in the assigned intervention over a period of ten to twelve weeks (details below). Further questionnaires were administered post-therapy (fifteen weeks post-randomisation). The trial data collected at six and twelve months were not used for the current study.

6.2.2. Interventions

Both interventions were delivered by general nurses who were recruited as novice therapists and completed training in CBT and SL specifically for this project. They were regularly supervised by experienced therapists (for details see Moss-Morris et al. 2009). Both interventions consisted of eight sessions. The initial one lasted 90 minutes and subsequent sessions lasted 50-60 minutes. Session one and four were face-to-face. The remainder were conducted by telephone. 84 out of 89 participants (94.3%) were considered to have received the intervention they were assigned to (i.e. had at least four sessions). 78 out of 89 participants (87.6%) completed all eight sessions. The mean number of sessions completed was 7.5.

6.2.2.1. Cognitive Behaviour Therapy (CBT)

The CBT was a manualised intervention developed for the saMS project (Moss-Morris et al., 2009). It was created primarily by Prof Moss-Morris and Prof Chalder, although I assisted with the development of the intervention whilst I was employed on the research project. Beck's cognitive model of emotion (Beck, 1976; Beck, 1991) was used to guide the development of the CBT model and therapy manual for this trial. Some basic principles from Acceptance and Commitment Therapy (Hayes, Follette, & Lineham, 2004; Hayes et al., 2006) were also incorporated. The CBT manual development also drew on findings from the systematic review in chapter 3 and the qualitative study in chapter 4.

The CBT package aimed to enable participants to achieve positive adjustment to their MS. The focus was on accomplishing optimal day-to-day functioning within the constraints of the disease, to minimize distress and manage symptoms. The treatment was structured but also individualized to meet participants' needs. The manual consisted of nine chapters which were used as appropriate depending on the formulation. Chapters included managing symptoms, tackling negative and unhelpful thoughts, setting goals and problem solving, managing social relationships and managing stress. A table summarizing the content of CBT can be seen in appendix N. The patient and therapist agreed on key areas to focus on and worked together to develop homework for the patient to tackle between the sessions. Participants were encouraged to bring along a partner or family member to session four which thirteen participants (27.7%) did. A booklet entitled 'Coping when

somebody close to you has MS' was provided for the patient to hand to a partner or family member if appropriate.

6.2.2.2. Supportive listening (SL)

In SL, participants had the opportunity to talk freely, extensively and confidentially about their experiences, thoughts and feeling about MS and its effect on their lives. If participants preferred not to focus on their MS, they could choose other topics to talk about which they felt were currently relevant to them. The therapist's role was simply to provide the participant with a non-judgemental, safe environment in which to express themselves. The intervention was based on a manualised SL intervention used within a recent trial of interventions for chronic fatigue syndrome (Wearden et al., 2006; Wearden et al., 2010). The intervention drew on theories and counselling techniques of Carl Rogers (1951) and included asking open questions, active listening skills, paraphrasing, empathising, reflecting and summarising. SL was unstructured and directed by the participant. Information was not specifically elicited from the participants, coping strategies or skills were not suggested, and tasks or homework were not given. SL was designed to control for the non-specific effects of therapy such as warmth and positive regard rather than being a formal intervention per se.

6.2.3. Measures

Data on the demographic and MS characteristics of participants was collected at baseline. Adjustment outcomes and potential process variables were measured at both baseline and post-therapy. Full details of the measures are presented in chapter 5 (section 5.2.2). A summary of these is given below.

6.2.3.1. Adjustment outcomes

The Work and Social Adjustment Scale (WSAS; Mundt et al., 2002) measures functional impairment.

The General Health Questionnaire-12 (GHQ; Goldberg, 1992) measures psychological distress.

6.2.3.2. CB variables proposed as mechanisms, moderators or predictors of improvement

The Psychological Vulnerability Scale (PVS; Sinclair & Wallston, 1999) measures unhelpful beliefs about the self.

The Beliefs about Emotions Scale (BES; Rimes & Chalder, 2010) measures unhelpful beliefs about the experience and expression of negative emotions.

The Acceptance of Chronic Health Conditions (ACHC; Stuifbergen, 2008) assesses acceptance of change in one's life due to a chronic health condition.

The Brief Illness Perception Questionnaire (BIPQ; Broadbent et al., 2006) assesses illness representations (*Consequences, Timeline, Personal Control, Treatment Control, Illness Identity, Concern, Coherence, Emotional representations).* The *timeline* item was omitted from current analyses due to its lack of variability and relationship to adjustment outcomes in chapter 5 analysis. As before, individual items were used due to inadequate internal reliability of the total score.

The Cognitive and Behavioural Responses to Symptoms Questionnaire (CBRSQ; Moss-Morris et al., 2011) assesses patients' responses to the experience of symptoms. The five cognitive subscales are *symptom-focusing, catastrophising, damage, fear/avoidance,* and *embarrassment.* The two behavioural subscales measure *all-or-nothing* behaviour and *avoidance/resting.*

6.2.4. Participants

As described in chapter 5, 94 participants completed baseline assessments. 89 (94.7%) of the original participants responded to the post-therapy questionnaire. Data from these 89 participants were used in the current analyses.

Participants were 72% female with an average age of 41.7. Around half were educated to at least degree level, 58% were married or cohabiting and 76% were white British. Mean time since diagnosis was 3.9 years and 79% had RRMS. As a result of exclusion criteria, no participants were considered to have substantial cognitive impairment. The mean EDSS was 5.0 indicating difficulty walking distances less than 500 metres and/or disability in a

number of functional systems (e.g. problems with vision, co-ordination). Tables displaying further demographic and disease characteristics of this sample can be seen in appendix O and P.

The five participants for whom post-therapy data was unavailable were compared to the 89 participants who provided data. Although findings have to be interpreted with caution due to the small number of cases without data, few differences were found in their baseline characteristics. Participants missing post-therapy data were more likely to be male ($\chi^2(1, n=90)$ 5.98, p = .014), and have worse cognitive impairment ($t(92)$ = -2.875, p= .005) but were not more likely to have withdrawn from therapy.

6.2.5. Data Analysis Strategy

6.2.5.1. Data preparation

Analyses were conducted in SPSS 17. Data was screened, and missing data were dealt with as described in Chapter 5 (section 5.2.3.1). Descriptive statistics were produced for adjustment outcomes and CB variables for the CBT and SL arms separately at both pre and post therapy. Residualised change scores were calculated by regressing post-therapy scores on baseline values of that variable. Continuous variables that were tested as non-specific predictors or moderators of the treatment arm were centred by deducting the sample mean from each score. Treatment arm was effects coded (-.5=SL, .5=CBT). Interaction terms were created by multiplying the centred predictor variable with the treatment arm.

6.2.5.2. Change in outcomes and potential mechanisms

The initial analyses explored change in variables between pre and post-therapy. The aim of this step was to select, from the set of potential mechanisms of improvement, those variables that were suitable for further study within mediation analyses.

First, paired sample *t*-tests (pre-post) were performed to examine whether significant change occurred between baseline and post-therapy on adjustment outcomes and potential mediators, predictors and moderators for the two different treatment arms. ANCOVA was then used to test for post-therapy differences between the treatment arms. Post-therapy scores were the DV variable, baseline scores were covariates and treatment group was the

fixed factor. CB variables that changed more in one treatment arm than another were then explored further to explore if they were mediators of treatment effects.

6.2.5.3. Mediation analysis

The most widely used approach to testing mediation is the causal steps approach whereby a series of regression analyses are used to examine paths between the independent variable (IV), mediator and dependent variable (DV) (Baron & Kenny, 1986). Mediation is deemed to have occurred if all paths are significant and the effect of the IV on the DV becomes zero (or decreases significantly) with the inclusion of the proposed mediator. This is often followed by the Sobel test to examine the null hypothesis that the indirect effect is zero. Recently this analysis approach has been heavily criticized on multiple grounds. Firstly, it lacks power, except when sample sizes are large (over 500) or the mediated effect is large (Hayes, 2009; MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002). Power to detect a medium effect in a sample size of 100 (i.e. similar to the current study) has been shown to be only .28 (MacKinnon et al., 2002). Secondly, the steps do not actually quantify and test an indirect effect: this is inferred through the presence of paths instead. Thirdly, Baron and Kenny require a significant path from the IV to DV. Yet a mediator can be causally between these variables even if the IV and DV are not associated so potential mediation can be explored even when there is no main effect (Hayes, 2009; Preacher & Hayes, 2004; Preacher & Hayes, 2008). Finally, statisticians warn that the Sobel test is inappropriate in many situations because it assumes large samples and a normal sampling distribution of the indirect effect (Cerin & MacKinnon, 2009; Preacher & Hayes, 2004; Preacher & Hayes, 2008).

Current best practice in mediation analysis is the use of bootstrapping to estimate the indirect effect (Hayes, 2009; Preacher & Hayes, 2008). Bootstrapping does not make unrealistic assumptions about the shape of the sampling distribution of the indirect effect. Bootstrapping is a nonparametric resampling procedure that involves repeatedly sampling from the data set and estimating the indirect effect in each resampled data set. An empirical approximation of the sampling distribution of the indirect effect is built and used to construct confidence intervals (CIs). Simulation studies show bootstrapping is a valid and powerful method for analysing mediation effects, with low risk of both Type I and Type II

errors (e.g. Briggs, 2006; Williams, 2004; Williams & MacKinnon, 2008; MacKinnon, Lockwood, & Williams, 2004).

Mediation analysis using bootstrapping can be achieved using either regression or structural equation modelling (SEM). SEM is often considered superior because of its flexibility, ability to control for measurement error, and assessment of the fit of the entire model. However, SEM requires large samples (Quintana & Maxwell, 1999; Tabachnik & Fidell, 1996). When sample size is less than 200 regression analysis is considered the appropriate analytical technique (Frazier, Tix, & Barron, 2004; Holmbeck, 1997).

This study used the INDIRECT macro developed by Preacher and Hayes (2008) to perform mediation analysis in SPSS. This macro allows for multiple mediators and statistical control of covariates. For the current analyses post-therapy distress or functional impairment served as DVs. Baseline distress or functional impairment was entered as a covariate. The IV was the treatment arm (CBT or SL). Residualised change scores for the CB variables were considered as potential mediators.

The observed dataset was randomly resampled 5000 times, in line with recommendations (Hayes, 2009). The mean of the indirect effects was used as the population parameter. When the 95% Confidence Interval (CI) around this parameter did not include zero, a significant indirect effect (i.e. mediation) was indicated. Bias-corrected accelerated CIs were used as these give both better power and lower type I error rates (MacKinnon, Lockwood, & Williams, 2004; Briggs, 2006). Effect sizes were calculated by determining the proportion of the total effect explained by the indirect effect.

6.2.5.4. Analysis of predictors and moderators of outcome

Hierarchical multiple regression was used to test whether variables predicted outcome, or moderated the relationship between treatment arm and outcome. In these analyses the baseline measure of the DVs (distress or functional impairment) was entered on step 1. Treatment arm (effects coded) and centred potential predictor (MS variables, demographic variables, or baseline status on CB variables or adjustment outcomes) were entered on step 2. On step 3 the interaction term was entered (arm*predictor variable). Significant effects of the potential predictors on step 2 indicated that the variable acted as a ‘non-specific predictor’ of outcome (Kraemer, Wilson, Fairburn, & Agras, 2002), predicting the DV regardless of treatment arm. Significant interaction terms on step 3 indicated that the

variable moderated the effect of treatment arm on outcome. Given that moderator analyses frequently lack power, Kraemer et al. (2002) argue that conventional interpretations of significance tests should no longer hold. Instead they suggest that moderation analysis should be considered exploratory and findings should be used for hypothesis generation, rather than interpreted and presented as conclusive. Given this argument and the likelihood of low power within this study, interactions at $p<.10$ are reported. To interpret and display interactions, graphs were produced following procedures recommended by Aiken and West (1991) using 'Interaction!' software (Soper, 2010).

6.3. Results

6.3.1. Pre-post therapy change

Appendix Q depicts results from paired sample t- tests which were used to explore change in adjustment outcomes and potential CB mediators. Overall, there was some improvement from pre to post-therapy in both treatment arms for most variables. However, more changes were statistically significant in CBT (12 out of 19 variables) compared to SL (5 out of 19 variables). Significant shifts in the more emotional variables (e.g. GHQ, ACHC, BIPQ Concern and Emotional Representations) were observed in both treatment arms. However, only CBT participants showed significant change in functional impairment, symptom-specific cognitions (e.g. CBRSQ cognitive subscales) and one of the behavioural responses (CBRSQ Avoidance/resting).

ANCOVA was performed to test whether post-treatment scores differed between treatment arms, controlling for baseline scores (Table 9). On the whole CBT participants demonstrated slightly lower (i.e. better) mean post-therapy adjustment outcomes. There was a significant effect of treatment arm for GHQ, but not WSAS. The between groups effect size for the GHQ (partial eta squared, η^2) would be considered medium (Cohen, 1992). Generally speaking, CBT participants had better post-therapy scores on CB variables (i.e. less unhelpful beliefs and behaviours) compared to SL participants. However, statistically significant between group differences ($p<.05$), were only found for BES and Catastrophising. In addition, between group differences approached significance for PVS, Symptom-focusing, and Embarrassment. All effect sizes were small (Cohen, 1992). Given that BES, PVS, Catastrophising, Symptom-focusing and Embarrassment changed significantly (or approaching significantly) more in CBT they were studied further as possible mediators.

Table 9: ANCOVA results for post-therapy adjustment outcomes and CB variables across treatment groups

		Post-therapy estimated marginal mean (controlling for baseline)		*F (df)*	*p*	Partial η^2
		CBT (*n*=47)	SL (*n*=42)			
Adjustment outcomes	GHQ	10.39	13.58	8.11 (2,89)	**.006****	.086
	WSAS	11.73	13.41	1.55 (2,86)	.217	.018
Process variables	PVS[1]	14.93	16.39	3.90 (2,88)	**.052**†	.044
	BES[1]	16.95	20.48	4.58 (2,89)	**.035***	.051
	ACHC[1]	33.99	32.84	1.10 (2,87)	.297	.013
	BIPQ					
	consequences	5.65	6.15	2.37 (2,89)	.128	.027
	personal control	5.43	5.43	.00 (2,89)	.911	.000
	treatment control	4.35	4.13	.17 (2,84)	.677	.002
	illness identity	5.43	5.46	.15 (2,88)	.700	.002
	concern	5.49	5.32	.15 (2,89)	.697	.002
	coherence	2.43	2.33	.08 (2,89)	.783	.001
	emotional representations	5.74	5.83	.04 (2,88)	.852	.000
	CBRSQ					
	fear/avoidance	8.33	8.76	.53 (2,89)	.470	.006
	catastrophising[1]	7.12	8.44	5.65 (2,89)	**.020***	.062
	damage	10.13	10.82	1.54 (2,88)	.217	.018
	embarrassment[1]	5.33	6.72	3.56 (2,88)	**.063**†	.040
	Symptom-focusing[1]	7.53	8.60	3.76 (2,89)	**.056**†	.042
	all-or-nothing	7.36	7.07	.292 (2,88)	.590	.003
	avoidance/resting	9.62	10.03	.441 (2,89)	.508	.005

*p<.05, **p<.01, †p<.10, high scores = worse, except for ACHC

[1]Selected as a potential mediator for mediation analysis

6.3.2. Mediation analysis

To aid interpretation of the analysis, Figure 5 illustrates the mediation models being tested. The top diagram shows path c, the total effect of the IV (treatment arm) on the DV (post-therapy distress or functional impairment). The bottom diagram dissects the total effect into a direct effect (path c') and a mediation, or indirect effect (paths a and b).

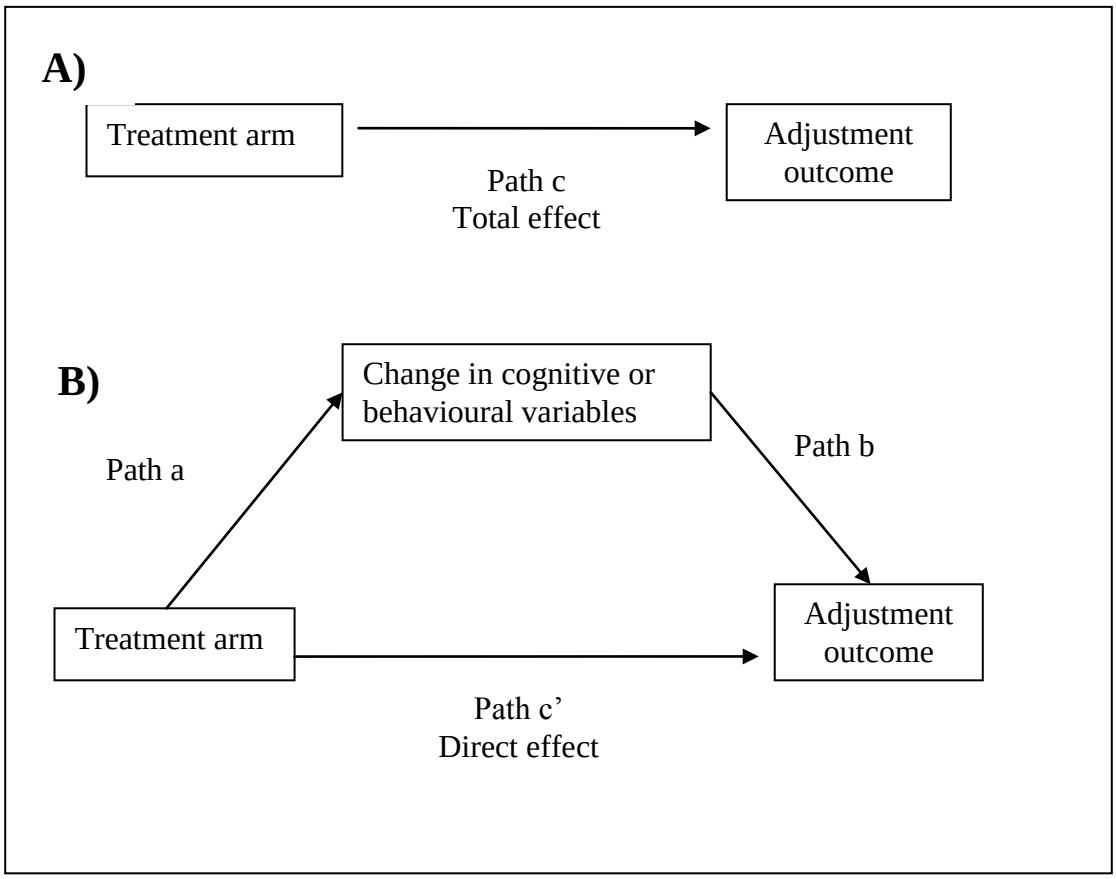

Figure 5:Paths tested in the mediation analysis

6.3.2.1. Mediation of change in distress

The results of the mediation analyses for distress are given in Tables 10 and 11. Table 10 displays regression coefficients for paths a, b, c, c' and the control variable (baseline GHQ). Table 11 shows estimated indirect effects for each purported mediator and bootstrapped CIs. Mediation is indicated if the CIs do not cross zero. Change in three variables, BES,

Catastrophising and Symptom-focusing, appeared to mediate the relationship between treatment arm and post-therapy GHQ.

The indirect effect for change in BES was estimated to be -.5768, CIs=-1.5283 to -.0172, and accounted for 17.6% of the total effect (Table 11). Table 10 shows that although CBT did not lead to significantly more reductions in BES than SL, reductions in BES were related to decreased distress. The indirect effect for change in Catastrophising was -.8040, CIs=-1.9318 to-.1597 and accounted for 25.2% of the total effect (Table 11). Table 10 shows that CBT reduced catastrophising more than SL and reduced catastrophising was related to decreased distress. The indirect effect for change in Symptom-focusing was -.4109, CIs=-1.3755 to-.0031, explaining 12.9% of the total effect (Table 11). This was despite the component a and b pathways failing to reach statistical significance (Table 10).

Change in PVS did not mediate the effect of treatment on distress (Table 11). CBT led to more change in PVS than SL but reductions in PVS were not significantly related to decreased distress (Table 10). Change in embarrassment also did not emerge as a mediator (Table 11). Reduction of embarrassment about symptoms was related to decreased distress but embarrassment did not change more in CBT compared to SL (Table 10).

As a final step, a multiple mediation analysis was run, including all five potential mediators simultaneously. As shown in Table 11, the overall indirect effect from the multiple mediators was significant (-1.2592, CIs -2.9216 to -.1630). Within this analysis only catastrophising showed a significant unique indirect effect. The whole model explained 29.4% of variance in post-therapy distress (adjusted R^2=.^{2}=.2943, F (7, 77) =6.00, p<.0000.

Table 10: Results from mediation analysis: GHQ

	Path a (IV to mediator)	Path b (M to DV)	Path c (Total effect of IV on DV)	Path c' (Direct effect of IV on DV)	Partial effect of control variables on DV
ΔBES (*n*=88)					
B	-3.0281	.1905	-3.2693	-2.6925	.3634
SE	1.7647	.0677	1.1390	1.1138	.0921
t	-1.7159	2.8141	-2.8703	-2.4173	3.9449
p	.0899	**.0061****	**.0052****	**.0178***	**.0002****
ΔCatastrophising (*n*=89)					
B	-1.2700	.6331	-3.1860	-2.3820	.3999
SE	.5603	.2054	1.1188	1.0987	.0885
t	-2.2668	3.0820	-2.8478	-2.1680	4.5187
p	**.0259***	**.0028****	**.0055****	**.0330***	**.0000****
ΔSymptom-focusing (*n*=89)					
B	-.3847	1.0680	-3.1860	-2.7751	.4031
SE	.2115	.5618	1.1188	1.1231	.0914
t	-1.8187	1.9009	-2.8478	-2.4709	4.4083
p	.0724	.0607	**.0055****	**.0155***	**.0000****
ΔPVS (*n*=87)					
B	-1.6312	.2406	-3.0236	-2.6310	.3861
SE	.7317	.1618	1.0992	1.1229	.0953
t	-2.2294	1.4873	-2.7508	-2..3431	4.0493
p	**.0284***	.1407	**.0073****	**.0215***	**.0001****
ΔEmbarrassment (*n*=88)					
B	-.3521	1.1659	-3.1421	-2.7315	.3883
SE	.2112	.5696	1.1299	1.1273	.0923
t	-1.6671	2.0467	-2.7808	-2.4231	4.2087
p	.0992	**.0438***	**.0067****	**.0175***	**.0001****

*p<.05, **p<.01

Table 11: Bootstrapped estimates of indirect effect (GHQ)

	Mean mediation effect	Bias corrected and accelerated 95% CIs		% of total effect explained
		Lower	Upper	
ΔBES	**-.5768**	-1.5283	-.0172	17.64%
ΔCatastrophising	**-.8040**	-1.9318	-.1597	25.24%
ΔSymptom-focusing	**-.4109**	-1.3755	-.0031	12.90%
ΔPVS	-.3925	-1.2717	.0202	12.98%
ΔEmbarrassment	-.4105	-1.4310	.0239	13.06%
Multiple mediation model	**-1.2592**	-3.0006	-.1932	41.17%
ΔBES	-0.3437	-1.1421	.0371	11.24%
ΔCatastrophising	**-0.5658**	-1.7421	-.0283	18.50%
ΔSymptom-focusing	-0.0601	-.6586	.3155	1.97%
ΔPVS	-0.1357	-.8790	.2259	4.44%
ΔEmbarrassment	-0.154	-1.1032	.1206	5.04%

6.3.2.2. Mediation of change in functional impairment

Tables 12 and 13 show results of the mediation analyses for functional impairment. Table 12 shows regression coefficients for paths a b c c' and the control variable (baseline WSAS). As noted earlier, there was no main effect of treatment arm on WSAS, although there was a trend for more improvement in the CBT group. Table 13 shows estimated indirect effects for each purported mechanism of change and bootstrapped CIs. Two significant indirect effects of treatment group on functional impairment were identified: changes in catastrophising and embarrassment.

The indirect effect of change in Catastrophising was estimated to be -.7617, CI= 2.2705 to -.0678, which was 45.5% of the total effect (Table 13). CBT reduced catastrophising more than SL and greater reductions in catastrophising was related to decreased impairment (Table 12).

Table 12: Results from mediation analysis: WSAS

	Path a (IV to mediator)	Path b (M to DV)	Path c Total effect of IV on DV	Path c' Direct effect of IV on DV	Partial effect of control variables on DV
ΔCatastrophising (*n*=86)					
B	-1.3807	.5517	-1.6727	-.9110	.6535
SE	.5444	.2661	1.3458	1.3700	.0828
t	-2.5363	2.0730	-1.2429	-.6650	7.8938
p	**.0131***	**.0413***	.2174	.5079	**.0000****
ΔEmbarrassment (*n*=86)					
B	-1.8137	.6835	-1.6727	-.4331	.6917
SE	.6671	.2096	1.3458	1.3294	.0769
t	-2.7186	3.2610	-1.2429	-.3258	8.9913
p	**.0080****	**.0016****	.2174	.7454	**.0000****
ΔPVS (*n*=85)					
B	-1.3009	.1734	-1.2243	-.9987	.6971
SE	.7389	.1928	1.2887	1.3144	.0778
t	-1.7606	.8992	-.9500	-.7598	8.9553
p	.0820	.3712	.3449	.4496	**.0000****
ΔSymptom-focusing (*n*=86)					
B	-.8264	.2994	-1.6727	-1.4253	.7039
SE	.5315	.2777	1.3458	1.3639	.0812
t	-1.5550	1.0784	-1.2429	-1.0450	8.6672
p	.1237	.2840	.2174	.2991	**.0000****
ΔBES (*n*=84)					
B	-2.9407	.2021	-1.6305	-1.0360	.7183
SE	1.7878	.0829	1.3736	1.3556	.0809
t	-1.6449	2.4391	-1.1870	-.7643	8.8775
p	.1039	**.0169***	.2387	.4469	**.0000****

*p<.05, **p<.01

The indirect effect of change in Embarrassment about symptoms was estimated as -1.2397, CIs= -2.9786 to - .3259. This was 74% of the total effect (Table 13). CBT produced larger reductions in embarrassment than SL. Reductions in embarrassment was related to decreased impairment (Table 12).

Changes in symptom-focusing and PVS were not mediators (Table 13). CBT did not produce more change than SL and reduced scores were not associated with decreased impairment (Table 12). Change in BES was also not a mediator (Table 13). Although reductions in BES were related to decreased impairment, BES did not change more in CBT than SL (Table 12).

Multiple mediation analyses including all five potential mediators simultaneously showed a significant indirect effect (-1.3163, CIs= -3.7754 to -.0371) (Table 13). Within this set of mediators, only embarrassment had a significant unique indirect effect. The model explained 51% of the variance in reductions in impairment (adjusted R^2=.5132, F (7, 75) =13.35, p<.0000.

Table 13: Bootstrapped estimates of indirect effect (WSAS)

	Mean mediation effect	Bias corrected and accelerated 95% CIs		% of total effect explained
		Lower	Upper	
ΔCatastrophising	**-.7617**	-2.2705	-.0678	45.54%
ΔEmbarrassment	**-1.2397**	-2.9786	-.3259	74.11%
ΔSymptom-focusing	-.2475	-1.2744	.1480	14.80%
ΔPVS	-.2256	-1.2085	.2335	18.43%
ΔBES	-.5944	-1.9291	.0481	36.46%
Multiple mediation model	**-1.3163**	-3.7754	-.0371	111.09%
ΔCatastrophising	-.3878	-1.6728	.2470	32.72%
ΔEmbarrassment	**-.7499**	-2.3304	-.0718	63.29%
ΔSymptom-focusing	.1045	-.3253	1.1581	8.82%
ΔPVS	-.0187	-.6702	.6334	1.58%
ΔBES	-.2643	-1.3790	.1145	22.30%

6.3.3. Correlation analysis

The ANCOVA results reported earlier in this chapter identified six variables that changed more in CBT than in SL. However, the t-tests indicated that many CB variables hypothesised to be mechanisms of change in adjustment outcomes changed in both treatment arms. This unexpected lack of significant 'a paths' from treatment group to change in CB variables meant that few variables could be considered to operate as mediators of the CBT effect. In view of this finding, it was decided that relationships between change in outcome and change in the possible mechanisms across both treatment arms should be explored. In other words whether, regardless of treatment arm, changes in CB variables were associated with improvement in adjustment outcomes. To this end, bivariate correlations were performed using residualised change scores of outcomes and potential mechanisms.

Table 14 shows the correlations between change in adjustment outcomes and change in the CB variables proposed as mechanisms in the adjustment process. It is worth noting that change in the two adjustment outcomes (GHQ and WSAS) were correlated (r=.53).

Table 14: Correlations between change in CB variables and change in adjustment outcomes

	ΔGHQ	ΔWSAS
ΔPVS	**.224***	.118
ΔBES	**.315****	**.275***
ΔACHC	**-.327****	-.181
ΔBIPQ- consequences	**.260***	n/a [1]
ΔBIPQ- personal control	-.146	.140
ΔBIPQ- treatment control	.055	.016
ΔBIPQ- illness identity	**.246***	**.301****
ΔBIPQ- concern	.163	.185
ΔBIPQ-coherence	.200	.163
ΔBIPQ-emotional representations	n/a [1]	**.352****
ΔCBRSQ- fear/avoidance	**.245***	**.278****
ΔCBRSQ- catastrophising	**.363****	**.241***
ΔCBRSQ- damage	**.301****	**.312****
ΔCBRSQ- embarrassment	**.253***	**.360****
ΔCBRSQ- symptom-focusing	**.245***	.138
ΔCBRSQ- all-or-nothing	.022	.054
ΔCBRSQ- avoidance/resting	.056	**.214***

*$p<.05$, **$p<.01$

[1] result not of interest due to mechanism variables tapping similar constructs to outcome under analysis

6.3.3.1. Correlates of change in distress

Table 14 shows that reduction in GHQ was associated with reduction in PVS, BES, Consequences, Illness Identity and all CBRSQ cognitive subscales. A reduction in GHQ was associated with increases in ACHC. Thus, results were in the expected direction showing that reductions in unhelpful thinking about self, emotions, MS and its symptoms and increases in acceptance were related to a reduction in distress. Correlation coefficients ranged from .23 to .36 ('small' to 'medium'; Cohen, 1992). Change in GHQ was not

associated with change in Personal Control, Treatment Control, Concern, Coherence, All-or-nothing behaviour or Avoidance/resting.

6.3.3.2. Correlates of change in functional impairment

Change in WSAS was positively and significantly associated with change in BES, Illness Identity and Emotional Representations, all but one of the CBRSQ cognitive subscales and Avoidance/resting (Table 14). Correlation coefficients ranged from .21 to .36 ('small' to 'medium', Cohen, 1992). Correlations were in the expected direction, showing that a reduction of unhelpful beliefs about emotions, MS and its symptoms and unhelpful symptom-related behaviour was related to a reduction in functional impairment. Change in WSAS was not associated with change in PVS, ACHC, Personal Control, Treatment Control, Concern, Coherence, Symptom-focusing or All-or-nothing behaviour.

6.3.4. Moderators and non-specific predictors of adjustment outcomes

Table 15 summarises findings from the series of regression analyses to explore whether variables functioned as non-specific predictors and/or moderators of post-treatment GHQ and WSAS. Due to space considerations, only the predictors and moderators significant at $p<.10$ are reported below. All other *p*s were >.10

Table 15: Summary of predictors and moderators of adjustment outcomes

	Post-therapy GHQ		Post-therapy WSAS	
	Predictor	**Moderator**	**Predictor**	**Moderator**
Demographic and illness variables				
Age				
Gender				
Time since diagnosis				
Current relapse status				
Recent relapse status				
EDSS				✓
Baseline CB variables				
PVS		✓✓		✓
BES		✓		
ACHC		✓		
BIPQ				n/a [1]
Consequences		✓✓		
Personal control	✓			✓✓
Treatment control				
Illness Identity				
Concern		✓		
Coherence				
Emotional reps.		n/a [1]		
CBRSQ				
Fear/avoidance		✓✓		
Catastrophising		✓		
Damage				
Embarrassment				
Symptom-focusing	✓✓	✓✓		
All-or-nothing		✓		
Avoidance/resting				

✓= p <.10

✓✓= p <.05

[1]Result not of interest due to predictor variables tapping similar constructs to outcome under analysis

6.3.4.1. Significant predictors and moderators of distress

High baseline Symptom-focusing and low baseline Personal Control were related to worse post-therapy distress regardless of treatment arm (Table 16).

Table 16: Non-specific predictors of GHQ

Predictor	*B*	*SE B*	*β*	*p*
BIPQ Personal Control	.435	.250	.162	.086†
CBRSQ Symptom-focusing	.329	.165	.189	.049*

†$p<.10$, *$p<.05$

Many baseline CB variables appeared to moderate the relationship between treatment arm and post-treatment distress. Significant moderators at $p<.05$ were PVS, BIPQ consequences, and CBRSQ fear/avoidance, and symptom-focusing. Those approaching significance ($p<.10$) were BES, ACHC, BIPQ concern , CBRSQ catastrophising and All-or-nothing behaviour (Table 17).

Table 17: Moderators of the effect of treatment arm on post-therapy GHQ

Interaction term	*B*	*SE B*	*β*	*p*	*R2 change*
Arm*PVS	-.252	.105	-.215	.019*	.046
Arm*BES	-.096	.057	-.154	.096†	.024
Arm*ACHC	.128	.074	.159	.086†	.025
Arm*BIPQ Consequences	-.490	.247	-.183	.050*	.032
Arm*BIPQ Concern	-.397	.233	-.159	.092†	.024
Arm*CBRSQ Fear/avoidance	-.286	.132	-.202	.033*	.038
Arm*CBRSQ Catastrophising	-.294	.160	-.169	.069†	.028
Arm*CBRSQ Symptom-focusing	-.367	.155	-.211	.020*	.024
Arm*CBRSQ All-or-nothing	-.287	.146	-.180	.053†	.031

†$p<.10$, *$p<.05$

Inspection of the nature of the interactions revealed a consistent pattern. When levels of the moderating baseline cognition or behaviour were low (i.e. adaptive, positive) post-therapy distress was similar between the two treatment arms, or slightly lower in SL. However, at high levels of the baseline CB variable (i.e. more unhelpful or extreme thoughts or behaviours), SL participants had substantially higher post-therapy distress than CBT participants. Figure 6 illustrates this effect (because of space limitations graphs are not shown for each moderating variable). A slightly different pattern was seen for CBRSQ Catastrophising with CBT superior to SL at all levels of baseline catastrophising scores, but with SL outcomes being particularly poor at high levels of catastrophising (Figure 7).

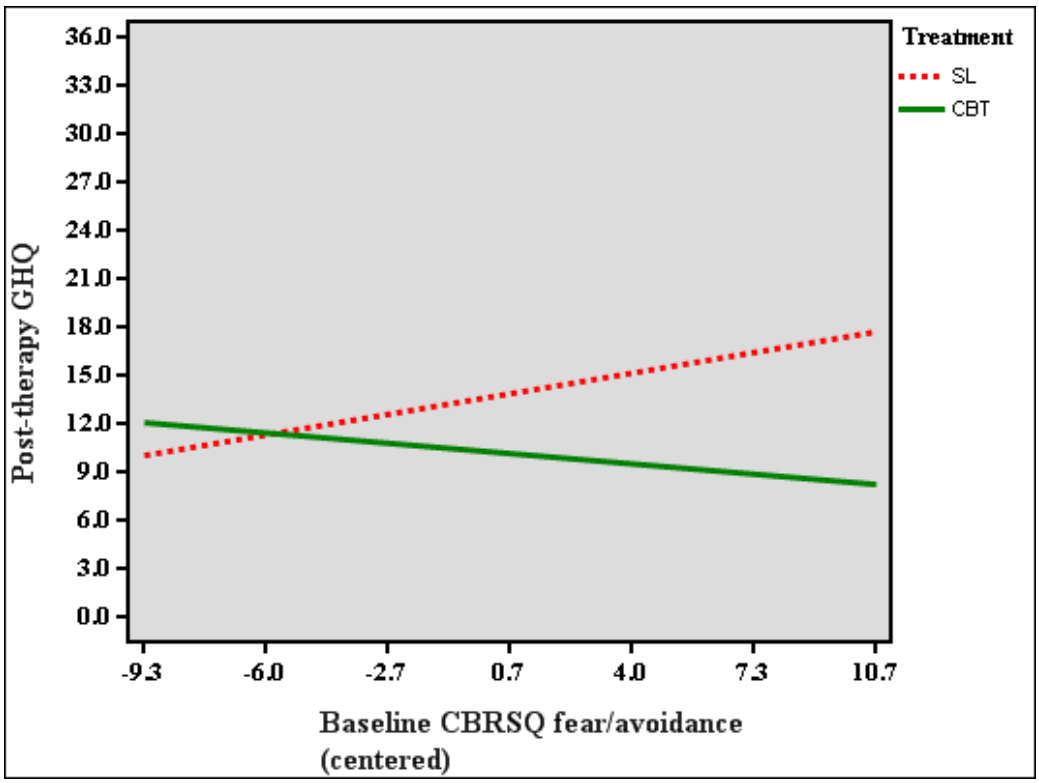

*Figure 6: Baseline CBRSQ fear/avoidance as a moderator of the effect of treatment arm on post-therapy GHQ**

*this pattern of interaction effects was also shown for PVS, BES, ACHC BIPQ consequences, concern, and CBRSQ fear/avoidance, symptom-focusing and all-or-nothing behaviour.

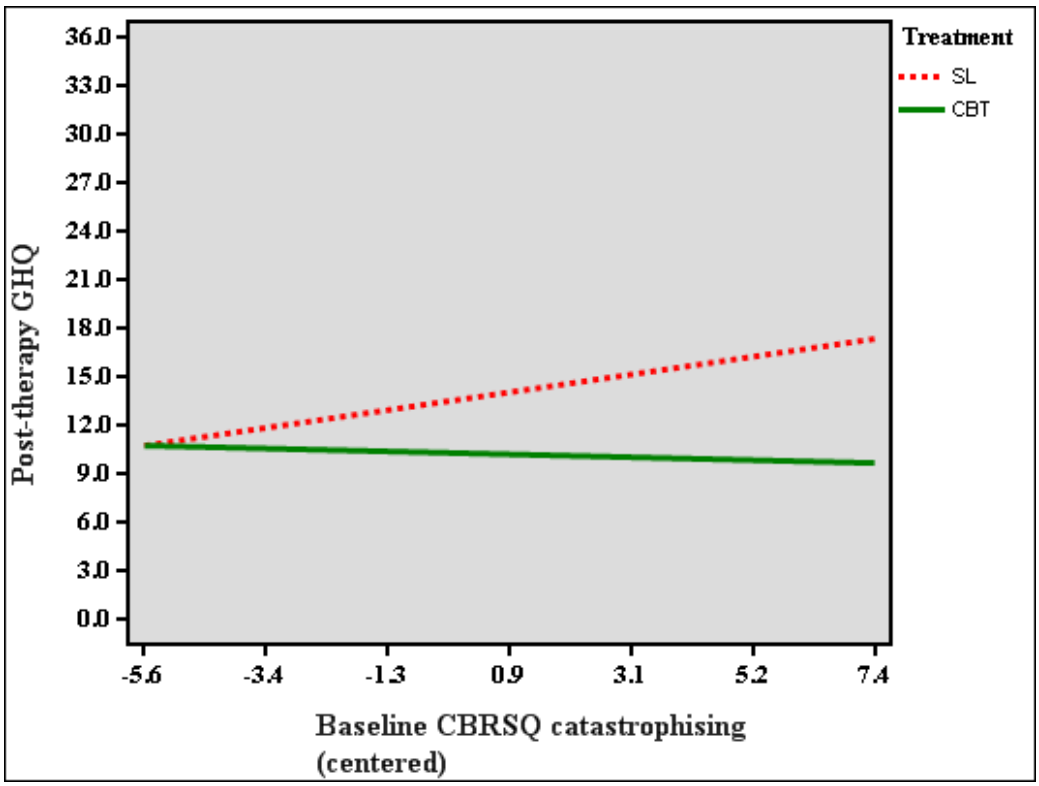

Figure 7: Baseline CBRSQ catastrophising as a moderator of the effect of treatment arm on post-therapy GHQ

6.3.4.2. Predictors and moderators of functional impairment

EDSS was a marginal moderator of the relationship between treatment arm and post-therapy functional impairment (Table 18). At low levels of baseline EDSS (i.e. low disability) SL participants had slightly lower levels of post-therapy impairment than CBT participants. However, this relationship was reversed at high levels of baseline EDSS with CBT participants showing lower post-therapy impairment than SL participants (Figure 8).

Two CB variables also functioned as moderators of post-treatment functional impairment: Personal Control ($p<.05$) and PVS ($p<.10$) (Table 18). The effects for both variables were similar: when baseline scores were low (i.e. more adaptive) SL participants had slightly lower post-therapy impairment than CBT participants. This relationship was reversed when baseline scores were high, with CBT participants showing lower post-therapy impairment than SL participants (Figure 9).

Table 18: Significant moderators of the effect of treatment arm on post-therapy WSAS

Interaction term	*B*	*SE B*	*β*	*p*	*R2 change*
Arm*EDSS	-1.138	.588	-.162	.056†	.023
Arm*BIPQ personal control	-.620	.310	-.162	.049*	.024
Arm*PVS	-.236	.131	-.143	.076†	.020

†$p<.10$, *$p<.05$

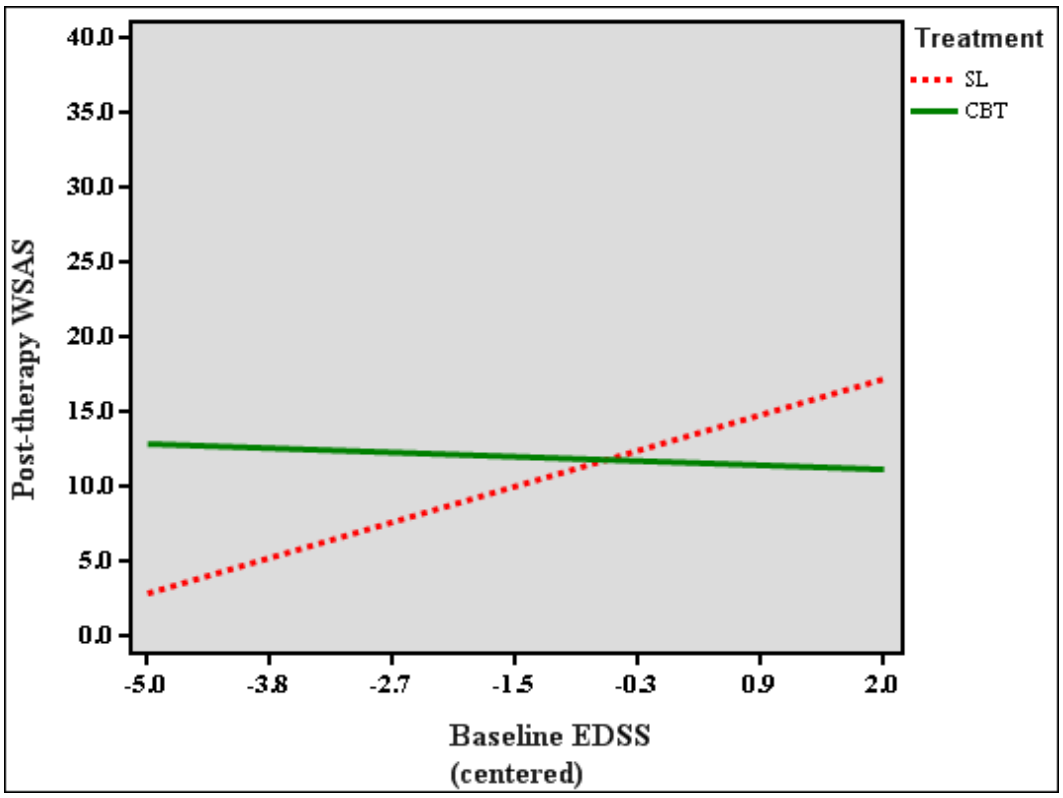

Figure 8: Baseline EDSS as a moderator of the effect of treatment arm on post-therapy WSAS

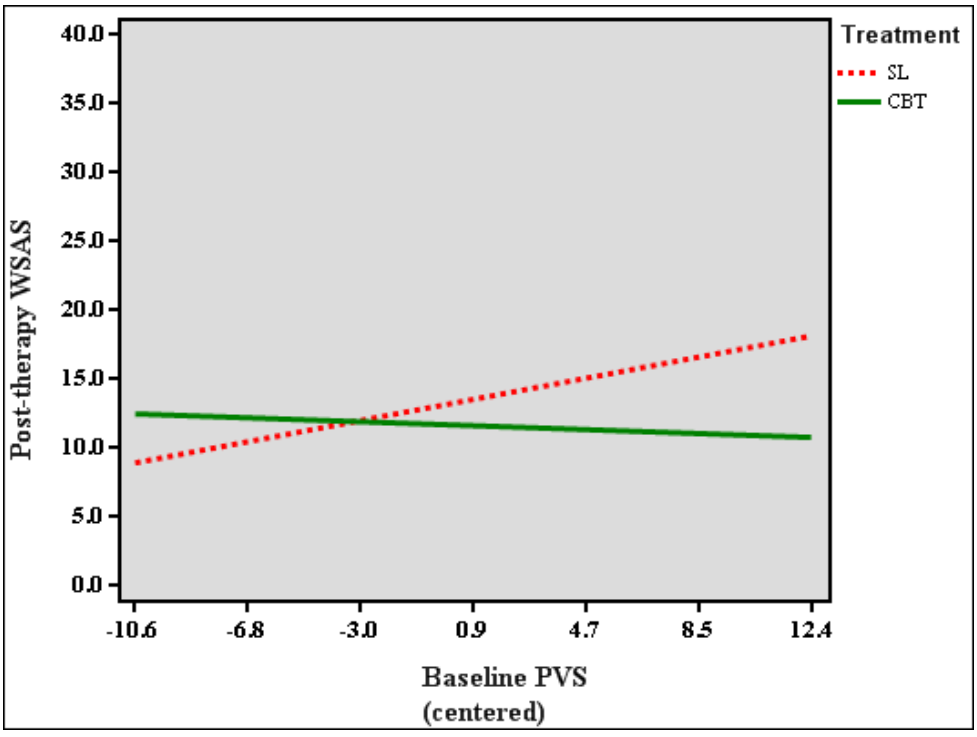

*Figure 9: Baseline PVS as a moderator of the effect of treatment arm on post-therapy WSAS**

*this pattern of interaction effects was also shown for baseline BIPQ personal control

After running all regression analyses, a set of checks (as detailed in chapter 5, section 5..3.4) confirmed the assumptions of linearity, normal distribution of residuals, independent errors were met. These checks also showed that multicollinearity was not a concern and suggested that no cases exerted undue influence on the models.

6.4. Discussion

6.4.1. Summary of findings

This study explored change within an RCT of psychological interventions in order to better understand factors and processes implicated in adjustment to MS. Distress improved significantly more in CBT participants compared to SL. Post-therapy functional impairment reduced somewhat in CBT but was not significantly different between groups. Just over half of the proposed CB mechanisms changed between pre and post-therapy. Changes were typically modest. Although the CBT group tended to improve more, only five variables were significantly, or marginally significantly different between treatment groups and were therefore analysed as potential mediators of the superior CBT effect.

Change in beliefs about emotions, catastrophising about symptoms and symptom-focusing each mediated the relationship between treatment arm and post-therapy distress. Change in catastrophising appeared to be the strongest mediating variable. Post-therapy functional impairment was reduced in CBT participants (non-significantly) more than SL via changes in catastrophising and embarrassment about symptoms. Change in embarrassment emerged as the strongest mechanism. When considering both treatment arms together, change in most of the CB variables was associated with change in adjustment outcomes in the expected directions.

MS status variables and participants' demographic characteristics did not predict post-therapy outcomes. However, baseline status on CB variables and neurological disability moderated the effect of treatment arm on adjustment outcomes such that the superiority of CBT compared to SL was greater when participants had high baseline disability or high scores on unhelpful cognitions and behaviours.

6.4.2. Interpretation of findings

6.4.2.1. Change mechanisms

As hypothesised beliefs about emotions mediated change in distress. As expected, unhelpful beliefs changed more in CBT and a substantial proportion of the total CBT effect on distress could be explained through change in this variable. Furthermore, as expected, SL participants also reported significant changes in beliefs about emotions. Regardless of treatment assignment participants whose beliefs became less negative also experienced reduced distress. These findings build on earlier cross-sectional findings of a relationship with distress, to suggest that beliefs about the acceptability of experiencing and expressing negative emotion contributes causally to distress in PwMS. It also appears that changes can be brought about by different types of interventions.

The other important mediators in this study were unhelpful symptom-related cognitions. The fact that these changed only in CBT makes sense because it explicitly dealt with unhelpful thinking whereas SL did not. Symptom beliefs were a specific focus of the CBT and catastrophising, symptom-focusing and embarrassment were all featured as examples within the treatment manual. These may have been frequently and/or particularly competently addressed by the novice nurse-therapists and may have resonated with the experiences of many participants and thus strategies for addressing these thoughts may have been adopted.

Reduced catastrophising about symptoms mediated improvements in both distress and functional impairment and had the strongest indirect effect in the multiple mediation analysis for distress. It is not surprising that reducing the tendency to catastrophise would improve both adjustment domains. Catastrophic thinking is negative and threatening and would likely contribute to distress. For example, somebody who frequently imagines being bedridden or wheelchair-bound would undoubtedly find this distressing. Catastrophic thoughts may dominate attention and mean people are less focused on current activities and goals. This might change behaviours (e.g. exercise, socialising) and/or might change the extent to which they perceive and report MS as intruding on their lives. The positive impact of reducing catastrophising corroborates and extends earlier research which found cross-sectional associations with higher impairment (Skerrett & Moss-Morris, 2006) and distress (chapter 5).

Symptom-focusing was another mechanism through which CBT appeared to reduce distress. Symptom-focusing is a negative process which will centre attention on unpleasant sensations and the experience of having MS. It may also provoke threatening and upsetting thoughts. In this way, symptom-focusing may relate closely to catastrophising. Indeed, analyses in chapter 5 showed these variables were highly correlated with each other. This shared variance would explain why symptom-focusing was not a significant unique mediator when considered in a multiple mediation model with catastrophising. The role of Symptom-focusing as a mechanism in current analyses fits with findings in chapter 5 of associations with distress, but not functional impairment.

Reductions in embarrassment about symptoms emerged as the main mechanism through which CBT reduced functional impairment. This was expected, given previously established correlations with functional impairment (Skerrett & Moss-Morris, 2006 and chapter 5). Inspection of the CBRSQ reveals how embarrassment would cause impairment. The embarrassment subscale items assessed beliefs that symptoms cause embarrassment but also beliefs that embarrassment prevents engagement in activities. MS can produce various symptoms that could create embarrassment in social situations including bowel and bladder dysfunction and slurred speech. It seems logical that embarrassed participants might reduce their involvement in social activities and have difficulties with social relationships, thus creating higher functional impairment. By reducing concerns about embarrassment within CBT people may feel more able to engage in previously-avoided activities.

Contrary to hypotheses, reduction in avoidance/resting behaviours did not mediate improvement in functional impairment. This variable taps limiting activities and avoiding exertion to manage symptoms (rather than avoiding social embarrassment). These behaviours reduced slightly in CBT but change was surprisingly small and not significantly different between groups, precluding its analysis as a mediator. Despite this, the correlations implied that avoidance/resting plays some role in change in impairment. Within both treatment arms participants who reduced avoidance and resting also showed reduced functional impairment. Given this finding, and the strong relationships identified between avoidance/resting and functional impairment in chapter 5 and Skerrett and Moss-Morris (2006) it seems that avoidance and rest may be an important influence on functional

impairment. However, it did not explain improvements in adjustment within this study because it did not change substantially within the current interventions. Possibly, these behaviours may be difficult to modify, particularly for inexperienced nurse-therapists. Perhaps if limiting activities and excessive resting had been more substantially altered, larger reductions in functional impairment may also have been achieved. Another possibility is that excessive avoidance/resting was not characteristic of the majority of the current sample and therefore not a focus within the CBT formulation. Indeed, an inspection of baseline CBRSQ avoidance/resting responses reveals that the mean score indicated slight *disagreement* with statements about these tendencies. Furthermore, no participants had baseline scores that would indicate consistent agreement with these subscale items. This would explain why change was modest and superior change in CBT was not realized. Unfortunately the current results leave open the question of reduced avoidance/resting as a mechanism for improving adjustment.

Another surprise was that changes in unhelpful beliefs about the self did not mediate the relationship between treatment arm and reduction in distress. CBT participants showed the expected superior change at post-therapy compared to SL participants. However, changes were small. The mediation analysis did not find an indirect effect for change in beliefs about the self although across both treatment arms, reductions in this variable were modestly associated with reductions in distress. Although CBT had a small impact on thinking about the self, these belief changes were unrelated to post-therapy distress. More substantial change may have been necessary to elicit reductions in distress. Alternatively, these beliefs may exert their influence on distress over a longer time period, perhaps through influencing responses to challenging situations and interactions with other people.

Several further CB variables could not be considered mediators because although they changed, change was not significantly different depending on treatment arm. For some of these variables, the post-hoc correlation analysis showed that, regardless of change at the group level, in situations where change did occur, adjustment outcomes also changed in the expected direction. Specifically, increased acceptance and reduced fear/avoidance were associated with reduced distress. Reductions in BIPQ emotional representations and CBRSQ fear/avoidance were associated with reduced functional impairment. From these simple correlation analyses it is impossible to conclude that changes in these cognitions and behaviours were responsible for the change witnessed in the adjustment outcomes.

However, the findings add to the body of evidence regarding the relevance of these factors in the adjustment process.

Several CB variables did not change in either treatment group: consequences, personal and treatment control, illness identity, and damage beliefs. However, some variables that showed no *average* change were nonetheless correlated with at least one of the adjustment outcomes. These were illness identity, damage beliefs and all-or-nothing behaviour. Conceivably, a substantial change in these variables may have produced more radical improvement in adjustment outcomes. For instance, successfully changing all-or-nothing behaviour and damage beliefs may have improved the effectiveness of the interventions for reducing functional impairment. Possibly the variables that did not change are more resistant to modification. Therapist inexperience or limited therapy time may have limited the extent to which these were addressed. Another plausible explanation for the lack of change is that many of the participants in the sample had low scores on these variables at baseline, leaving little scope or need for improvement. Whatever the reason for the lack of change, because these factors did not change significantly for the participants as a whole they can be neither ruled in or out as possible adjustment mechanisms. Future intervention research that successfully modifies these variables should consider them as possible mediators.

6.4.2.2. Moderators and predictors of change

Taken together the predictor and moderator analyses suggest that therapy outcomes do not depend on either demographic or MS characteristics. This suggests that, contrary to expectations, the gains made within the interventions studied here are similar across patients with different types of MS and patterns of disease activity and severity. The exception was that whereas post-treatment functional impairment did not differ overall between treatment arms, under conditions where participants had moderate or high EDSS post-therapy impairment was lower in those assigned to CBT. Therefore, this more severely affected subgroup of patients may be particularly well suited to CBT. Alternatively, these patients may have had higher baseline impairment scores and therefore greater reductions post-therapy.

This study also found consistent interactions between baseline status on CB measures and treatment arm for predicting outcomes. Participants scoring highly on these variables

achieved better adjustment outcomes in CBT. In participants with low scores for these problematic CB tendencies there was less difference in outcomes between therapy arms. In summary, although CBT tends to be a superior treatment for distress and (to a lesser extent) functional impairment, this effect is stronger in people showing evidence of maladaptive CB responses prior to starting the intervention.

6.4.3. Study limitations

6.4.3.1. Power

A key limitation of this study that it was not specifically powered to detect mediation and moderation effects. The study used data from an RCT that was powered on primary outcomes rather than mediation and moderation analysis. Additionally it is probable that the trial was somewhat underpowered even for primary analyses. 94 participants were included, although the power analysis suggested 122 would be needed to detect a medium effect with .80 power for two primary outcomes (Moss-Morris et al., 2009). Low power is widespread in psychological intervention research which examines mediators and moderators (Aguinis & Gottfredson, 2010; Frazier et al., 2004; Kraemer et al., 2002). However, it is problematic because when hypotheses are not confirmed it is unclear whether the results are not significant because the theory was wrong or because the test lacked sufficient power. Importantly, however, when significant results are discerned in underpowered studies such as this, it increases confidence that these are substantial effects.

Regarding moderation analysis, effect sizes for interactions tend to be small, necessitating large samples to detect them (Frazier, Tix, & Barron, 2004). Furthermore, moderation analyses have more power when the IV and DV show substantial relationships. In this study, the relationship between treatment arm and functional impairment was not significant. Another factor hindering detection of moderation effects is the dramatic effect measurement error has on power. Aiken et al. (1991) showed that the power of interaction tests is reduced by up to half with reliabilities of .80 rather than 1.00. The reliability of current study variables was within the range conventionally regarded as acceptable (i.e. >.70) but none were perfect. 'Courseness' of outcome measures also reduces power. Ideally, the outcome measure should have as many response options as the product of the response options of the predictor and moderator (Frazier et al., 2004). The GHQ has 12

response options, suggesting it is acceptable for most analyses, whereas the WSAS only has 5 options suggesting low power.

Power may also have hindered detection of mediators, despite the use of bootstrapping which is considered the most powerful approach. As with moderation, measurement error also reduces power in mediation analysis (Frazier et al., 2004). Relations among the mediator, predictor, and outcome can also affect the power of mediation tests. Path b power decreases when path a is strong so as path a increases a larger sample size is needed

In order to surmount power problems, this study followed recommendations to breach the usual conventions for interpreting significance (Kraemer et al., 2002; McClelland & Judd, 1993; Kazdin, 2007). This allowed the detection of four mediators and consistent patterns of interactions between CB baseline variables and treatment arm. These results should be considered exploratory and hypothesis-generating rather than definitive. The current findings can guide the next generation of research, informing the design of more powerful studies.

6.4.3.2. Comparisons to an active treatment

Another limitation concerns the lack of a no treatment control group. The RCT SL arm was designed to control for non-specific treatment factors such as therapist time and patient expectations. However, SL was a reasonably effective intervention, reducing distress and several potential CB mechanism variables. The study design means that it cannot be confidently concluded that the interventions were responsible for change. It is possible that positive change might occur over time without intervention. However, it seems unlikely that statistically significant changes would occur over 15 weeks (pre to post-therapy) in the absence of intervention or a change in circumstances. Although participants were early stage MS patients, the mean time since diagnosis was 3.4 years so it is hard envisage why, at this stage, cognitions would spontaneously become more positive and adaptive.
The conclusion that the interventions were indeed responsible for the changes is supported by findings from the saMS trial which showed that by 6 and 12 months follow-up the adjustment outcome and CB variables tended to revert to or towards baseline levels (Moss-Morris et al., 2011).

Comparing CBT with an active treatment comparison group also hindered the mediation analysis. Because several of the purported change mechanisms changed equally in CBT and SL these factors could not statistically be shown to be mediators. This is because mediation analysis tests whether treatment arm predicts change in the mediators. In the absence of between-group differences in change these variables could not be shown to be mediators. Instead, the study could only establish that change in these variables was correlated with change in the adjustment outcomes, a finding that cannot allow conclusions regarding their role as causal mechanisms in the adjustment process.

6.4.3.3. Establishing causality

Despite significant statistical mediation results, the current research design cannot definitively establish causality. Kazdin (2007) outlines key criteria for demonstrating causal mechanisms using mediation analysis, some of which were addressed in this study. Purported mediators were experimentally manipulated within an RCT, statistical associations were established, specificity of mechanisms was determined by showing that hypothesised variables were mediators, but others were not, and mechanisms of action were accounted for by theory. However, the study design cannot definitively establish that change in purported mechanisms occurred prior to change in outcomes. Outcomes were measured at post-therapy but the mediator was pre to post-therapy change, meaning that change could have occurred at, or very close to the post-therapy measurement. Adequately establishing temporal order of change is extremely difficult in psychological interventions since both mechanism variables and outcomes would be expected to start changing during therapy**.** Multiple measures of both purported mediations and outcomes throughout the therapy period may be required (Kazdin, 2007). However, such data collection poses practical problems including participant burden. Furthermore it seems unlikely that change processes would occur at the same time for all participants. An unresolved challenge for research is evaluating mechanisms that vary in course across individuals.

6.4.3.4. Capturing the individual nature of adjustment

Another limitation of this study concerned its attempt to plot out change mechanisms in a sample that varied considerably in terms of adjustment difficulties experienced. Earlier

chapters have described how adjustment is best conceptualised as multifaceted and involving emotional, social, and functional aspects. The saMS trial did not address one specific adjustment problem (e.g. depression) and participants did not have to have elevated distress or impairment scores for inclusion. Some had clinically significant distress scores, some were highly functionally impaired, whereas others had low distress and/or impairment levels. Furthermore, although the GHQ and WSAS capture two key aspects of adjustment, participants inevitably experienced other difficulties not assessed in the trial such as low self-esteem, anger or loneliness. Given the various issues affecting participants and the multiple factors that would be expected to influence adjustment it seems unrealistic to expect consistency in changes across participants. For example, whilst a substantial proportion of participants may become less distressed as catastrophic thinking about symptoms reduced, others may not have had these sorts of thinking styles initially but reduced distress via increased acceptance or illness coherence perceptions. Others may have changed in ways, perhaps unmeasured in the study. For example they might not have been distressed at baseline yet may have experienced a high level of support from the therapeutic relationship, and begun to appreciate the importance of talking to other people, which might have improved family relationships. A different approach may be necessary for a more fine-grained analysis of changes experienced by individuals and the factors that produce change in something as broad as adjustment to chronic disease.

6.4.3.5. Effect sizes

A caveat concerning the calculation of mediation effect sizes requires mention. Statistical effect sizes are imperative for communicating the magnitude of effects and practical importance and are superior to ambiguous descriptive terms such as ‘full’ or ‘partial’ mediation (Preacher & Kelley, 2011). The current study reports the indirect effect as a ratio of the total effect, a common practice (Preacher & Kelley, 2011). However, Preacher and Kelley argue that despite its intuitive appeal it has limitations including making small indirect effects appear of substantial importance, especially when the total effect is small. Indeed, interpretation of the total effect size for the current multiple mediation analysis for functional impairment is confusing because the total effect is non-significant, creating an indirect effect which exceeds the total effect. Preacher and Kelley recommend reporting κ^2, (the ratio of the obtained indirect effect to the maximum possible indirect effect). This is an emerging area of statistical debate and at present the means to calculate κ^2 within the

mainstream statistical software is not available for analysis with covariates or multiple mediators.

6.4.4. Implications

Due to its limitations, conclusions from this study must be tentative. Nonetheless findings have implications for theoretical understanding and future research on adjustment in MS and efforts to improve adjustment in pwMS.

6.4.4.1. Implications for theory and research

This study provides preliminary evidence that change in unhelpful cognitions and behaviours achieved within a therapy context is, in part responsible for improvements in adjustment outcomes. This finding, in combination with research reviewed earlier in this thesis, and the results of the other empirical chapters, supports a CB model of adjustment to MS. In other words adjustment outcomes such as distress and functional impairment are influenced by a range of variables pertaining to how the individual thinks and behaves.

Future studies to explore adjustment processes in MS are required to build upon these results. In particular, investigations of the mechanisms of interventions that achieve stronger effects than the current trial will be enlightening. Future research should also address the current study limitations including adequate power. Results from the saMS trial and the current study will assist researchers in power calculations and considering variables to measure. Interpretations of mediation results will be more straightforward if future studies compare active interventions to no treatment control conditions.

The individual differences in types and magnitude of adjustment difficulties and the pathways through which change occurs suggests that an approach such as mediation analysis which combines data from participants may overlook important processes operating within individuals. A complementary approach would be qualitative research to study in detail and in context how change unfolds and what processes might be operating that influence improvements. Single case study methods would also provide useful data to pick apart this complex area.

6.4.4.2. Implications for improving adjustment to MS

Future formal interventions for reducing distress and functional impairment in pwMS may benefit from including attempts to change the variables that mediated the success of the CBT in the current study, namely catastrophising, embarrassment, symptom-focusing and beliefs about emotions.

However, the current research does not support abandoning other processes or mechanisms. This study cannot rule out other mechanisms of improvement in distress and functional impairment. There were not large improvements to mediate, particularly for functional impairment. An intervention that was more successful in changing impairment may shed light on important mechanisms that were not apparent in this study. Furthermore, this study selected a limited set of variables. Many other processes that were not measured within this study are likely to change within CBT, SL and other interventions. Previous research, including other chapters of this thesis suggest many theoretically plausible mechanisms for improvement in adjustment. These would include for instance, increases in social support, problem-focused coping, and self-efficacy.

An important indication from the study is that improving adjustment outcomes is not only achieved via CBT. All CB variables that emerged as significant mediators of the effect of CBT were also correlated with change in adjustment outcome regardless of therapy arm. This suggests that changing these, through various means should improve adjustment. CBT may be a particularly effective approach for identifying and modifying unhelpful beliefs and behaviours. However, other psychosocial interventions may also successfully change variables that functioned as mediators in the current study. For example counselling, expert patient programmes and peer support could potentially deliver benefits through influencing these factors. Changes to unhelpful beliefs may also influence adjustment outcomes outside of formal intervention settings. For example, somebody could conceivably change their views about expressing negative emotion following positive emotional encounters with other people and receiving appropriate support and empathy from other people. Involvement with patient organisations may provide good quality information about symptoms and relapses which may reduce catastrophising and symptom-focusing.

Discussing symptom concerns with MS nurses, other pwMS, friends and family members may reassure and reduce embarrassment about symptoms.

An important finding was that there appeared to be little link between the effectiveness of the interventions and illness status. This suggests that patients should not be selected for psychological interventions on the basis of their disease characteristics. Conversely, findings regarding the moderating effect of baseline CB variables and EDSS suggests that these variables are useful to consider when recommending interventions for pwMS. Those that score highly would be particularly suited to receiving CBT. One qualification of the conclusions regarding treatment moderators is that the participants represented the lower end of the spectrum of MS severity. The RCT specifically sampled people with early stage MS and excluded those who were more than ten years from diagnosis, needing to use a wheelchair, and with substantial cognitive impairment. Furthermore, the sample included only nineteen participants with progressive MS. Therefore this study cannot establish whether the lack of predictive value of most illness characteristics, and the moderating effect of EDSS and CB baseline status would extend to people with more severe MS.

6.4.5. Conclusions

This was the first study to examine whether change in cognitions and behaviours mediate the effects of psychological interventions for adjustment to MS and to investigate characteristics of patients that may explain differences in treatment effects. The superior effect of CBT was partially explained by greater reductions in beliefs about emotions and three types of symptom beliefs. These could be useful targets for attempts to improve adjustment outcomes. Furthermore, regardless of therapy arm and average change at the group level, participants whose unhelpful cognitions and behaviours reduced also experienced reductions in distress and functional impairment. Illness variables were not important predictors of therapy outcome but people with high neurological disability and high levels of unhelpful CB variables particularly benefited from CBT.

The study design has significant limitations and some null results from the RCT may have prevented more variables being implicated as important mechanisms and moderators. Recommendations for further research to corroborate and extend current findings have been made. The following chapter continues to consider mechanisms and processes involved in adjustment within the saMS trial using a qualitative approach.

Chapter Seven: A Qualitative Study of Change within Adjustment Interventions

7.1. Introduction

7.1.1. Chapter overview

The previous chapter tested hypotheses about the plausibility of a number of CB variables as mechanisms of improvement in psychological adjustment outcomes within a treatment trial. This chapter continues to examine adjustment to MS within psychological interventions. However, this time, qualitative methods are used. The current study aimed to elicit participants' experiences of interventions in their own terms in order to better understand mechanisms of change within therapy. It was expected that findings would provide insights that could enhance understanding of factors and processes involved in adjustment in pwMS.

7.1.2. Methods for investigating therapy change processes

As described in Chapter 6, although RCTs have provided good quality evidence regarding the efficacy of various psychological interventions, we have much less evidence to help us understand about the mechanisms and processes through which treatments produce change. The standard way that psychological treatment mechanisms are investigated is using quantitative methods, where variables that are hypothesised to be responsible for change are assessed within a trial and then statistical analysis is used to formally assess the plausibility of these factors as mediators of the treatment effect. Chapter 6 reviewed the handful of studies which have performed such analyses of various psychosocial interventions for pwMS. This methodology was then adopted in order to formally test whether a set of pre-specified CB variables were mechanisms through which CBT improved two specific adjustment outcomes: distress and functional impairment.

This research strategy offers useful information about whether findings support or refute a priori hypotheses about theorised mechanisms. However, these types of studies have some significant limitations. Firstly, they are constrained to narrow, predetermined ideas about how the intervention is working and can only shed light on potential mechanisms that have

been decided upon and measured in advance. Secondly, they assume simple models of how improvement occurs whereby mechanisms of change are the same for all participants. For example, the study in the previous chapter examined whether, for the sample as a whole, reductions in excessive resting and avoidance behaviours reduced functional impairment. This pathway may be relevant for some people (those that do rest and avoid excessively and find this interrupts their functioning) but not the sample as a whole. In short, although mediation studies add to our understanding of change processes within therapy, they appear to be inadequate tools for understanding the complex and nuanced processes at work within psychological interventions. (Elliott, Slatick, & Urman, 2001). Qualitative methods, on the other hand, are particularly well placed to elicit rich descriptions and explanations of change processes and experiences within individuals (e.g. Carey et al., 2007; Clarke, Rees, & Hardy, 2004; Elliott et al., 2001; Hodgetts & Wright, 2007; Kazdin, 2007; Klein & Elliott, 2006; Carey et al., 2007). They can develop insight and explanations of therapy processes from participant accounts, rather than from existing theories and research. For this reason, qualitative therapy process research provides an alternative and complementary approach to quantitative process analyses such as mediation.

Another benefit of using qualitative methods to understand therapy experiences is that they can provide fresh insight into the outcomes achieved within therapy. The psychometrically reliable, valid instruments used to quantitatively measure change in RCTs help to answer questions about efficacy and give reliable data on effect sizes. However, when researchers choose outcome measures, they may restrict the capacity of clients to report their experience and require them to parcel experience into pre-defined categories (Klein & Elliott, 2006). For example, a focus on distress or depression as a primary outcome in a RCT may overlook improvements in broader domains such as confidence, self-esteem and social functioning which may be more important outcomes for the patient and/or may be involved in the process whereby an individual's depression improves.

Exploration of how participants experience therapies may give insight into what changes (or not) as well as how change occurs (or not). An open-minded, inductive exploration may yield different findings from what we as researchers or therapists expect. This sort of data may strengthen or weaken our theoretical models, contribute to the debate over the importance of therapy-specific factors (e.g. behaviour modification techniques within CBT) and non-specific factors (e.g. therapeutic alliance), and shed light on necessary and

sufficient factors that are essential to change processes. Furthermore, investigation of whether therapy meets patient expectations and is considered acceptable and beneficial provides vital information which may inform better tailoring of therapy to meet the needs of the population in question, potentially improving adherence and reducing drop-outs. Finally, in depth analysis of accounts of therapy experiences may indicate certain groups for whom the therapy appears to work better or worse. Shedding light on possible moderators of treatment effects such as demographic characteristics or personality type will be important for both future research and clinical practice (e.g. client-therapy matching).

7.1.3. Previous qualitative research on therapy change processes

Qualitative research on change processes within a range of psychological interventions has tended to reveal the importance of pan-theoretical factors in producing change such as therapeutic alliance, and the importance of just talking, learning and motivation (Carey et al., 2007; Clarke et al., 2004; Elliott et al., 2001). The limited qualitative research on CBT mechanisms tends to suggest that, in addition to these general therapeutic factors, clients value and appear to gain benefit from the specific cognitive and behavioural elements that are theorized to be the mechanisms of change in CBT. One such study analysed patients' accounts of cognitive therapy for depression (Clarke et al., 2004). The authors describe themes relating to the importance of the therapist, feeling safe, engaging and not resisting. However a core set of themes showed how the clients had understood and taken on the specific language and rationale of cognitive therapy. Themes related to realising the importance of dealing with thoughts, uncovering core beliefs, discovering patterns, testing out what had been learned, and grasping the CBT model. Another study examined families' experiences of CBT for young people with chronic fatigue syndrome. In particular, behavioural mechanisms such as behavioural activation through activity plans and diaries were deemed important for change by participants. However, non-specific therapy factors such as the opportunity to talk and feel validated were also considered central to a positive and therapeutic experience (Dennison, Stanbrook, Moss-Morris, Yardley, & Chalder, 2010).

To date, only two qualitative studies have explored psychological interventions for pwMS. A recent study investigated experiences of using computerised CBT ('mood gym' and

'beating the blues') for depression in MS (Hind et al., 2009). Findings pointed towards the inappropriateness and burden of the currently available computerised CBT programmes for pwMS and depression and the need for tailoring interventions specifically to their problems, experiences and capabilities. On a practical level, the programmes were experienced as problematic due to fatigue, memory and concentration difficulties. Symptoms (e.g. problems using hands, visual disturbances) could interfere with mouse use and reading information on screen. Lack of human input seemed to aggravate feelings of social isolation and participants felt they needed face-to-face empathic support. Participants had difficulty defining problems and setting realistic goals to work on without a therapist. They also appeared to have difficulty grasping a core aspect of CBT-distinguishing between external stimuli and their own responses. Patients felt that the programmes did not acknowledge their MS and its interaction with depression and failed to legitimise emotional responses to MS-related losses. Themes also revealed that examples, vignettes and questionnaires used within the interventions were inappropriate for participants; some were insensitive to their condition (e.g. focusing on sports and exercise as an adaptive coping strategy), other comments related to the programme not being adequately age and culture specific. Perhaps due to the rather negative experiences of therapy, this study shed little light on change processes within interventions for pwMS.

Another study investigated patients' experiences of lay led expert patient programmes (Barlow, Edwards, & Turner, 2009). Participants identified useful aspects, including enhanced self-confidence, being reminded of previously used techniques, relaxation, pacing and goal setting for fatigue management. Meeting similar others, social comparison and role models were also considered important. The study also identified areas where changes to the programme could be considered for example, there was dissatisfaction with forced social contact. Frustration was also expressed at the inability of course tutors to deviate from planned content and their lack of expertise in answering disease-specific questions because they were not health professionals (even though this is not what was intended from the intervention). Gender differences were also discovered which may be important considerations in delivering acceptable programmes. Males were generally less positive about the intervention and seemed to value a more informational approach without sharing so many personal emotive topics, whereas women valued the interactive processes inherent in the group setting.

7.1.4. The current study

This study explored patients' experiences of having CBT or SL within the saMS trial (Moss-Morris et al., 2011). It aimed to enrich understanding of the adjustment to MS and if and how it changes within the context of psychological interventions. In particular, the qualitative methodology used here and the inductive, open-minded analyses was intended to complement the quantitative analysis reported in Chapter 6 by offering a different, patient-based perspective on what changes, how, why and under what circumstances.

7.2. Method

7.2.1. Recruitment

This study was approved by NHS and University Research Ethics Committees and research governance offices. Participants were recruited from the sample of the trial participants described in Chapter 5 and Chapter 6. Details of trial eligibility criteria, recruitment processes and sample characteristics are described in Chapter 5.

This interview study was an optional extra study nested within the main trial and potential participants were provided with written information (appendix J) and given the opportunity to discuss this aspect of the study prior to providing written consent (appendix L). 91 out of 94 trial participants (97%) consented to participate in this interview study. When each of these participants completed their trial intervention and their post-therapy questionnaire assessment their details were passed to the interviewer who then selected a sub-sample of these to interview. Sampling was initially opportunistic. However as more interviews took place it became increasingly purposive. The aim here was to achieve a sample with maximum variation in terms of experiences of the interventions. Choice of participants was made on the basis of intervention type (CBT or SL), demographic and MS characteristics. Sampling also deliberately selected people with different overall attitudes towards the therapy they received as gleaned from responses to two simple Likert-scale questions on their post-therapy questionnaire (satisfaction with therapy and perceived improvement). Importantly, the sample was not selected to be representative of the trial participants but to include people likely to hold different viewpoints.

Thirty nine people were identified for inclusion in the interview sample. However, when contacted four changed their minds about participating (one was busy, the others did not provide reasons) and three arranged an interview but were subsequently unavailable after multiple attempts to interview them. Therefore, thirty two participants were interviewed. Recruitment ceased when the interviewer became confident of repetition (or "saturation") in accounts, and approximately equal numbers of participants from each treatment group had been interviewed.

Unfortunately two recordings were of unusable sound quality. The final analysed sample therefore consisted of 30 participants.

7.2.2. Participants

Demographic and disease data was taken from participants' baseline trial questionnaires. The sample was around three quarters female, with a wide age range centred around the early 40s. Participants had been diagnosed with MS from between six months and ten years and most had RRMS. MS severity (measured by the self-report EDSS (Bowen et al., 2001) ranged from minimal symptoms (e.g. slight disturbances in sensation or vision) to needing to use a stick or cane to walk short distances.

Fifteen participants had experienced CBT, fifteen had SL. Participants were sampled from both London and Southampton and therefore had different nurse-therapists delivering the intervention. As per the sampling strategy, participants varied in terms of their questionnaire ratings of satisfaction with therapy and perceived improvement. All participants had completed the full 8 sessions of therapy. Appendix R and S contain further details of participants' demographic, illness and treatment characteristics.

Although efforts were made to specifically sample participants who had withdrawn from therapy, regrettably these were also the individuals who had not consented to this study, had changed their mind after agreeing to be interviewed, or had arranged an interview but could not subsequently be contacted.

7.2.3. Interviews

Interviews were conducted by one of two female health psychology researchers who had not been involved in any aspect of the therapy trial. The interviewers were selected for their interviewing competence and experiences of working with people with long-term health problems. However, they were deliberately kept naïve to details of the trial in order to be more impartial than the researchers involved in the trial. It was hoped that this would maximise the probability that participants would feel comfortable giving honest accounts of their experiences, both positive and negative. It was emphasised to participants that there were no wrong answers and that they should simply be open about their experiences within the trial, in order that the researchers could get a better understanding of the therapies, and be able to improve them if necessary. Interviewers emphasised their lack of experience of the two therapies and encouraged the participants to give plenty of detail to help them understand it.

The interviewers initially telephoned participants to introduce themselves, remind the participants about the purpose and nature of the interview aspect of the research, and schedule in an appointment for an interview. Interviews were scheduled for as soon as possible after the completion of the post-therapy questionnaire assessment although with flexibility in order to accommodate the participants' needs. Interviews typically took place nine weeks after finishing therapy (shortest = 4 weeks, longest = 17 weeks). Telephone interviews were used because MS symptoms including gait disturbances, balance problems, severe fatigue and unpredictable symptoms would have made participation in a face-to-face interview more burdensome and effortful and may have restricted the recruitment of participants.

The interview consisted of a series of broad, open-ended questions and a number of prompts relating to expectations of the interventions, how participants found the therapy, and changes they had experienced. Key questions included: 'Can you start by telling me what you were expecting from the therapy sessions?', 'How did you find the therapy overall?', 'Can you tell me what you liked about the therapy?' 'Can you tell me what you disliked about the therapy?', and ' Tell me about anything that you feel has changed from having the therapy' (The full interview schedule can be found in appendix T)

Although the same key questions were asked to all participants the interviews departed from the schedule in order to be able to follow up unexpected material introduced by the participants by using neutral questions and prompts such as "Could you tell me more about that?" and "Can you give me an example?". Interviews typically lasted for around forty minutes (range from 11 minutes to 2 hours 7 minutes). Many pwMS have significant difficulties with fatigue and concentration which might explain why some interviews were short. Alternatively, some individuals simply may not have had a lot that they wished to say.

All interviews were recorded and transcribed verbatim. Transcripts were later checked for accuracy against the recordings.

7.2.4. Analysis

The data analysis approach was based on inductive (i.e. data-driven) thematic analysis methods (Braun & Clarke, 2006; Joffe & Yardley, 2000) and included some grounded theory coding and analytic techniques (Charmaz, 2006). Interview recordings were listened to repeatedly and transcripts were reread in order to become highly familiar with the data. Next, transcripts were studied for common and salient themes. This involved initial open-coding whereby transcripts were scrutinised on a line-by-line basis and labels were attached to text segments which appeared to indicate important material in relation to the research questions. The NVivo software package was used for the coding. This programme allows the user to select segments of text and label it as an instance of a code. Essentially, this provides a detailed coding manual that can be edited and easily searched and queried.

As analysis progressed through the 30 transcripts and more codes were added, similar codes were organised into themes. Constant comparison was used in order to ensure that the emerging themes remained close to the data. This process involved continually cross-referencing the emerging understanding of the data and initial theme definitions against raw interview transcripts in order to ensure that themes created were sensitive to the data rather than led by the analyst's preconceptions or theoretical perspective.

The analysis process was iterative and involved altering definitions, removing redundant themes, fusing together, clustering and linking themes, and creating a hierarchical organisation of main themes and sub themes. Themes were created which covered both CBT and SL. However, patterns in theme occurrence within the transcripts were subsequently explored, including examination of differences in theme presence and context dependent on treatment group. Coding and emerging themes were periodically discussed with the interviewers and academic supervisors in order to highlight clarifications or modifications that might be necessary and to prevent the development of an idiosyncratic account of the data. As themes were developed, deviant cases (i.e. examples which did not conform to identified patterns) were deliberately sought out to ensure all data was incorporated into the analysis and that themes were flexible and comprehensive enough to accommodate the different patterns.

The inductive thematic analysis resulted in the development of 64 initial grounded codes which were initially organised into 14 themes describing experiences of psychological interventions for adjustment to MS (Appendix U and V). As a final step, memoing, clustering and diagramming (Charmaz, 2006) were used to lift these empirically-grounded themes to more abstract and theoretical concepts and to attempt to explain processes of adjustment as experienced within psychological interventions. This resulted in ten final themes.

7.3. Findings

7.3.1. Overview

Figure 10 depicts the final themes within a model which displays hypothesized processes involved in personal change within adjustment interventions.

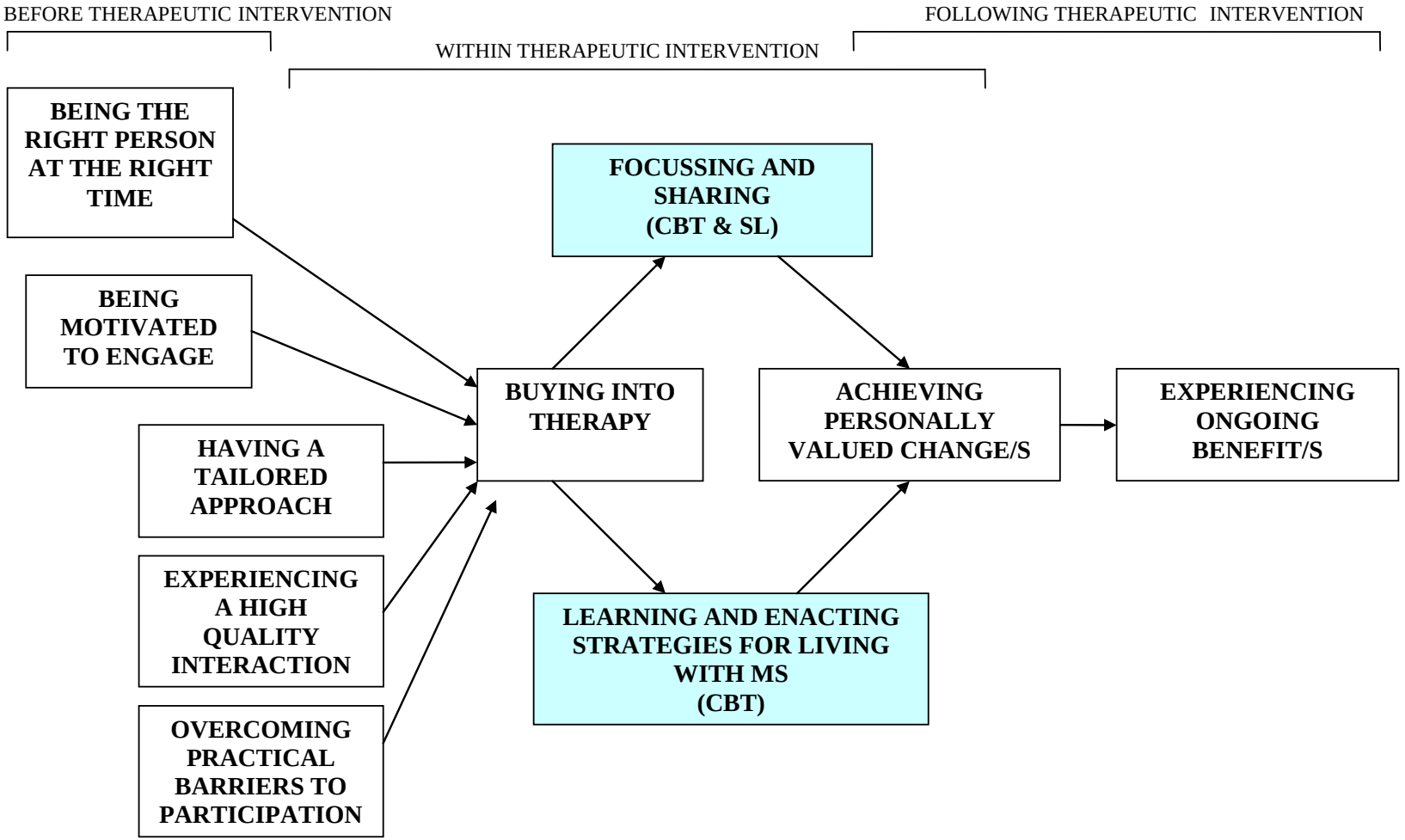

Figure 10: Hypothesised links between themes relating to the adjustment process in interventions

Outcomes of the therapy process, *Achieving personally valued change/s* and *Experiencing ongoing benefit/s* appeared to be linked to two key categories of helpful therapeutic processes. The first of these was *Focusing and sharing* which was described within accounts of both CBT and SL. The second was *Learning and enacting strategies for living with MS* which was only a feature of experiences of CBT. These two categories of helpful therapeutic processes could be engaged in to a greater or lesser extent, depending on participants *Buying into therapy*. The extent to which patients bought in, or engaged was influenced by a number of factors. These were: *Being the right person at the right time*, *Being motivated to engage*, *Having a tailored approach*, *Experiencing a high quality interaction*, and *Overcoming practical barriers to participation*.

In the following sections the components of the model and their links are further described. The account of the hypothesized processes involved in personal change within adjustment interventions starts with the key therapeutic processes identified in the analysis. Next, the apparent facilitators of engagement in therapy are described. Finally, benefits which appear to have been derived from therapy are discussed, including the extent to which these outcomes persist in the longer term.

The discussion of themes is grounded in illustrative quotations[3] relating to the CBT and SL but the analytic focus within this thesis chapter is more on understanding features of the adjustment process within interventions and identifying factors that appear of importance for successfully promoting adjustment in pwMS rather than a specific evaluation of these interventions as delivered within the RCT.

To maintain anonymity, participants' names have been replaced with a participant number (e.g. P1) and other identifying characteristics have been removed

7.3.2. Focusing and Sharing

Participants who had experienced either CBT or SL frequently described how the experience of therapy had involved becoming more tuned into their thoughts and feelings about MS, and other difficulties in their lives. They also described how therapy had

[3] In order to enhance the readability of the quotations, words such as 'umm' 'err' and repetitions of words have been removed. Whilst conducting this editing, care has been taken to preserve the meaning.

permitted the valuable experience of sharing these with others. These processes appeared to be a key route through which positive change occurred.

The opportunity to talk to and be listened to by a professional who was employed specifically for that purpose was perceived as highly valuable by many participants from both treatment arms. Several participants described lacking other appropriate people to talk to about MS-related distress and challenges.

> I think it was nice to have someone to listen to my woes. And the fact that they were objective, someone that wasn't emotionally involved with my life. It was very useful for me because I was able to tell her things I probably wouldn't tell other people. (P18, CBT)

The importance of a neutral listener was a particularly common theme within SL participants. Many SL participants highlighted the therapeutic nature of releasing or offloading thoughts and feelings. This included significant emotional issues, but also everyday issues and concerns.

> I enjoyed the offloading as well… because I carry [laughs] an awful lot of… burden in my head. (P3, SL)

Despite finding the opportunity to talk beneficial, many SL participants described finding it hard to produce material to talk about, especially after the initial few sessions. Without input and direction from the therapist some felt burdened by the need to fill the silence, and many stated that this resulted in repetition or talking about unconnected, insignificant topics. They felt that this lack of focus and two-way communication limited the usefulness of the SL.

Many participants described how the therapy sessions had led to the recognition of and clarification of their own problems, thoughts and feelings. Understanding of their own responses to people and situations was heightened and future courses of action appeared clearer.

> I felt it was very therapeutic and it allowed me for the first time ever really to develop my own thoughts (P30, SL)

Having a specific time and place set aside to think and reflect was described as unusual and useful. The process of saying things out loud (particularly SL), or writing things down (particularly CBT, e.g. in homework tasks) also appeared to enhance awareness.

> It carved out time where I had to stop and think and take you know take time out: from the rest of life and work, from home, from anything else in life and to stop and think about me and what was going on (P19, SL)

Trial data collection procedures, including the follow-up questionnaires and the interview for this study, were seen by some as providing further, useful, opportunities for reflection.

A few participants found that reflecting on, or talking about distressing things, resulted in becoming upset during and/or after sessions. Some felt this was necessary and beneficial. Others wanted to avoid getting upset and therefore did not want to reflect on certain material within therapy (e.g. a family bereavement).

Some participants found that involving their spouse or family in the therapy process was a helpful experience. Only a minority of participants took up the opportunity to bring a family member to a therapy session (only an option in CBT). Of those that brought a family member to the therapy session some found it opened channels for communication and increased understanding between the couple.

> It was it was a good chance to see how [partner's name] really felt about my diagnosis 'cause I think he was always quite wary of saying stuff in front of me… I think it just provided a safe environment to be really honest… about how he was feeling, how I was feeling. (P8, CBT)

Other CBT participants whose partner/spouse attended felt the sessions had elicited problems but not effectively dealt with them. More positively, however, participants from both interventions described getting family members involved in the therapy more broadly. For example, some family members read the therapy manual or partner booklet or were updated by the participant about what had been discussed in sessions. Such involvement was deemed useful, facilitating openness and stimulating communication about difficult issues.

> He didn't come along but I was telling him about it and that. So it was good to speak to talk to him about it and running, you know, going saying what had happened, going through what I'd done that day […] also there was some booklets and everything that I brought back, he was reading through those I felt it really got support from him as well which was good. (P23, CBT)

Several participants described how therapy prompted action towards goals, and the initiation of problem-solving or health-promoting behaviours. In SL this appeared to result from reflection and heightened awareness leading to confidence and clarity**.**

> It gave me a sort of bit more confidence to go and talk to various people […]'cause I'd got my thoughts clarified. (P14, SL)

In CBT goal-oriented action frequently appeared to result from specific taught strategies (described below), as well as feeling pressure or responsibility from having to report back progress to the therapist in future sessions.

7.3.3. Learning and enacting strategies for living with MS

A consistently useful aspect of therapy described by participants was the opportunity to learn skills and strategies to deal with MS**.** This theme was only present in the accounts of CBT participants. Many participants were unspecific about what they had learned, e.g. "ways of dealing with things" "a toolbox of skills".

> This certainly gave me the tools to offer for the ongoing care of my MS if you see what I mean, to actually help me help myself I suppose. (P24, CBT)

Other participants detailed how they had learned ways of dealing with symptoms such as fatigue or pain, through adapting their lifestyles, particularly adjusting levels of activity, pacing themselves, setting goals, problem-solving, and prioritising.

> It was good to be able to learn things to deal with when I'm thinking right, I'm tired, I'm not gonna bother doing that 'cause I'm tired. And learn little strategies for how to sort of cope with that and plan, I almost plan my week now. (P28, CBT)

For several participants, developing insight into how thinking influences mood, behaviour and symptoms was a critical part of therapy. Sometimes, however, participants simply reduced this process to positive thinking, or a positive mental attitude. Others gave examples which demonstrated their understanding and implementation of the CBT process of identifying unhelpful thoughts and developing more balanced, realistic alternatives.

> The overwhelming thought is when you're first diagnosed is 'oh no this disease is just going to take over and I'm going to end up in a wheel chair and that's it'. And you do have those thoughts come flooding over but its learning what to do with those thoughts and I think the course has helped to underline that. (P15, CBT)

Some described how they were now using thought modification techniques naturally without writing it down or working through it systematically.

The teaching of skills for dealing with unhelpful thoughts was not appreciated by all participants. Some participants were convinced that talking about or dwelling on negative things is unhelpful or even dangerous to wellbeing. Therefore they were highly resistant to therapy which encourages you to consider or identify negative or upsetting thoughts. These participants wanted an approach which was focused on positivity.

> It didn't seem positive. It all seemed to be based on negative things. One thing that I kept getting asked was negative thoughts. Well I don't have them and the people I know who have also got M.S. ... don't seem to have them. So it seemed to be, so it seemed to me... everything was always basing everything on negativity which doesn't seem right... (P4, CBT)

Furthermore, thought modification appeared complex to properly grasp especially when tackling it later on, without a therapist available. Some felt more time was needed here.

Part of the process of learning new strategies and skills was having current ways of doing things challenged. Many participants appreciated a new perspective or point of view and found this useful, especially given the therapist's skill in introducing new ideas. Nonetheless, some participants reported (at least initial) resistance towards new ways of doing things. Good therapist communication skills, a trusting therapeutic relationship, and

sensitive matching of new strategies to the particular problems of the participant appeared to be important for overcoming this resistance. The following sections expand upon these issues.

7.3.4. Buying into therapy

One factor which appeared to be fundamental in determining whether a participant benefited from and was satisfied with their therapy experience was the degree to which they related to and engaged with the approach. Being open-minded, willing to open up to the therapist, and give the approach a fair chance was identified by participants as important. What also appeared essential was being willing and able to put in time and effort.

> What you put in, you get out of it (P17, CBT)

Many participants in both therapy arms reported a high level of interest in and enjoyment of the sessions and, where applicable, the homework. A minority of participants were unable or unwilling to find fault with any aspect of the therapy and appeared to find it ideal for their needs. On the other hand, some disliked their allocated therapy and did not agree with its rationale and methods. Participants who did not like or relate to their allocated approach did not report benefits and did not appear to engage fully as they saw no point in this.

> I didn't want to continue 'cause I didn't think I was sort of the right person for it or you know agreeing with it, I didn't like it at all. (P13, CBT)

A number of factors appeared to be important in determining whether the person optimally engaged with their therapy and got maximum benefit. These are discussed in turn below.

7.3.5. Being motivated to engage

All participants were to some extent motivated to try out the interventions, as they had volunteered to take part in the therapy trial. However, participants differed in the nature of their motivations and expectations.

Most participants expressed some hope that therapy would lead to improvements such as learning new ways of coping, being more accepting and feeling less burdened by negativity. One participant reported expecting physical improvement to his condition. Other participants had fairly low expectations or were sceptical about the extent to which it would engender change. Nonetheless they were happy to participate. This appeared to be linked to curiosity, as well as a more altruistic motivation to help others in the future by contributing to science in general, and understanding of MS specifically.

> The reason why I decided to do this is because I thought it might help other people who's in the same situation as me. (P12, CBT)

The fact that personal gain or improvement was not always a motivation to take part in therapy within the RCT meant that not all participants felt they were particularly suitable for or in need of psychological interventions for MS.

7.3.6. Being the right person at the right time

People who perceived that they were strong, practical, positive, and stable frequently suggested that they were not well-suited to having an adjustment-related intervention. Several participants stated that certain sorts of people would benefit more than themselves from the intervention they experienced. This included people who were struggling, negative, depressed and unstable.

> For people who are worried and anxious about MS. For those people I think it's just the thing. For people like me who… [sighs] who don't really need to talk about it, then I think it doesn't make so much difference (P1, SL)

> I presume it might be helpful to somebody who's… I don't know, unstable, depressed. (P21, SL)

Participants commonly discussed the relevance of disease status with respect to therapy availability. However, there was little consistency in opinion. Some participants felt their intervention was suitable for the newly-diagnosed.

> I already had been, had MS, for a few years, so it's not like I was just diagnosed the previous months, in which case it would have been… maybe a whole lot more helpful. (P1, SL)

Others felt that it was not particularly relevant until MS had posed significant challenges. That said, some considered CBT as a useful preparation for future challenges.

> Although not now relevant to my actual condition at that time[…] but obviously it prepares you for a worse situation (P18, CBT)

A few people found CBT such a useful approach that they suggested its usefulness for people at any stage of MS (as well as for other chronically ill populations, and healthy individuals). In addition to disease status and severity, a person's state of mind, and in particular ability and willingness to tackle MS-related issues was deemed highly relevant to treatment effectiveness. Several people described how having accepted the diagnosis and having got to grips with how it might effect them was a prerequisite of treatment effectiveness. The relevance of relapses and exacerbations was also discussed, including how the physical and emotional reaction to relapses would negatively influence a patient's ability to think and reflect at that time.

> There's actually there's no room for anything else……. When that's going on it's like … through the fear your universe has become extremely narrow. And there is its like there's no peripheral vision. (P7, SL)

That said, having therapy at a time when stressful life events and day-to-day problems could be used as discussion material was described as useful. Essentially, it appeared that having current, rather than past or imagined future difficulties to work on was desirable. Nonetheless, the therapy itself could also be seen as a stress or a burden if it coincided with difficult experiences.

> So it came along at a very useful time in my life as well… so you know positive and a slight feeling of being burdened by it (P11, CBT)

7.3.7. Experiencing a high quality interaction

For many participants, building up a comfortable and strong bond with the therapist was seen as critical to having a positive therapy experience.

> The therapist was…extremely friendly and helpful …I felt very comfortable with her from the beginning so that was good. (P11, CBT)

Many participants said they liked the therapist and they believed her to possess positive characteristics. Most participants perceived the therapist to have relevant skills and expertise and to understand the issues involved in living with MS. This was considered vital. However, one participant suggested that the therapist may not have had extensive enough understanding of the medical side of MS.

A common theme for SL participants was that communication within sessions was stunted and unnatural. This was due to the one-sidedness of the talk, and the limitations on how the therapist could respond. Participants found this frustrating and unnecessarily restrictive.

> I don't mind talking. I talk quite a lot I do [laughs]. I do it for a living almost, but the fact that you're talking about yourself… and you're not getting a response almost, you're just literally just keep talking (P5, SL)

The appropriateness of the telephone format was an issue which divided participants. Some found telephone contact surprisingly easy and successful. Others were uncomfortable with this format and felt it posed a barrier to feeling engaged and supported. An important example of this was occasions where participants became upset. On the whole, participants valued the face-to-face sessions, especially for establishing an initial bond. Several participants indicated a preference for more face-to-face sessions.

7.3.8. Having a tailored approach

Most CBT participants felt that the collaborative, individualised approach had ensured a focus on relevant manual chapters and useful homework tasks. Despite the personalising of the sessions a few participants indicated that the CBT manual itself was too general. In

particular, it was perceived as having been designed for people with RRMS, and thus not matched to the needs of those with progressive disease.

SL participants had the opportunity to tailor their sessions to exactly what they wanted to discuss. However, directing the sessions was an unwanted responsibility for many people, who suggested that a more structured and directive approach would be more beneficial.

> In a way you need more guidance, you need someone who's sort of, I find, you need someone who's asking you, sort of guiding you in a certain direction. (P32, SL)

Several participants found the length of the intervention inappropriate for their needs. Many SL participants felt that fewer than eight sessions would be enough (as they were running out of things to say). However, some felt continuation was necessary.

> It suddenly comes to a stop […] I wanted to continue, particularly with the issues that I was dealing with. So it sort of left me a bit in the air really. (P14, SL)

In CBT some people would have preferred a longer intervention, and some felt rushed going through each chapter (especially challenging negative and unhelpful thoughts).

7.3.9. Overcoming practical barriers to participation

Participants described the importance of convenience in promoting engagement in therapy. Many participants appreciated the telephone format in order to make the therapy accessible for people with mobility difficulties. Nonetheless, many participants said they would be happy and able to travel to sessions. A few participants described how the intervention they had experienced, particularly CBT, had failed to take account of their MS-related symptoms and limitations. Problems included difficulties with writing (in CBT homework), problems lifting or carrying the large and heavy CBT manual and discomfort from holding the telephone for prolonged periods.

7.3.10. Achieving personally valued changes

Changes attributed to interventions varied substantially across individuals in terms of presence, domain, obviousness, value and duration of benefits.

A common outcome described by participants was improved communication. Participants also described heightened confidence in social situations, especially dealing with people's reactions to MS. Participants reported being more thoughtful, confident or comfortable in communication with family and friends about both MS and other issues.

> It sort of made me realise that I can talk about it without getting upset. I can talk about it openly and you know its not, maybe it isn't as taboo as I thought it was. (P16, SL)

In both interventions positive experiences of sharing during therapy and heightened clarity appeared to produce confidence in talking to others. In CBT, specific skills and strategies seemed to have also contributed towards improved communication including problem-solving strategies and assertiveness. Linked to improved communication, many participants described improved relationships with other people.

> I've been able to… sort of relate to the family better really. (P14, SL)

Participants described being better able to manage negative emotions and reactions. This included being upset, down, wound up, stressed, anxious, angry or short-tempered. These mood states were reported to still occur but be better handled and easier to attenuate. Many participants linked these improvements to strategies learned in therapy, particularly awareness of and challenging unhelpful thoughts which are involved in distress (CBT only), and being more aware of negative mood states and one's typical reactions (both interventions).

> I think about my M.S. every single day and that will never change but I don't … a thought will come into my head now and I can get rid of it as quickly as it came in. I'm not in that same dreadful thought process that I was before (P8, CBT)

Several participants discussed how the therapy had made them feel more normal. Realising that there were other people in similar situations who think and feel the same way provided reassurance and reduced feelings of isolation.

> You realise that a lot of people have the same.. same thoughts that you have. And before that I didn't know that other people felt the same way about things that I did…. So that was very very useful to me because it made me feel better that I sort of wasn't the only one that was feeling that way. (P6, CBT)

Participants, particularly those who had CBT, described new or renewed confidence and feeling more in control. They described heightened self-efficacy for managing MS and dealing with challenges successfully and were more confident about the future.

> It give me my confidence back, you know things that I was doing you know, the way I was handling my life with the MS was good. (P27, CBT)

Many participants described increased achievement as a therapy outcome (more common in CBT). The therapy process had led to or encouraged the achievement of various goals or tasks such as engaging in hobbies, applying for disability benefits, and gaining employment. In CBT, achievement appeared to be linked to goal setting and planning.

Participants from both interventions described attitude changes. Many described more optimism and a positive outlook. Several participants claimed to have changed their ways of thinking about MS, including developing a more complete and realistic acceptance of its ongoing presence in their lives

> If I've got anything from it its help in acceptance of the condition in the first place and accepting it into my life. (P16, SL)

A few participants, (mostly CBT) described becoming easier on themselves. They discussed relief encountered through rethinking goals, reassessing priorities, and becoming more flexible with standards for their own behaviour.

> It helped me to look at the way I behaved and my reactions […] if I'm fatigued I sometimes can lose objectivity and beat myself up (P28, CBT)

A minority of participants reported little or no change from therapy. This tended to be more common for the SL participants and those who disagreed with the logic of their intervention. One participant felt disappointed that he had not experienced physical improvement from therapy. Other participants felt that they were already coping very well with MS, and so found they had little to gain from therapy.

> I'm making changes as I go and I try and stay positive anyway so there wasn't really anything for me to change (P1, SL)

Participants typically reported that therapy-related changes were subtle, gradual and difficult to spot or distinguish from other factors. Several participants suggested that the real test of the usefulness of therapy would come from situations such as relapses and disease progression.

> I think the test will come when there is a relapse I think. […] as the disease progresses that's when I will be able to tell how much of this is going to have an effect on me really. (P15, CBT)

One CBT participant noticed the benefits from CBT when a subsequent relapse badly affected her vision; by using thought strategies and problem-solving methods she had learned in therapy she was able to manage her distress.

7.3.11. Experiencing ongoing benefits

Whether participants continued to experience positive outcomes from the therapy appeared to be linked to whether participants had learned and practiced strategies for living with MS or simply experienced focusing and sharing. Without learning anything to put into practice, there was little ongoing benefit.

> It's not going to teach you any kind of technique or skill or habit or whatever that you can then apply to make it useful in the times when you are not having it. (P7, SL)

For this reason, many SL participants felt that there was nothing to carry forward once therapy had ended.

> It feels as though it's done, gone, forgotten (P20, SL)

Some missed the sessions and the therapist and a few even felt lonely, grieving the loss of the therapist as a friend.

> You kind of miss it because it's like everything it becomes part of your life and for me I've got quite a limited life (P22, SL)

Conversely, most CBT participants described an ongoing positive legacy of having the therapy through having acquired skills and strategies to use in the future. The availability of the CBT manual to refer to after the intervention had ended appeared to support this.

> I go back to the manual and I read through it you know and it sparks everything back off in me, you know so it's really good, it's fantastic. (P27, CBT)

Nonetheless, some CBT participants described difficulties continuing with what was learned and maintaining gains without the therapist.

> I got upset and I thought right this is when my CBT should be kicking in and I tried to sit down and think about what was going on, what the negative thought was and I identified it was I was 'personalising' but I don't know what to do with it 'cause I needed someone to talk to (P15, CBT)

7.4. Discussion

The following sections summarise the key findings, their implications and their relationship to existing research and theory. First, the apparent change processes are discussed. Facilitators of engagement in adjustment interventions are then considered. Finally the perceived outcomes of therapy are discussed. The chapter then ends with a consideration of study strengths and limitations and the conclusions drawn from this study.

7.4.1. Change processes

The findings help to shed light on what people in both CBT and SL considered helpful in promoting positive outcomes. Beneficial therapeutic processes appeared to fall into two main categories; a) those that were about reflection, sharing and consideration of problems, feelings and emotions and b) those that were about learning specific coping strategies.

Participants from both interventions described the value of being able to share experiences with a kind, empathic, and neutral therapist. Several participants expressed how this opportunity was not available to them elsewhere or that it was inappropriate to burden their spouse or family with this. The provision of emotional support therefore appears to be important; specifically when it can be given without any perceived negative consequences for the support provider. This links to previous published findings of adequate social support being an important factor for adjustment (reviewed in chapter 3) but, like the findings from the qualitative study in chapter 4, highlights a potentially valuable role of formal support from outside the patient's friends and family.

In addition to the role of support, there appeared to be another aspect to the value of sharing within therapy; the talking processes appeared to prompt emotional engagement with and reflection on MS-related difficulties as well as an emotional release. A beneficial role for becoming more able and willing to experience and share negative emotional responses fits with the more general literature on emotional regulation in chronic illness (outlined in Chapter 2) and findings from earlier chapters of this thesis. Chapter 4 revealed that some patients appear to believe that tolerating, expressing and sharing negative emotions is inappropriate and Chapter 5 demonstrated that such beliefs about emotions are correlated with increased distress. The suggestion from the current study that sharing and becoming aware of emotions is a therapeutic process also fits with findings from the quantitative analysis of therapy mechanisms in chapter 6. That analysis found that reductions in negative beliefs about emotions mediated reduction in distress during CBT. Furthermore, both CBT and SL appeared to be able to reduce these beliefs to some extent and in both groups reduced unhelpful beliefs about emotions was associated with reduced distress. The current study suggests that a useful process occurring within therapy is the modification of these beliefs via positive experiences of focusing on and sharing difficult emotions within the sessions. The qualitative analysis from this study also produced some additional insights as to why changes in emotional regulation may be beneficial. Some

patients reported that processing distressing thoughts and emotions created clarity which then allowed or prompted the adoption of problem-focused coping behaviours. As discussed below, the value of taking practical steps to managing MS-related problems has been well established in previous research.

Learning and practicing adaptive ways of coping with MS was one of the key processes that CBT participants consistently identified as being helpful. Different participants found different aspects of the intervention most relevant for them. However, participants frequently described appreciating very practical strategies such as pacing, activity planning and setting goals. These were considered extremely relevant. The apparent benefits of applying these types of strategies corresponds to the literature which links problem-focused coping to positive adjustment outcomes in MS (reviewed in chapter 3). It also links to the qualitative study reported in chapter 4, where participants described problem-focused, practical ways of coping to be helpful for many aspects of living with MS. The fact that the strategies being taught within CBT fit easily with ways in which pwMS naturally approach dealing with MS may explain why, in this study, these sorts of strategies were appreciated and considered relevant.

Learning to recognise and challenge negative and unhelpful thoughts was described as extremely helpful for some respondents who were able to use this to reduce distress. In the present study participants described successfully using thought modification techniques to deal with thoughts about MS and its impact (e.g. catastrophising about symptoms) and this leading to a reduced emotional response. The types of thoughts people described having around symptoms and MS echos previous literature which suggests unhelpful cognitions about illness and symptoms as being important for adjustment to MS (including chapter 3, 4 and 5). The current findings also fits well with findings from Chapter 6 which found that changes in catastrophising about symptoms, embarrassment about symptoms and symptom-focusing mediated change in adjustment outcomes. Some current participants also described the usefulness of applying thought techniques to other life areas and described some of their more general unhelpful thoughts (e.g. perfectionism, concerns about other peoples' judgements of them). This is in line with earlier findings that distress in MS is also related to wider unhelpful ways of thinking and responding to situations (chapter 3 and 5) . Quantitative analyses of the change process within the saMS trial suggested that reductions in unhelpful thinking about the self (e.g. perfectionism, need for

approval) was related to reduced distress, although the analysis did not support the role of this variable as a mediator of improvement in adjustment (Chapter 6).

In contrast, several participants reported thought modification skills as being difficult to grasp. Furthermore, the current study revealed that several participants were angered or disenchanted by this approach, feeling that considering negative thoughts was an irrelevant or even dangerous endeavour. A need for demonstrating positivity and optimism and successful coping and an unwillingness to admit to thinking negatively was documented in the qualitative study reported in chapter 4. Potentially, because of this, cognitive restructuring work may not always be an appropriate or beneficial approach for adjustment interventions. Alternatively, it may be necessary to adapt the delivery of the cognitive restructuring components of CBT, spend more time on these aspects, use more experienced therapists, or better communicate the relevance of thinking styles in order to reduce participants' resistance to considering negative thoughts.

An interesting finding from this study was that the two identified sets of therapeutic processes (*focusing and sharing*, and *learning and enacting strategies for living with MS*) were not particular to formal psychological interventions. It appears that they may have been occurring as part of a more general process of adaptation for many participants, outside of their experiences of therapy. Some participants commented that strategies they learned were relatively common sense and were already being put into practice. Activities like pacing, prioritising, ensuring adequate rest and relaxation, and sleep hygiene were skills that some participants were independently adopting. Even addressing negative thoughts through identifying them and explicitly considering their validity was something that some participants recognised they had been doing independently, in a more subtle way. The fact that the therapeutic processes also occurred in settings outside of therapy did not mean that they were not usefully addressed in therapy. Several participants welcomed a refresher and the reassurance that their current management techniques and natural coping styles were advocated by the therapy framework. Others who did not already use similar strategies found they were learning novel ways of dealing with problems.

7.4.2. Facilitators of engagement

The study results suggest some important factors to consider when delivering interventions to pwMS. These factors appear to be significant influences on whether the person engages with the therapeutic approach on offer and, in turn gets full experience of the apparently beneficial therapeutic processes that were identified.

Full engagement with the therapy appeared to be related to motivations for having the interventions and participants' perceptions of whether they were the sort of person who needed therapy. In this trial there appeared to be a group of participants who did not feel they were suitable for the intervention and were only participating for altruistic reasons; in order to help with MS research. Most previous studies of psychological interventions have specifically recruited participants with a certain level of morbidity: either a diagnosis of major depression or elevated depression or distress scores.(e.g. Mohr et al., 2001; Mohr et al., 2002; Mohr et al., 2000; Mohr et al., 2005). In the current trial the intervention was open to early stage MS patients regardless of any assessment of psychological or social functioning, with the aim of addressing broader indicators of adjustment (Moss-Morris et al., 2009). It is not clear from this study whether this was a useful approach; some people felt they were not the right sort of candidate for the therapy as they did not need it. Nonetheless some of these people unexpectedly obtained benefits.

The tendency for some participants to consider themselves unsuitable candidates for the interventions may relate to a process of trying to avoid stigma and the adoption of an identity of somebody who is not coping or is weak or unstable, This resonates with the findings in chapter 4 around avoiding membership of the "cripple club" and an identity as a disabled person. Similar findings have emerged in other qualitative research which seeks to understand responses to, and acceptability of health interventions. Yardley et al. found that older people showed resistance to falls prevention therapy; they found falls prevention advice and intervention stigmatising, humiliating, and an announcement of being infirm. Therefore they considered that it was not suitable for them, but for older, weaker, more disabled others. Yet, when framed positively as something that maintained long-term independence and autonomy (e.g. strength and balance training) rather than coping with a weakness or a problem, people found messages more acceptable (Yardley, Donovan-Hall, Francis, & Todd, 2006). Ensuring that a therapy is described and delivered in such a way that it does not stigmatise or threaten a patients' identity may be important for engaging people, especially when some patients may not consider themselves in need, yet may still benefit from self-management advice and support. Whilst the interventions within the

saMS trial were framed as support with adjustment in order to achieve the best possible psychosocial outcomes, both had some degree of focus on problems. CBT involved identifying unhelpful thinking and behaviours and their contributions to negative outcomes and SL may have often elicited descriptions of difficulties and problems, aspects of the interventions which a minority of participants found problematic and unhelpful.

Both therapies appeared to be of most benefit when the participant was in agreement with the treatment rationale, and personality and preferences matched the therapy style. The structured and problem-focused CBT approach may suit some patients, whereas a simple listening intervention may be more appropriate for others. Chapter 6 also found that individual differences influenced the success of therapy, and showed that pre-therapy cognitive and behavioural tendencies predicted outcome. Overall, it seems that having a choice of therapies on offer and matching these to the individual's characteristics would be beneficial.

The results of this study also raise questions about timing of offering interventions with respect to disease status. Participants had mixed views about whether an early stage MS intervention was appropriate, or whether a certain level of experience of physical impairment, relapse or disease progression was necessary for the interventions to be relevant. This lack of consistent differences in treatment efficacy dependent on MS type and duration fits with Chapter 6's findings that these factors did not predict or moderate the effects of therapy on the adjustment outcomes. Nonetheless, from the current study it seemed that participants believed that some degree of acceptance and openness towards engaging with the idea of MS was necessary. Perhaps, a one-size-fits-all approach to provision of interventions (e.g. soon after diagnosis) is inappropriate. Patients may need to be monitored and referred on demand, or during specific challenges.

The therapists seemed to play a key role in engaging participants in therapeutic strategies and having a good therapeutic alliance and high-quality interactions (whether face-to-face or by telephone) seemed to be a prerequisite to getting properly involved in the interventions. Therapists' skills in collaborating with the participant and matching sessions to their own problems and needs was considered vital and usually accomplished within CBT. However, participants wanted direction from the therapist and did not seem completely comfortable with setting their own therapy agendas (in SL). Therefore, it appears that therapists need to achieve a balance between recognising important areas to

structure the sessions around, and allowing the participant the scope to make the material fit with their own experiences. Furthermore, although not possible within the current context of a manualised RCT, adapting the length of a therapeutic intervention to the requirements of the participants could be important as participants differed greatly on what they wanted and felt they needed. Furthermore, the current finding that some CBT participants found the CBT was too rushed and wanted more of the intervention in order to fully capable of using learned strategies independently is in line with the trial findings that the effect size of CBT was much smaller at twelve month follow-up (Moss-Morris et al., 2011). It may be that some pwMS would find a longer intervention more useful, and/or may benefit from some booster sessions.

Finally, practical barriers were highlighted as impacting on the ability to engage in therapeutic processes within the interventions. Flexibility for session scheduling and minimising travel appeared important for this, not just due to MS-related difficulties but as a result of family and work demands. However, whether the degree of flexibility available within the trial could be replicated in more realistic clinical settings is questionable. In addition, the results showed the need to pay detailed attention to the whole range of potential MS symptoms and impairments when designing interventions. The therapy within the saMS trial had been designed to reduce the need to travel (and therefore tackle access problems for people with limited mobility) but had not adequately considered a variety of other symptoms that made physically handling the manual and the telephone difficult for some. Designing interventions with sensitivity to MS symptoms is essential. Failure to do so in the current trial led to some frustration with the therapy, negatively affecting the experiences of participants, and making it more problematic to engage with potentially therapeutic processes. This finding echoes previous themes in the qualitative exploration of experiences of PwMS with web-based CBT for depression (Hind et al., 2009) .

7.4.3. Perceived outcomes and benefits

The findings suggest that outcomes of therapy are highly variable between participants, not simply in terms of the amount of change, but also in terms of domains of change. Multiple positive outcomes of both therapies were described ranging from achievement of goals to improvements in relationships and communication. Some of the outcomes appeared to be

only loosely related to MS (e.g. dealing with life stresses, ongoing problems with spouse/family). The perceived benefits did not, for the most part, correspond directly to the primary outcomes assessed within the trial (Moss-Morris et al., 2009). For example, the trial aimed to reduce emotional distress as measured by the general health questionnaire (Goldberg, 1992). However, perceptions of an absence or reduction of distress was not a consistent finding in this study. Some people mentioned feeling more in control of negative moods when they occurred but this would not necessarily be picked up by a measure like the GHQ. This study also did not consistently elicit accounts of improved MS-related functional impairment (the other primary outcome in the saMS trial). Some CBT participants described increasing activities and achieving more but others appeared to be learning that reducing activity, standards and expectations was an adaptive response to their MS symptoms. Thus some people appeared to be reducing what they were doing and taking on more manageable tasks (e.g. cutting back on household chores or other activities to preserve energy). Vitally, though, interview participants were concurrently reporting feeling more content with and accepting of this level of activity. However, the instrument used to measure functional impairment in the trial (the WSAS; Mundt et al., 2002) would record this as a worse outcome. This may explain the apparently disappointing trial results with respect to reducing functional impairment (Moss-Morris et al., 2011). Further work is needed to develop better measures for tapping adjustment domains relating to the impact of MS.

Another key insight from this study is that changes in adjustment outcomes are very highly personal – different participants changed in different ways. Furthermore, valued outcomes may not be what researchers were aiming for or expecting. Participants seemed to be happy with changes in the sorts of variables researchers typically consider to be predictors or mediators of adjustment (e.g. improved interactions with others, increased social support, enhanced confidence or control) even without changes in levels of distress or impact of disease. Interventions which aim to change a concept as broad as adjustment to a chronic illness should consider means of measuring outcomes in ways that are specific to the individual in order to capture relevant changes. It may be useful to ask participants to identify areas they wish to change at baseline, and then measure a corresponding variable as their own primary outcome.

Finally, patients' perceptions regarding duration of benefits and reasons for continued benefits are interesting. The fact that learning and adopting self-management strategies

(from CBT) was seen as the reason for ongoing benefits is in line with the model of an ongoing process of adjustment to multiple MS challenges or critical events (chapter 3). From this study, it seemed that ongoing effort was required for developing longer-term positive adjustment, rather than a quick fix or sudden breakthrough within a therapeutic intervention. It seems that intervention focus needs to be on management techniques that will continue to be beneficial to patients in the future, rather than simply dealing with immediate issues.

7.4.4. Study strengths and limitations

The qualitative approach allowed the emergence of findings that were not expected and could not be gained from either the RCT (Moss-Morris et al., 2011) or the quantitative study of potential mechanisms of therapy effectiveness (chapter 6). This demonstrates the utility of supplementing trials with qualitative process and evaluation research.

The combination of rigorous inductive analysis procedures from the thematic analysis plus the use of some grounded theory coding techniques ensured that findings were grounded in the data but also enabled theorising about links between themes/concepts. Nonetheless, in an ideal world it would have been preferable to use further grounded theory strategies, including concurrent data collection and analysis and theoretical sampling. Unfortunately, choice about adopting these methods was limited by the fact that this study was nested within another, larger project (the saMS trial). As trial co-ordinator I was prevented from conducting the interviews myself because I was required to remain blinded to treatment group allocation. Furthermore, it is unlikely that I would have been perceived as a neutral interviewer because participants knew I was involved in the trial design and management as they had spoken to me during recruitment, screening and enrolment. Therefore interviews were carried out by other health psychology researchers, and analysis was conducted by myself later, when all participants had finished the trial and all quantitative data had been collected. Had it been possible to conduct the interviews and analyse them concurrently, further exploration of emerging understandings of themes and concepts within the data would have been possible by deliberately sampling participants who would provide relevant information. Furthermore, the interview schedule could have been modified to probe areas of emerging interest. This could have led to theoretical saturation

and ultimately contributed to a fuller and more authoritative model of hypothesised adjustment processes.

The use of interviewers independent from myself and the rest of the trial research team did have some clear advantages. Firstly, because the interviewers introduced themselves as being inexperienced in the trial interventions and interested in finding out about this, they elicited detailed descriptions of both CBT and SL from the perspective of the patients. It is also likely that using uninvolved interviewers allowed the collection of data which went beyond socially desirable responses. It is impossible to definitively judge whether participants were providing honest accounts (and indeed, from a qualitative research standpoint it would not usually be considered that one true or accurate account exists). However, some participants did provide extensive critical comments. Furthermore, positive remarks about interventions were usually accompanied by detailed accounts of what participants liked and why they found elements of the therapy useful, enhancing confidence that they did indeed feel positive about the interventions and derive benefits.

It is important to note that some participants' memory for details of therapy and/or their ability to articulate this appeared to be limited. A few participants simply read out the names of CBT chapters, with general comments about them being good or useful, without describing exactly what they had experienced or how it worked for them. It also appeared to be hard for participants to describe *how or why* things were changing and factors that may have been responsible for change. A large proportion of the data collected related to fairly concrete aspects of the therapy experience such as liking the therapist, finding face-to-face contact more suitable than telephone calls or appreciating having a convenient time slot. This data is useful for evaluating the specific interventions as delivered within the trial, and improving the interventions in response to participant feedback. However, this is not a focus of this thesis. Despite these limitations, participants consistently described various processes which they found therapeutic and clearly articulated a range of benefits they felt they had derived from participation in the interventions. Problems with memory and articulation may be due to subtle MS-related cognitive impairment (participants had been screened for *severe* cognitive impairment as this was a trial exclusion criterion). Alternatively, the time between therapy and interview may have been too long. The interventions themselves had taken place over a period of around 10 weeks, and then there had been an average delay of around 9 weeks prior to the interview. Ideally, interviews would have taken place either immediately post-therapy or even at different points during

therapy (e.g. at the start, middle and end). However, this was not an appropriate design to use within the context of an RCT as interviewing about therapy experience during therapy may have had effects on the quantitative outcome data, for example through encouraging further reflection, prompting adherence and effort, and having further time with an interested listener. Therefore, interviews had to take place after the post-therapy questionnaires had been received, leading to a lag between therapy and interviews.

The purposive sampling meant that a varied sample was interviewed, including people differing in terms of age, gender, disease variables and questionnaire-based satisfaction and improvement ratings of the intervention they received. Although qualitative research does not seek to analyse a representative sample, the interview sample was broadly reflective of the trial sample as a whole and covered a range of viewpoints. Regrettably, it was not possible to sample any of the fourteen participants who withdrew from the interventions during the trial. This is a limitation as it would have been interesting and informative to explore reasons why individuals did not feel the interventions were beneficial, appropriate or convenient for them. This might have taken the analysis further towards theoretical saturation and could have added to confidence in the themes and the model of adjustment processes within therapy.

Finally, whilst this analysis suggests factors that appear important for adjustment interventions and hypothesises links between derived themes, qualitative studies, by their very nature cannot establish causal mechanisms or between group differences. Research using different designs would be needed to follow up on current findings. Furthermore, this analysis is based on a specific context: volunteers with early stage MS having either CBT or SL within a RCT. It may be that the same or similar processes are important within other similar interventions, populations or other contexts but further research would be needed to establish this.

7.4.5. Conclusion

This study explored patients' experiences of two psychological interventions for improving adjustment to MS. The findings identified a wide range of psychosocial changes following both interventions which had not been tapped within the saMS trial or the quantitative analysis in chapter 6. The findings also shed light on two sets of processes which appeared

important for change; *Focusing and sharing* and *Learning and enacting strategies for living with MS*, of which the latter appeared particularly important for sustaining longer-term benefits. Overall, this study suggests that both non-specific factors such as sharing problems and becoming aware of thoughts and feelings, and specific strategies for coping with MS which are a particular focus in CBT, were considered useful and acceptable to patients. Whether participants fully engaged or bought into therapy appeared to be related to their perceptions of being the right sort of candidate for the intervention, their expectations and motivations, the therapeutic relationship, the tailoring of the interventions, and practical considerations. These findings have implications for both researchers and clinicians in terms of ensuring that participants are able to make the most of interventions on offer.

Chapter Eight: Discussion

8.1. Chapter overview

This final chapter concludes the thesis by considering the contributions of the research programme as a whole. The first section summarises the work conducted in this thesis, pulling out key findings, themes, messages and new contributions. A discussion of implications for improving adjustment to MS is then presented. Finally, limitations of the research programme are reflected upon and implications for future research are set out.

8.2. Major findings and conclusions from the thesis

8.2.1. Previous theoretical and empirical literature and my working model of adjustment to MS

This thesis aimed to understand the nature of psychological adjustment to MS and elucidate modifiable factors that psychological interventions could address in order to promote successful adjustment. I began by reviewing evidence that MS is a disease that can present considerable challenges for patients and for which poor psychosocial outcomes are frequently observed. As the theoretical literature on adjustment to chronic disease was explored it became apparent that there are many potential ways of conceptualising what it means to be well-adjusted. Furthermore, there appeared to be multiple theories which have value for explaining what influences adjustment outcomes and identifying where it may be possible for psychological treatments to intervene. It was clear, however, that no single theory provided an adequate overall explanation of the adjustment process in MS; incorporating all important variables, and considering all the pertinent aspects of adjustment outcomes. For instance, cognitive models of psychopathology (e.g. Beck, 1979; Seligman, 1981) emphasise information processing biases and unhelpful cognitions that contribute to depression, but do not explain social and role functioning, satisfaction with life, QoL, or more generalised emotional distress. On the other hand, the CSM (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 2001) can explain a wider range of adjustment outcomes but focuses on cognitive representations and behavioural responses to the illness and its symptoms, but does not incorporate other thoughts and behaviours which seem to also be important influences. There was, however, no indication that the different theoretical frameworks were incompatible. The processes they depicted did not contradict each other, rather they had somewhat different focuses and remits. Given the aims of the

thesis, focusing on a single existing model to drive the empirical research appeared too restrictive.

The systematic review identified published research on psychological variables that predict or explain adjustment outcomes in pwMS. This large body of research literature had not previously been reviewed, therefore the synthesis and critique offered by this thesis is a unique and important contribution. Review findings reinforced the suggestion from the theory chapter that there are many candidate theories that might help to predict, understand and alter adjustment outcomes in pwMS. There was no clear message from the systematic review that any single theory, variable or category of variables appeared superior to others. Although some variables had a more robust evidence base, this appeared to be due to having been more frequently and carefully researched, rather than necessarily being more promising for explaining adjustment in MS.

In order to start to integrate existing theory and research, and to provide an overall means of conceptualising the complex process of adjustment to MS, a working model was developed. This model, based on findings from the systematic review brings together variables from different theoretical frameworks that existing MS research indicated is related to adjustment to MS. The model adds to the existing MS adjustment literature by making sense of the numerous research studies which each identify different cognitive and behavioural factors and their relationships to specific adjustment outcomes. It draws on various theoretical frameworks which, standing alone explain only isolated elements of the adjustment process. The model is also unique in that it speculates about the process of adjustment to MS and proposes that MS adjustment is a continuous, dynamic process whereby critical events such as diagnosis, relapse and disease progression disrupt equilibrium leading to adverse psychosocial outcomes. The model emphasises the importance of the individual's current cognitions and behaviours and their personal and social resources which are hypothesised to be proximal influences on whether they achieve positive or negative longer-term adjustment outcomes. The model also speculates the involvement of some more distal psychological factors which may influence both the extent to which critical events are disruptive to that individual, and the cognitive and behavioural responses the individual displays when faced with MS. Given that this is the only MS-specific model which highlights targets for change within psychological interventions, it could make a valuable clinical contribution.

The four empirical studies within this thesis used different methodologies to investigate different questions about the factors and processes involved in adjustment to MS. As intended, this 'composite analysis' (Yardley & Bishop, 2009) contributed to an overall understanding of what adjustment is and how it might be improved. The two quantitative studies directly tested the more proximal elements of the model by investigating whether a range of CB variables influence different adjustment outcomes. The two qualitative studies were more open-ended explorations of the experience of adjustment from the perspective of pwMS. They also offer insights into whether the model represents a helpful way of conceptualising MS adjustment, enriching and sometimes challenging understanding gained from other sources.

The different studies and the different methodologies inevitably produced multiple insights and specific results. However, several overall themes arose from the research programme. Firstly, the thesis established the importance of a range of different cognitive and behavioural variables in explaining and improving adjustment outcomes. Secondly, the thesis highlighted the diverse nature of challenging MS-related events which can disrupt the status quo and trigger difficulties with adjustment. Thirdly, the thesis identifies complexities and uncertainties about how we should conceptualise and measure successful adjustment. These issues are discussed in the sections below.

8.2.2. The importance of cognitive and behavioural variables in explaining adjustment outcomes

One of the consistent messages from the empirical work in this thesis was that adjustment outcomes are influenced by the individual's thoughts and behaviours. Echoing the theoretical and systematic review chapter, no single existing theory appeared adequate for capturing important modifiable factors involved in adjustment to MS. Rather, in line with the suggested CB model, a range of variables from different theories and models were important.

Within the qualitative studies, participants described how their personal dispositions, resources, thoughts and actions had a bearing on emotional distress, social and functional impairment and satisfaction with life in the context of MS. Many of the inductively-derived findings matched well with variables proposed in the CB model; increasing confidence in the model, especially as the qualitative work had not deliberately sought to

find evidence for these variables. As well as lending support to the model, the qualitative work also built upon previous studies that had been included in the systematic review. For instance, existing studies had linked problem-focused coping (McCabe & De Judicibus, 2005; Pakenham, 1999) and social support (McCabe et al., 2004; Pakenham, 1999; Schwartz & Frohner, 2005) to positive outcomes such as good mental health and quality of life. Uncertainty (McNulty et al., 2004; Wineman et al., 1994) and threatening perceptions of MS (Jopson & Moss-Morris, 2003) have been linked to negative adjustment outcomes such as depression. The qualitative study of adjustment experiences added to understanding of the importance of these variables by providing descriptive detail about the sorts of problem-focused coping pwMS employ, the types of social support available and appreciated, and the nature of unhelpful beliefs patients have about their disease, and how and why these change over time.

Importantly, the qualitative study of adjustment experiences provided insights that had not been apparent from existing research and drew attention to other psychological factors of potential importance in predicting and explaining positive adjustment outcomes. For example, learning to manage other people's responses to MS appeared to promote adjustment as did downwards social comparison. Changing priorities, goals and standards emerged as potentially helpful, but maintaining some continuity of lifestyle and valued activities also appeared important. Whilst some of these variables have been highlighted in the wider chronic disease literature (e.g. Sprangers & Schwartz, 1999; Carver & Scheier, 1999) the thesis was the first research to identify these as of relevance for aiding adjustment in context of MS.

Qualitative findings were occasionally at odds with those identified in the existing research. A seemingly important insight from the inductive analysis of patients' experiences of adjustment was that there were some variables that had been fairly consistently linked to either good or bad outcomes in the existing quantitative literature but which participants' accounts suggested had complex and perhaps inconsistent relationships to outcomes. For example, denial and avoidant coping are typically linked to worse outcomes (e.g. Arnett et al., 2002; Pakenham, 1999) but seemed to be helpful for some participants in terms of helping them to maintain emotional wellbeing and self-esteem. Similarly, acceptance, a factor usually considered to be adaptive (e.g. Telford et al., 2006) seemed to be more multi-dimensional than is apparent from previous studies and did not always seem necessary or helpful. These insights require further investigation but the results suggest a

more complex relationship between some CB factors and adjustment outcomes. Certain cognitions and behaviours may be helpful at some points in the disease trajectory but not at others, or may improve some aspects of adjustment outcomes but hinder others.

The quantitative studies, corresponding to the proposed model, found relationships between CB variables from different theoretical perspectives and two different adjustment outcomes; distress and functional impairment. Variables that the systematic review and initial qualitative study indicated were promising but have so far received inadequate attention were investigated. The importance of the patients' responses to symptoms in explaining adjustment outcomes suggested by the CSM (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 2001) and identified by earlier research (Douglas et al., 2008; Osborne et al., 2007; Skerrett & Moss-Morris, 2006) was replicated and extended. This variable appears to be of considerable importance in this disease which is characterised by the presence of multiple unpredictable, potentially embarrassing and threatening symptoms which need to be responded to in an adaptive way. The importance of unhelpful and negative beliefs about oneself and also about expressing and tolerating negative emotions were also shown to be important. These factors have been little explored in MS but have been implicated in other physical and mental health contexts. The role of negative views of the self is key to theories of depression (Beck, 1976) and the types of unhelpful beliefs measured in the current research has been theorised to create vulnerability to poor psychological outcomes in stressful situations (Sinclair et al., 1998). Emotional processing has become increasingly prominent in the general chronic disease literature (e.g. Cameron & Jago, 2008; de Ridder et al., 2008; Gross, 2002). A key conclusion from this work was that a consideration of both cognitions and behaviours relating to the illness itself and broader beliefs and actions is relevant in order to explain important adjustment outcomes.

The quantitative components of the thesis also started to develop a clearer picture of how, out of the numerous variables that are related to adjustment outcomes, some are more important for explaining emotional outcomes and others are more important for explaining limitations on the patient's activities and functioning. Specifically, the usefulness of variables more typical of health psychology theory and research in explaining functional impairment was identified, whereas variables influenced by clinical psychology models and therapies appeared to be particularly useful for explaining distress.

Another key contribution of the thesis was demonstrating that the development of more positive and adaptive beliefs and behaviours mediated improvement in adjustment outcomes observed within a psychological intervention. This is an important step in advancing the literature which has reported some effective interventions for improving aspects of adjustment in pwMS (Foley et al., 1987; Mohr et al., 2000; Mohr, Boudewyn, Likosky, Levine, & Goodkin, 2001; Mohr et al., 2005; Rigby, Thornton, & Young, 2008; Schwartz, 1999) but has not addressed how and why these work, or linked interventions to a theory or model of adjustment. The quantitative analyses of change within interventions provide support for one of the central tenets of the CB model: that changing CB factors influences adjustment outcomes. No one variable explained all of the change in outcomes. However, as a range of beliefs and behaviours became more adaptive, adjustment outcomes also improved. Improvements in the way that participants responded to their symptoms appeared to mediate improvements in adjustment outcomes, as did the development of more adaptive attitudes towards tolerating and sharing negative emotions. Again, this study reinforced the conclusion that it is necessary to draw on multiple theories and consider a range of factors to explain MS adjustment outcomes.

The qualitative investigation of change within adjustment interventions also suggested the relevance of multiple possible pathways to positive outcomes and stressed the many different aspects of interventions that appeared to help participants. One of the apparently beneficial processes participants identified was learning specific ways to manage MS symptoms and impairment, often very problem-focused and practical. This corresponds with systematic review findings and theoretical work from stress and coping frameworks about the adaptive nature of employing problem-focused coping strategies (McCabe & De Judicibus, 2005; Pakenham, 1999) and of self-efficacy for managing MS-related challenges (Shnek et al., 1995; Shnek et al., 1997).

The qualitative analysis of therapy processes also suggested an important role for the emotional processing and sharing of emotional material in promoting positive outcomes of therapy. These findings complemented the quantitative findings of the importance of beliefs about emotions and lead to an overall conclusion that being able and willing to acknowledge, process and share negative emotions is related to reduced distress in people with MS, and that interventions that provide opportunities and positive experiences of this may influence the way that people regulate their emotions and reduce distress.

8.2.3. The nature of 'critical events'

Another key message from the empirical studies was the importance of considering a diverse range of different events and experiences as having the potential to disrupt equilibrium. The initial working model had suggested that MS-related events such as the development of symptoms, relapse, diagnosis and disease progression could create disruption to wellbeing and quality of life. The accounts of pwMS within the qualitative studies supported the notion of these events acting as triggers for adjustment difficulties. However, the qualitative studies also shed light on other triggers, or critical events, which are not current, observable medical factors. The threat of future physical decline was frequently mentioned as something that created distress and dissatisfaction with life. As well as declines in physical health and ability to function and remain independent, participants described dealing with actual or potential changes to their identity as normal, healthy people as being key events that affected their adjustment outcomes.

8.2.4. The complexities of successful adjustment

From the previous literature it was apparent that successful adjustment involves achieving positive outcomes in various domains including emotional wellbeing, social and role functioning and quality of life. The quantitative work in this thesis investigated two key adjustment outcomes; distress and functional impairment with low distress and low functional impairment considered as indicators of good, or successful adjustment. However, the qualitative studies made clear the highly individual nature of what outcomes are important to people. The analysis of therapy experiences revealed that some participants wanted to feel less overwhelmed by negative thoughts and emotions, some wanted to feel more confident about the future, some wanted to be able to talk to and interact with their friends and family better. Different outcomes may well be important to different people, and to the same people at different points in time. What participants seem to consider to be valuable or meaningful outcomes of therapy or indicators of positive adjustment do not always necessarily match what researchers expect or measure as outcomes in quantitative research.

The qualitative work also challenged the idea of being able to easily categorise individuals as well or poorly adjusted. In line with the model, participants described a dynamic process

where disruptions to wellbeing occurred in response to a number of major or minor events such as relapse, attacks of severe fatigue, and day-to-day life stressors. However, through listening to the participants' accounts of their adjustment experiences it became clear how changeable 'outcomes' are, even over very short time periods (e.g. days). Therefore, it appears to be problematic to try to meaningfully assess adjustment outcomes at one point in time, especially in the absence of contextual information about disease activity and other stressors.

A key insight from this thesis was that in addition to positive and negative adjustment outcomes it is necessary to consider the stability of a person's adjustment status. The adjustment of some pwMS appeared to be characterised by its partial and precarious nature; currently satisfactory but under threat from possible future relapse, physical decline and forced lifestyle change. This 'precarious adjustment' has not been well captured in previous studies but is important as it suggests that simple measurement of current distress, functioning and quality of life will not provide a clear picture of the person's success in adjusting to the numerous past, present and future difficulties resulting from MS.

8.3. Implications for improving adjustment outcomes for pwMS

8.3.1. Means of achieving better adjustment outcomes

All thesis chapters supported a model whereby modifiable psychological variables are important determinants of adjustment outcomes in the face of MS. This implies that attempts to improve psychosocial functioning of pwMS will be successful if they involve reducing maladaptive beliefs and behaviours and promoting adaptive thoughts and actions.

Many participants in the qualitative research described how the emotional turmoil and disrupted functioning experienced in response to MS diagnosis, symptom exacerbations or physical deterioration assuaged over time without any formal intervention. This suggests that there is a natural adjustment process which many participants will go through; an important and optimistic message that health professionals and MS patient organisations could communicate to newly diagnosed patients. Improvement occurring outside of interventions appeared to be driven by acquiring information about MS, drawing on emotional support and practical advice, and making practical changes to lifestyle, and developing realistic and/or optimistic ways of viewing MS and the future. Again, health

professionals and patient organisations and family members may be able to prompt and support patients to adopt these helpful behaviours and attitudes.

Although many pwMS appear to be able to achieve good outcomes without professional support, the qualitative and quantitative research nested within the saMS trial, demonstrated that relevant psychological variables can be successfully modified within interventions, and that these changes appear be mechanisms through which improvements in adjustment outcomes can be fostered.

Relevant targets for psychological interventions

As described above, one of the key conclusions from this thesis was that a variety of psychological variables are involved in determining adjustment outcomes which could potentially be addressed in interventions. The studies in the systematic review imply that interventions could aim to reduce cognitive appraisal of stressors as threatening, promote problem-focused coping rather than avoidant emotion-focused strategies, promote self-efficacy, encourage optimism, foster the development of less threatening and more accurate beliefs about MS and symptoms, facilitate the development of adequate social support and encourage acceptance of MS. Findings from qualitative studies imply that other important intervention techniques may include helping pwMS to develop confidence and social skills for dealing with other people's reactions, develop strategies to preserve a positive identity, and become aware of and willing and able to express difficult emotions and thoughts about MS. The quantitative studies indicated that depending on the target outcome for improvement (i.e. distress, functional impairment) different psychological variables were of different importance. It appears that in order to reduce the functional impairment resulting from MS, addressing illness and symptom-related beliefs and behaviour is of considerable importance. If the aim is to reduce emotional distress, a wider range of cognitions also seem relevant including maladaptive beliefs about oneself and about expressing and sharing negative emotions.

The conclusion that there is no one indicator of good adjustment, no single key thinking process or behaviour that determines successful adjustment and that there may be differences between patients and within patients over time in factors that influence outcomes suggests that interventions will need to be tailored to the individual and their current circumstances. Rather than designing interventions which focus on modifying

specific variables for all participants (e.g. an intervention focused on emotional processing, or an intervention based on changing beliefs about symptoms) interventions need to carefully assess a) the adjustment outcome/s of most relevance to try to improve for each individual and b) the specific thoughts and behaviours that appear to be important for that individual. The CB model is broad and flexible enough to be a helpful guide. Those designing and delivering interventions might use the model to consider a range of modifiable psychological factors that tend to be associated with certain outcomes but would need to carefully assess individual patients and create a formulation that is customized to their adjustment issues.

8.3.2. Suitability for psychological interventions

Many participants within the empirical studies appeared to be experiencing, or have previously experienced substantial negative psychosocial consequences of MS. Participants in the qualitative studies reported experiencing depression, anxiety, reduced life satisfaction and disturbances to relationships, roles and activities. Furthermore, in the quantitative research some participants demonstrated high levels of distress and functional impairment. The identification of psychosocial difficulties in pwMS is in keeping with a large body of existing quantitative (Patten et al., 2003; Zorzon et al., 2001; Kern et al., 2009; Hakim et al., 2000; Nortvedt et al., 1999; McCabe & McKern, 2002) and qualitative literature (Irvine et al., 2009; Boeije et al., 2002; Edmonds et al., 2007; Irvine et al., 2009; Mohr et al., 1999; Finlayson et al., 2005; Somerset et al., 2002). Furthermore, qualitative study participants described a desire for additional support with psychological aspects of MS, discussed this as an unmet need, and supported the notion of the provision of formal adjustment interventions. Formal psychological interventions to promote improvement in a range of indicators of adjustment to MS therefore seem appropriate and acceptable to many patients.

A recent Cochrane review noted that future studies should seek to delineate who would benefit most from psychological interventions for MS and when in the disease trajectory interventions are most appropriate (Thomas et al., 2006). Thesis findings provide some relevant insights. For the most part, there was little evidence that disease status variables were predictors of current adjustment outcomes, or response to psychological interventions. Therefore it did not appear helpful to refer people to interventions on the basis of disease characteristics such as being newly-diagnosed, or having severe or active disease. The exception to this was that those patients with high EDSS scores were more likely to be

more functionally impaired than those with lower disability and tended to have better outcomes from CBT compared to SL. Regarding choice of therapy, moderation analysis of the saMS trial data showed that the presence of thoughts or behaviours known to be associated with undesirable adjustment outcomes, indicated suitability for CBT rather than a listening intervention. Therefore, screening for unhelpful beliefs and behaviours may be useful if a choice between different interventions types is available. The qualitative study of therapy experiences suggested that individual's readiness to engage in an intervention and perceptions of its current and future relevance appears to be a critical consideration when offering interventions.

Another important issue emerging from the thesis research was that various factors may make it difficult for pwMS to opt into and/or fully engage in adjustment-related interventions. The qualitative study of adjustment experiences revealed that pwMS can find thinking about becoming disabled, and imagining threatening future events extremely distressing and so this is sometimes carefully avoided. This may discourage participation in interventions that might touch on sensitive subjects or involve meeting other pwMS. Both qualitative studies also revealed a preoccupation with the need for positive thinking and the desire to demonstrate successful coping in some pwMS. This implies that some pwMS may find elements of interventions difficult, such as talking about past and present difficulties, negative emotions and negative thinking. In order to make psychological adjustment interventions acceptable to a wide range of pwMS it may be necessary to frame them in very positive, non-threatening and non-stigmatising way. Therapy elements which address negative thinking or which expose participants to thinking or talking about uncontrollable future losses may need to be particularly sensitively delivered.

Because adjustment to MS is a process involving ongoing change in response to a series of critical events (e.g. relapse, physical deterioration) it appears likely that interventions will be of most use if they promote long-term adaptive cognitions and behaviours. However, the qualitative study of intervention experiences, suggests that new skills or behaviours learned and started during psychological interventions require reinforcement and support once therapy has finished and the individual has to deal with subsequent MS-related difficulties. This may go some way to explaining results from the saMS trial which found that most benefits were not sustained at twelve month follow-up (Moss-Morris et al., 2011). Long-term reinforcement of skills and insights from adjustment interventions could be achieved through provision of materials (e.g. therapy manuals) or perhaps more effectively,

through booster sessions or follow-ups at opportune times. Finally, the qualitative study of interventions also revealed that issues of flexibility, convenience and consideration of MS symptoms and impairments are vital in allowing pwMS to capitalise on opportunities to improve adjustment and indicate ways in which interventions can be made appropriate for people with MS-related physical impairments.

8.4. Limitations and future directions

8.4.1. Methodological limitations of the research programme

8.4.1.1. Systematic review approach

The systematic review, as a starting point of this thesis, aimed to identify and critique existing research on links between adjustment outcomes in MS and modifiable psychological variables. Given these aims and the fact that this growing body of literature had not been previously reviewed the broad and liberal inclusion criteria were appropriate. However, this also resulted in a heterogeneous selection of studies to review, precluding an overall synthesis or the use of meta-analysis. Furthermore much of the primary research reviewed used small samples, cross-sectional designs and had design limitations which, although providing some preliminary evidence, make the review conclusions tentative. Eventually, there should be enough research to conduct more focused reviews on the roles of individual cognitive and behavioural variables, to limit review inclusion criteria to higher quality studies, and to conduct meta-analysis.

8.4.1.2. Statistical power

Low statistical power, especially for the moderation and mediation analyses is a weakness of the quantitative studies. Ideally, sample size should be calculated on the basis of the research design and expected effect size/s. In this case, however the sample sizes were determined by a power analysis for the primary outcomes in the saMS trial within which the thesis research was nested. Because of power issues, current results have to be interpreted with caution and replication of findings in adequately powered studies would be desirable.

8.4.1.3. Lack of change during the treatment trial

Another limitation concerns the analyses of treatment mechanisms when, unexpectedly, functional impairment and several CB variables did not change significantly more in CBT compared to SL. This meant that it was unclear whether some of the hypothesised mechanisms of adjustment were wrong or whether this was merely not evident because the CBT was not superior to SL in changing the mediator. Interpretation of individual studies of mediation within trials should be considered in light of evidence from other sources: cross-sectional, longitudinal studies and qualitative research in MS and in other chronic illnesses.

8.4.1.4. Qualitative data collection and analysis

Constraints on the timescale of the thesis research meant that it was not possible to conduct concurrent data collection and analysis. This is regrettable since sampling and collecting data in response to emerging themes and analytic ideas could have led to further insights and increased confidence in theorising about the themes and their relations. Understanding could also have been enhanced by studying participants at different intervals over time. This would have allowed important insights into changes over time and how adjustment unfolds in the context of relapses, disease progression, and increasing disability. Such research was beyond the scope of the existing thesis but would make a valuable future contribution.

8.4.1.5. Sampling

The empirical research succeeded in recruiting from both NHS and patient organisations and obtaining a varied sample in terms of demographic and disease characteristics. However, all samples were self-selected; and therefore possibly different in important ways from non-volunteers.

Little can be done to address the problem of research samples consisting of volunteers. However, future studies may be able to reduce biases due to sampling. A centralised register of pwMS in the UK would enable research information to be mailed to a representative sample, rather than relying on patients currently in contact with health professionals or patient organisations. Unfortunately, such a register does not currently exist. Additionally, simplifying information and consent procedures, for example through

reducing the amount of written detail on information sheets and having the researcher available in clinics to describe the research and answer questions may help to reduce reliance on particularly motivated individuals.

The thesis research specifically sampled people with early stage MS and without severe disease. This was valuable because this group has not been well studied compared to patients with later stage, more disabling MS. However, it also means that the research findings may be of less relevance to people in the latter category. Future research should examine the applicability of current conclusions to patients with longer disease duration and those at the more severe end of the disease spectrum.

Finally, since three of the empirical studies used samples from the saMS trial this restricted the samples to those meeting the trial inclusion criteria. and may have biased the sample towards people who want to change and/or who are experiencing more difficulties. Replication and extension of the current research findings in a broader population of pwMS is needed.

8.4.1.6. Self-report of disease status

Another limitation concerns the self-report of disease variables in all studies. Ideally participants would have seen a neurologist to confirm their MS type, disease severity and relapse status upon entry to the studies. Unfortunately, cost, time and participant burden, made this impossible. Although not ideal, self-reported disease data compares reasonably well to neurologist assessments (Bowen et al., 2001; Gulick, Cook, & Troiano, 1993; Ratzker et al., 1997).

8.4.1.7. Contribution of mixed methods research strategy

Use of both qualitative and quantitative methods allowed the phenomenon of adjustment to MS to be studied from various perspectives, each addressing slightly different research questions and building on other parts of the thesis. However, there might have been more effective ways of integrating the qualitative and quantitative research. For instance, completing the systematic review prior to designing the qualitative study of experiences of adjustment would have allowed the interview schedule to elicit information relevant to all elements of the model. It could also have guided theoretical sampling of participants, providing a more extensive way of triangulating findings. It may also have been useful to have concluded both the review and the first qualitative study before designing the

quantitative studies. This could have resulted in decisions to assess different variables as potential predictors or mechanisms of adjustment.

8.4.2. Recommendations for future research

In addition to the aforementioned methodological issues which future research should address where possible, the current research programme highlights numerous areas of interest for future research. Some of the key areas are outlined below.

8.4.2.1. Potentially important adjustment process variables

Illness perceptions and responses to symptoms were important correlates and mechanisms of change in two key domains of adjustment outcomes. These would therefore appear to be a useful focus for future research. The CBRSQ (Moss-Morris et al., 2011) seems a particularly useful measure to pursue in future research. If the role of reducing unhelpful responses to MS symptoms (such as catastrophising, avoidance of embarrassment, symptom-focusing) as mechanisms for reducing functional impairment is replicated, future studies could investigate effective ways of changing these. This thesis showed that symptom responses changed within an 8 week multi-component CBT intervention delivered one-to-one by a nurse-therapist. However, a shorter but more focused intervention might be suitable for addressing symptom responses if the goal was specifically to reduce functional impairment.

The finding that unhelpful beliefs about the self and about emotions are associated with distress and can be changed by interventions suggests that these variables are worth researching further. If further evidence suggests that these factors influence adjustment outcomes, ways to facilitate improvement in these variables could be pursued.

Several variables which emerged from the qualitative studies as potentially important require quantitative research to establish their pervasiveness and degree and consistency of relationship to adjustment outcomes. This includes knowledge about MS, social and communication skills, strategies for accommodation and assimilation, adjustment of goals and priorities, and issues around acceptance, avoidance and denial.

Finally, the pre-MS elements of the CB model which propose an influence of early experiences in developing core beliefs and influencing goals, behaviours and values, were not focused on in the current thesis research. Future research should seek to establish the impact of early experiences and pre-morbid cognitive and behavioural factors on the current cognitive and behavioural responses of pwMS, and their adjustment outcomes. The ideal research designs would be prospective; assessing individuals prior to the development of, or diagnosis of, MS and following them up over the course of the disease. However, given that MS is estimated to affect 100-140 in every 100,000 in the UK (Compston et al., 2005) this would require huge samples and significant resources and therefore be very challenging to research. Retrospective studies of early experiences and/or studies of people in the process of diagnosis may be able to go some way to establishing the importance of pre-MS psychological variables.

8.4.2.2. Development of measures of adjustment processes and outcomes

The investigation of some of the variables highlighted as potentially important in this thesis is hindered at present by the absence of existing measures that are applicable to the MS context. Future research could focus on constructing reliable and valid measures to capture these variables. Examples include illness-related communication and interpersonal skills, knowledge about MS and the extent to which people modify standards and priorities.

Acceptance was another factor that appeared to be important for understanding adjustment outcomes but was inadequately captured by available measures. Findings from this thesis suggested that the existing measures (e.g. Pakenham & Fleming, 2011; Stuifbergen, 2008), do not capture all of the complex issues surrounding acceptance in the context of MS for instance acceptance of current difficulties as part of life, acceptance of potential future losses of physical abilities, acceptance of a disabled/sick label or identity, acceptance of change in lifestyle, and the usefulness of maintaining a fighting spirit. A comprehensive measure designed specifically for pwMS would improve the ability of future research to uncover relationships between various different domains of acceptance and their (perhaps dissimilar) relationship to positive and negative adjustment outcomes.

Research attention could also be focused on developing tools to better capture MS adjustment outcomes. Many measures are available to assess a patient's current and/or recent emotional and social functioning and QoL. However, none of these seemed to capture the issue of 'precarious adjustment'. A measure that tapped 'precarious

adjustment' could be useful for identifying pwMS who may be at risk of negative outcomes in the future. An MS-specific measure which taps into a wider range of relevant adjustment outcomes would also be of use both clinically and in research.

8.4.2.3. Research methods

More good quality prospective research on the factors elucidated by this thesis, that appear to have a role in predicting or explaining adjustment outcomes is needed. Of particular importance would be research which tracks pwMS from time of diagnosis (or ideally, but practically very difficult, prior to diagnosis) over the course of the disease to better establish the course of adjustment and the CB variables involved. However, intervention research that modifies purported mechanisms and demonstrates a resulting improvement in adjustment outcome measures would provide the strongest evidence for the importance of CB variables. This type of research is currently scarce in the psychosocial MS literature and should be included in intervention studies where possible To get a fuller picture of change, potential mediators and outcomes should ideally be assessed pre, mid and post-therapy and at long-term follow-ups.

As the current thesis demonstrates, qualitative exploration of participants' experiences of interventions is a useful tool to begin to elucidate how and why people's adjustment outcomes change (or don't). Analysis of audio or video recordings of therapy sessions may also prove enlightening. Future use of inductive qualitative approaches as well as quantitative research is important, providing insights that might otherwise be overlooked, and helping to interpret quantitative findings and guide future research.

8.5. Conclusion

This research programme confirmed that adjustment to MS is a complex process with many influences. It also highlighted how it can follow different pathways for different individuals. No single existing theory adequately captures all relevant aspects, however, a broad cognitive behavioural model appears to be a useful way of understanding adjustment and guiding interventions to improve it.

This thesis demonstrated that successful adjustment to MS is multifactorial, incorporating a variety of psychosocial outcomes. A number of MS related events and experiences appear to trigger disruption to a person's equilibrium. However, the thesis found evidence that a

range of cognitions and behaviours have relevance to understanding whether individuals achieve positive or negative adjustment outcomes following a period of disruption. Specified cognitions and behaviours appear to have differential relationships to particular outcomes; negative illness-related beliefs and behaviours are more strongly related to functional impairment whereas unhelpful cognitions related to the self and related to dealing with negative emotions appear to influence emotional distress. By modifying cognitions and behaviours within interventions it appears that adjustment outcomes can be improved. This thesis has pinpointed a number of potential cognitions and behaviours which may be important targets for adjustment interventions. It has also provided insights into how interventions should be designed and delivered in order to be helpful and appropriate to pwMS. Continued research efforts to understand the most important factors that determine a range of adjustment outcomes and the most effective and appropriate ways to modify these should lead to better understanding of useful psychological interventions for pwMS.

Appendix A: Systematic review search terms

PsychINFO

1. exp Multiple Sclerosis/
2. exp Occupational Adjustment/ or exp Adjustment/ or exp Emotional Adjustment/ or exp Social Adjustment/
3. exp Adaptation/
4. exp Distress/
5. exp Anxiety/
6. exp "Quality of Life"/
7. exp Well Being/
8. "illness impact".mp.
9. "perceived functioning".mp.
10. "subjective functioning".mp.
11. "perceived impact".mp.
12. multiple sclerosis impact scale.mp.
13. "work and social adjustment scale".mp.
14. exp Self Report/
15. functioning.mp.
16. impairment.mp.
17. 15 or 16
18. 14 and 17
19. predict$.mp.
20. exp Risk Factors/
21. determin$.mp.
22. correlat$.mp.
23. exp Reactive Depression/ or exp Major Depression/ or exp "Depression (Emotion)"/
24. 19 or 20 or 21 or 22
25. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 18 or 23
26. 1 and 24 and 25
27. limit 26 to (english language and (original chapter or original journal article or reprinted chapter or reprinted journal article) and yr="1980 - 2007")

MEDLINE

1. exp Multiple Sclerosis/
2. emotional adjustment.mp.
3. psychosocial adjustment.mp.
4. psychological adjustment.mp.
5. occupational adjustment.mp.
6. exp Adaptation, Psychological/
7. exp Social Adjustment/
8. distress.mp.
9. exp Anxiety/
10. exp Depression/
11. exp "Quality of Life"/
12. wellbeing.mp.
13. "illness impact".mp.
14. "perceived functioning".mp.
15. "subjective functioning".mp.
16. "perceived impact".mp.
17. "multiple sclerosis impact scale".mp.

18. "work and social adjustment scale".mp.
19. exp "Self Assessment (Psychology)"/ or self report.mp.
20. functioning.mp.
21. impairment.mp.
22. 20 or 21
23. 19 and 22
24. exp Risk Factors/
25. determin$.mp.
26. predict$.mp.
27. correlat$.mp.
28. 24 or 25 or 26 or 27
29. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 23
30. 1 and 28 and 29
31. limit 30 to (english language and yr="1980 - 2007" and (journal article or technical report))

EMBASE
1. exp Multiple Sclerosis/
2. ADJUSTMENT/
3. psychological adjustment.mp.
4. psychosocial adjustment.mp.
5. emotional adjustment.mp.
6. occupational adjustment.mp. or Job Adaptation/
7. psychological adaptation.mp.
8. psychosocial adaptation.mp.
9. Social Adaptation/
10. distress.mp.
11. exp ANXIETY/
12. exp DEPRESSION/
13. exp "Quality of Life"/
14. exp WELLBEING/
15. "illness impact".mp.
16. "perceived functioning".mp.
17. "subjective functioning".mp.
18. "perceived impact".mp.
19. "multiple sclerosis impact scale".mp.
20. "work and social adjustment scale".mp.
21. exp Self Report/
22. functioning.mp.
23. impairment.mp.
24. 22 or 23
25. 21 and 24
26. predict$.mp.
27. Risk Factor/
28. determin$.mp.
29. correlat$.mp.
30. 26 or 27 or 28 or 29
31. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 25
32. 1 and 30 and 31
33. limit 32 to (english language and yr="1980 - 2006" and (article or journal or report))

CINAHL

1. exp Multiple Sclerosis/
2. exp SOCIAL ADJUSTMENT/
3. psychological adjustment.mp.
4. psychosocial adjustment.mp.
5. work adjustment.mp.
6. emotional adjustment.mp.
7. exp Adaptation, Psychological/
8. distress.mp.
9. exp DEPRESSION/
10. exp ANXIETY/
11. "Quality of Life"/
12. exp Psychological Wellbeing/ or wellbeing.mp.
13. "illness impact".mp.
14. "perceived functioning".mp.
15. "subjective functioning".mp.
16. "perceived impact".mp.
17. "multiple sclerosis impact scale".mp.
18. "work and social adjustment scale".mp.
19. exp Self Assessment/
20. functioning.mp.
21. impairment.mp.
22. 20 or 21
23. 19 and 22
24. exp Risk Factors/
25. determin$.mp. [mp=title, subject heading word, abstract, instrumentation]
26. predict$.mp.
27. correlat$.mp.
28. 24 or 25 or 26 or 27
29. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 23
30. 1 and 28 and 29
31. limit 30 to (english and yr="1980 - 2007" and (brief item or doctoral dissertation or journal article or masters thesis))

Web of Science

1. Multiple Sclerosis
2. Psychological adjustment
3. Emotional adjustment
4. Social adjustment
5. Occupational adjustment
6. Psychological adaptation
7. Quality of life
8. Wellbeing
9. Illness impact
10. Subjective functioning
11. Perceived impact
12. multiple sclerosis impact scale
13. work and social adjustment scale
14. self report
15. functioning

16. impairment
17. risk factor
18. determin*
19. correlat*
20. predict*
21. "perceived functioning"
22. depression
23. 15 or 16
24. 23 and 14
25. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 21 or 22 or 24 17 or 18 or 19 or 20
26. 1 and 25 and 26

Appendix B: Systematic review table of included studies

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
1	Aikens, Fischer, Namey, & Rudick (1997)	L	27/22	Perceived stress (Life Experiences Survey) Coping (Ways of Coping Questionnaire- Revised)
2	Arnett, Higginson, Voss, Randolph, & Grandey (2002)	C	55	Coping (COPE)
3	Arnett & Randolph (2006)	L	?/53	Coping (COPE)
4	Barnwell & Kavanagh (1997)	L	75/71	Self-efficacy (Self-efficacy for mood control and social activity scales)
5	Beatty et al. (1998)	C	43	Spirituality (Spiritual Perspective Scale) Coping (Ways of Coping Checklist)
6	Bruce, Polen, & Arnett (2007)	C	93	Affective memory biases (Affective Reading Span Task)
7	de Ridder, Schreurs, & Bensing (2000)	C	96	Optimism (Life Orientation Test) Coping (Coping Inventory for Stressful situations)
8	de Ridder, Fournier, & Bensing (2004)	L	50/?	Optimism (Revised Version of the Life Orientation Test, Comparative Risk Judgment Rating Form) Self-efficacy (Generalized Self-efficacy Scale)
9	Devins, Seland, Klein, Edworthy, & Saary (1993)	L	94 gave data at all time-points	Control (Control Ratings Scale)
10	Dupont (1996)	C	116	Acceptance of illness (Acceptance of Illness Scale)
11	Feinstein (2002)	C	140	Perceived stress (Social Stress and Support Interview) Social support (Social Stress and Support Interview)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
12	Fournier, de Ridder, & Bensing (1999)	C	73	Optimism (Optimism & Pessimism Scale, Optimism-Pessimism Prescreening Questionnaire, Comparative Risk Judgment Rating Forms, Forced-Choice Attributional Style Questionnaire, Life Orientation Test) Self-efficacy (Generalized self-efficacy Scale) Coping (Coping Inventory for Stressful Situations)
13	Fournier, de Ridder, & Bensing (2002)	C	98	Optimism(Comparative Risk Judgment Rating Forms, Revised version of the Life Orientation Test) Self-efficacy (Generalized Self-Efficacy Scale, Coping (Coping Inventory for Stressful Situations)
14	Gilchrist & Creed (1994)	C	24	Perceived stress (Social Stress and Support Interview) Social support (Social Stress and Support Interview)
15	Gold-Spink, Sher, & Theodos (2000)	C	18	Illness uncertainty (Uncertainty in Illness Scale) Optimism (Life Orientation Test)
16	Halligan & Reznikoff (1985)	C	60	Locus of control (Internal-External Scale)
17	Harrison, Stuifbergen, Adachi, & Becker (2004)	C	454	Acceptance of illness (Acceptance of illness Scale) Health promoting behaviors (Health Promoting Lifestyle Profile)
18	Hickey & Greene (1989)	C	45	Locus of control (Multidimensional Health Locus of Control) Coping (Focus of Coping Scale) Hopelessness (Beck Hopelessness Scale)
19	Jean, Beatty, Paul, & Mullins (1997)	C	74	Coping (Ways of Coping Checklist)
20	Jean, Paul, & Beatty (1999)	C	56	Coping (Ways of Coping Checklist)
21	Jopson & Moss-Morris (2003)	C	168	Illness representations (Illness Perceptions Questionnaire-Revised)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
22	Kneebone, Dunmore, & Evans (2003)	C	54	Helplessness regarding MS (MS Attitudes Index) Dysfunctional cognitions (Psychological Vulnerability Scale)
23	Kneebone & Dunmore (2004)	C	495	Attributional style (Attributional Style Questionnaire-Survey)
24	Korostil & Feinstein (2007)	C	140	Perceived stress (Social Stress and Support Interview) Social support (Social Stress and Support Interview)
25	Kroencke, Denney, & Lynch (2001)	C	166	Illness uncertainty (Uncertainty in Illness Scale) Coping (The Ways of Coping Questionnaire)
26	Lynch, Kroencke, & Denney (2001)	C	188	Hope (The Hope Scale) Illness uncertainty (The Uncertainty in Illness Scale) Coping (The Ways of Coping Questionnaire)
27	MacLeod & MacLeod (1998)	C	25	Personal control (Recovery Locus of Control)
28	Marks & Millard (1990)	C	31	Perceptions of family characteristics (Family Environment Scale) Perceived stress (Hassles and Uplifts Scale) Coping (Ways of Coping Checklist) Locus of control (Health Locus of Control Scale)
29	McCabe & McKern (2002)	C	381	Coping (Ways of Coping Questionnaire)
30	McCabe (2002)	C	381	Coping (Ways of Coping Questionnaire)
31	McCabe, McKern, McDonald, & Vowels (2003)	L	381/321	Coping (Ways of Coping Questionnaire)
32	McCabe, McKern, & McDonald (2004)	C	381	Coping (Ways of Coping Questionnaire) Social support (Social Support scale of World Health Organization Quality of Life-100 Scale)
33	McCabe & Di Battista (2004)	L	?/251	Coping (Ways of Coping Questionnaire)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
34	McCabe (2005)	L	243 gave data at all time-points	Coping (Ways of Coping Questionnaire)
35	McCabe & De Judicibus M. (2005)	C	113	Perceived stress (Economic Pressure Scale) Coping (Ways of Coping Questionnaire)
36	McCabe (2006)	L	381/283	Coping (Ways of Coping Questionnaire)
37	McIvor, Rikland, & Reznikoff (1984)	C	120	Social support (Perceived Social Support Inventory)
38	McNulty, Livneh, & Wilson (2004)	C	50	Illness uncertainty (Uncertainty in Illness Scale) Spirituality (Spiritual Wellbeing Scale)
39	Mohr, Goodkin, Gatto, & Van der Wende (1997)	C	101	Coping (Ways of Coping Inventory)
40	Mohr et al. (1999)	C	94	Coping (Ways of Coping Inventory)
41	Mullins et al. (2001)	C	78	Illness uncertainty (Uncertainty in Illness Scale)
42	Noy et al. (1995)	C	20	Denial (Hackett-Cassem Scale)
43	Osborne, Jensen, Ehde, Hanley, & Kraft (2007)	C	125	Pain coping (The Chronic Pain Coping Inventory) Catastrophising (Catastrophising scale or the Coping Strategies Questionnaire) Pain beliefs (Survey of Pain Attitudes) Social support (Multidimensional Scale of Perceived Social Support)
44	Pakenham, Stewart, & Rogers (1997)	C	122	Appraisal (Folkman Appraisal Scales) Coping strategies (Ways of Coping Checklist- Revised)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
45	Pakenham (1999)	L	122/96	Perceived stress (modified version of Social Readjustment Rating Scale) Appraisal (Folkman Appraisal Scales) Coping (Ways of Coping Checklist Revised) Social Support (Zich and Temoshok's Social Support Scale)
46	Pakenham (2001)	C	113	Coping (Coping with MS Scale)
47	Pakenham, (2005a)	C	404	Benefit-finding (Mohr's Benefit-finding Subscale)
48	Pakenham, (2005b)	C	222	Benefit-finding (Mohr's Benefit-finding Subscale)
49	Pakenham (2006)	L	502/404	Coping (Coping with MS Scale) Benefit-finding (Mohr's Benefit-finding Subscale)
50	Patten, Metz, & Reimer (2000)	C	136	Perceived Stress (Canadian National Population Health Survey) Social support (Canadian National Population Health Survey)
51	Patten & Metz (2002)	C	632	Hopelessness (Beck Hopelessness Scale)
52	Riazi, Thompson, & Hobart (2004)	L	89/89	Self-efficacy (MS Self Efficacy Scale)
53	Ron & Logsdail (1989)	C	116	Social support (Social Support and Stress Interview) Perceived stress (Social Support and Stress Interview)
54	Rumrill, Jr., Roessler, & Fitzgerald (2004)	C	1310	Perceived stress (Perceived Stress Scale)
55	Schiaffino, Shawaryn, & Blum (1998)	L	?/66	Illness representations (Implicit Models of Illness Questionnaire)
56	Schwartz & Frohner (2005)	C	69	Social support (Social Support Scale of the MS Quality of Life Inventory)
57	Schwartz & Kraft (1999)	C	44	Social support (Social Provisions Scale) Perceived partner responses to disability (Spouse Response Inventory) Perceived family environment (Family Environment Scale)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
58	Shnek, Foley, LaRocca, Smith, & Halper (1995)	C	80	Learned helplessness (MS Attitudes Scale) Self-efficacy (MS Beliefs Scale) Cognitive distortions (Cognitive Beliefs Questionnaire)
59	Shnek et al. (1997)	C	80	Learned Helplessness (MS Attitudes Scale) Self-efficacy (MS Beliefs Scale) Cognitive distortions (Cognitive Beliefs Questionnaire)
60	Skerrett & Moss-Morris (2006)	C	149	Cognitive and behavioural responses to symptoms (Cognitive and Behavioral Responses to Symptoms Questionnaire)
61	Stuifbergen (1995)	C	61	Social Support (The Interpersonal Relationship Inventory) Relationship characteristics (The Interpersonal Relationship Inventory) Self-efficacy (Self-Efficacy Scale, Self-rated Abilities for Health Practices Scale) Perceived stress (Demands of Illness Inventory) Health-promoting behavior (Health Promoting Lifestyle Profile) Perceived barriers to health behaviors (Barriers to Health Promoting Activities for Disabled Persons Scale)
62	Stuifbergen, Seraphine, & Roberts (2000)	C	786	Social Support (The Interpersonal Relationship Inventory) Self-efficacy (Self-rated Abilities for Health Practices Scale) Health-promoting behavior (Health Promoting Lifestyle Profile) Perceived barriers to health behaviors (Barriers to Health Promoting Activities for Disabled Persons Scale)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
63	Stuifbergen, Blozis, Harrison, & Becker (2006)	L	621 at Time 1/560 at all time-points	Health-promoting behavior (Health Promoting Lifestyle Profile- exercise/physical activity subscale)
64	Taillefer, Kirmayer, Robbins, & Lasry (2002)	C	40	Symptom attribution (Symptom Interpretation Questionnaire) Hypochondriac beliefs (Illness Behavior Questionnaire)
65	te Wildt & Schultz-Venrath (2004)	C	94	Magical ideation (Magical Ideation Scale)
66	van der Werf, Evers, Jongen, & Bleijenberg (2003)	C	89	Neuroticism (Eysenck Personality Questionnaire) Helplessness (Illness Cognition Questionnaire)
67	Wassem (1992)	C	62	Self-efficacy (Self-efficacy for adjustment behaviors scale) Outcome expectancies (Outcome expectancy scale)
68	Wineman (1990)	C	118	Social support (Social Network List and Support System Scale) Illness uncertainty (Mishel Uncertainty in Illness Scale)
69	Wineman, O'Brien, Nealon, & Kaskel (1993)	C	61	Illness uncertainty (Mishel Uncertainty in Illness Scale)
70	Wineman, Durand, & Steiner (1994)	C	433	Appraisal (Appraisal Scale) Coping (Ways of Coping Checklist) Illness uncertainty (Mishel Uncertainty in Illness Scale)
71	Wineman, Schwetz, Goodkin, & Rudick (1996)	C	59	Illness uncertainty (Mishel Uncertainty in Illness Scale) Coping (Jalowiec Coping Scale)
72	Zeldow & Pavlou (1988)	C	81	Personality traits (California Psychology Inventory)

[a]Studies are classified as longitudinal if at least some relevant analyses include longitudinal data. If overall study design is longitudinal but analyses of interest are based on cross-sectional data; studies are classified as cross-sectional.

[b] Where applicable, sample size figures are given for different time-points (Time 1/Time 2/Time 3)

Appendix C: Systematic review update table of included studies

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
73	Aarstad, Lode, Larsen, Bru, & Aarstad (2010)	C	86	Coping (COPE)
74	Arden-Close, Moss-Morris, Dennison, Bayne, & Gidron, (2010)	C	64	Illness-related Couple communication (Couples Illness Commuinication Scale)
75	Bambara, Turner, Williams, & Haselkorn (2010)	C	451	Perceived Social support (Medical Outcomes Study Modified Social Support Scale)
76	Bamer, Cetin, Johnson, Gibbons, & Ehde (2008)	C	1268	Perceived Social Support (Modified Social Supoprt Survey)
77	Beeney & Arnett (2008)	C	93	Memory bias (Affective Reading Span Task)
78	Bodini et al. (2008)	C	58	Alexithemia (20-item Toronto Alexithymia Scale)
79	Brajkovic et al. (2009)	C	68	Coping (COPE)
80	Brown et al. (2009)	L	101 at baseline 74 and 96 had data for the different longitudinal analyses	Stressors (Life events and difficulties schedule) Coping (Ways of Coping Questionnaire) Optimism (Life orientation test) Health locus of control (multidimensional health locus of control scale) Social support (Sarason social support questionnaire) Health behaviours (Health behaviour questionnaire)
81	Chalk (2007)	C	329	Coping (Coping with MS Scale) Cognitive appraisals (Cognitive appraisal of illness scale) Social Support (Social Support Questionnaire)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
82	de Groot et al. (2008)	L	156 had data at all time points	Perceived Social Support (Social Support List Discepancies) Locus of control (Multidimensional health LOC scale) Personality traits (Eysenck Personality Questionnaire; neuroticism, psychoticism and extraversion subscales)
83	Douglas, Wollin, & Windsor (2008)	C	105	Pain beleifs (Pain beliefs and perceptions inventory) Pain coping strategies (Pain coping strategies questionnaire)
84	Gay (2010)	C	115	Alexithymia (Toronto Alexithymia Scale Coping (Coping about Health Injuries and Problems) Social Support (SSQ-6)
85	Hart, Vella, & Mohr (2008)	L	127 had data for both time points	Benefit-finding (Stress-Related Growth Scale) Optimism (Life Orientation Test—Revised;)
86	Jaracz et al. (2010)	C	210	Social support (Social Provisions Scale)
87	Johnson, Terrell, Sargent, & Kaufman (2007)	C	44	Stress and Social Resources (Life Stressors and Social Resources Inventory Adult Form)
88	Kindrat (2007)	C	30	Body image (Body-Image Ideals Questionnaire)
89	Krokavcova et al. (2008b)	C	207	Social support (perceived social support scale)
90	Krokavcova et al., 2008a)	C	203	Mastery (Pearlin–Schooler Mastery Scale)
91	Lester, Stepleman, & Hughes, (2007)	C	82	Self-efficacy for MS management (Self-Efficacy for Managing Chronic Disease)
92	McCabe & O'Connor, (2009)	C	77	Economic pressure(economic pressure scale).

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
93	Moreau, Schmidt, Joyeux, Bungener, & Souvignet (2009)	C	255	Coping (Coping Inventory for Stressful Situations)
94	Motl, McAuley, Snook &, Gliottoni (2008)	C	292	Physical activity (accelometer and Godin Leisure-Time Exercise Questionnaire)
95	Neter, Litvak, & Miller (2009)	C	101	Goal disengagement/reengagement (Wrosch's goal tendency questionnaire) Illness perceptions (IPQ)
96	Pakenham & Cox (2009)	L	388 provided data at both time points	Benefit-finding (67-item BFiMSS).
97	Pakenham & Fleming (2011)	L	128 provided data at both time points	Acceptance (MSAQ)
98	Phillips et al., (2009)	C	86	Emotional regulation strategies (ERQ):
99	Phillips & Stuifbergen (2009)	C	118	Social Support (3 scales of the Personal Resources Questionnaire)
100	Rabinowitz & Arnett (2009)	L	53	Coping (COPE)
101	Ryan et al. (2007)	C	74	Social support (social provision scale)
102	Spain, Tubridy, Kilpatrick, Adams, & Holmes (2007)	C	580	Illness perception (BIPQ)
103	(Stepleman et al., 2010)	C	199	Patient Activation (PAM-13) Self-efficacy (MSSE)
104	(Stroud & Minahan, 2009)	C	121	Physical activity (IPAQ)

Study reference	Study (first author/date)	Design[a]	N[b]	Psychological factors examined (measures used)
105	(Stuifbergen, Brown, & Phillips, 2009)	C	442	Health promoting behaviours (Health Promoting Lifestyle Profile) Perceived barriers to health behaviors (Barriers to Health Promoting Activities for Disabled Persons Scale)
106	(Suh, Motl, & Mohr, 2010)	C	96	Physical activity (accelorometer)
107	(Tyszka & Farber, 2010)	C	48	Health Promoting Behaviours [HPLP–II]
108	Vargas & Arnett (2010)	C	90	Social Support Questionnaire (SSQ), Hassles and Uplifts Scale (HUS) Memory bias (Affective Reading Span Task)
109	(Yorkston et al., 2008)	C	112	Self-efficacy (28 item self-efficacy for participation in life activities questionnaire)
110	(Ytterberg, Johansson, Holmqvist, & Koch, 2008)	L	219 had data at all time points	Sense of coherence (13 item SOC scale)

Appendix D Participant information sheet for Chapter 4

DATE: 2 February 2007
VERSION NUMBER: 2

Participant Information Sheet

RCT of CBT and supportive listening for adjustment to multiple sclerosis (Ref 07/MRE12/6)

STUDY 1: PATIENTS' EXPERIENCES OF MULTIPLE SCLEROSIS:
AN INTERVIEW STUDY

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

Who is conducting the study?
This study is part of a larger research project which is being conducted by researchers at Southampton University, The Institute of Psychiatry at King's College and local MS services. The lead Investigators are Dr Rona Moss-Morris, Professor Lucy Yardley and Professor Trudie Chalder.

This phase of the research will be conducted by a Postgraduate student in Health Psychology under the supervision of the Lead Investigators. Some of the data from this study will be written up as part of an MSc thesis.

What is the purpose of the study?
Research has shown that MS can be a particularly difficult illness for people to adjust to. For example, coping with the uncertainty and unpredictability of MS, unpleasant symptoms, taking medication, and changes to lifestyle can all be challenging. A research project is taking place where a new type of therapy is being developed to help people adjust to the diagnosis and experience of Multiple Sclerosis.

As part of this project the researchers want to talk to people with MS to find out about the issues that are important to them.

Why have I been chosen?
You have been approached about this study because you have Multiple Sclerosis and have been diagnosed within the last eight years.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. Whether or not you take part will not affect the standard of care you receive.

What will happen to me if I take part?
If you agree to take part a member of the research team will contact you. They will arrange with you a convenient time to conduct an interview on the telephone. The interview will last somewhere between 30 minutes and one hour. The interviewer will not be part of the team involved in your treatment. They ask you some questions about how you feel about your MS, how it affects your life, how you cope, and what sort of support you find helpful. There are no right or wrong answers- the researchers want to find out about your views and experiences. The interview will be recorded so that the researchers can write it up and study it at a later date.

Expenses and payments
Unfortunately we are not able to pay you for your participation.
The research will take between 30 minutes and one hour of your time but there are no costs to participants associated with the project.

What are the possible disadvantages and risks of taking part?
It is possible that some people might find it distressing to talk about their experiences with MS. If you get upset you can skip questions, take a break or decide not to continue with the interview. If you are very distressed we will offer you some sources of support. .

What are the possible benefits of taking part?
There may not be any immediate or direct benefits to yourself. However, some people may find it helpful or interesting to talk about their illness and how it affects them. Your participation will help us to develop a better idea of how we can help people with MS.

What if there is a problem?
In the unlikely event that you are unhappy with the way that the research is conducted the Southampton University complaint mechanisms are open to you. The person to contact in this regard is Caroline Allee, Manager of the School of Psychology (tel. 02380 593995, email callee@soton.ac.uk).

Will my taking part in the study be kept confidential?

- Yes. All the information about your participation in this study will be kept confidential. The procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998. After the interview your name will be swapped for a participant ID number (e.g. on the audiotape of the interview and the interview transcript). Information about you will be stored securely and will be available only to members of the research team. It will be used only for the purposes of the current study. Data from this study will be retained for 10 years and subsequently disposed of securely.

- When the study is written up and published we will use some quotes from interviews as examples of what people have said. If we use any extracts from your interview they will not contain your name or anything that identifies you as an individual (e.g. your town or workplace)

What will happen if I don't want to carry on with the study?
If you decide to take part you are still free to withdraw from the study at any time without having to give a reason.

What will happen to the results of the research study?
The results will be used to help the researchers develop an intervention to help people adjust to MS. The study may also be written up for publication in scientific journals and may be presented at scientific conferences.
If you would like to know the results you can be provided with a summary sheet.

Who is organising and funding the research?
The research is being funded by the Multiple Sclerosis Society. It is being organised and conducted by researchers from Southampton University, Southampton University Hospitals NHS Trust, The Institute of Psychiatry, King's College, and King's College Hospitals.

Who has reviewed the study?
The study has been reviewed by the Thames Valley Multi-Centre Research Ethics Committee and the UK Multiple Sclerosis Society.

Contact details for further information

If you would like to discuss your potential involvement in this research further please contact:

Name: Miss Laura Dennison
Job title: Trial Co-ordinator
Telephone number: 02380 597657
Email address: L.K.Dennison@soton.ac.uk
Address: Department of Psychology, Shackleton Building, University of Southampton, Highfield Campus, Southampton, SO17 1BJ

ALTERNATIVELY: Fill in the attached contact details form, return it in a stamped addressed envelope and one of the researchers will contact you

Please retain this information sheet.

If, after discussing the research with us, you decide that you wish to participate we will ask you to complete and return a consent form. You will get a copy of the consent form to keep.

Thank you for taking time to read this information sheet.

Appendix E: Contact details sheet for Chapter 4

Contact details form

RCT of CBT and supportive listening for adjustment to multiple sclerosis (Ref 07/MRE12/6)

STUDY 1a:

PATIENTS' EXPERIENCES OF MULTIPLE SCLEROSIS: AN INTERVIEW STUDY

Please complete this form if you think you might be interested in taking part in this study.

I agree to a researcher from Southampton University contacting me to discuss my potential involvement in this research project ☐

I understand that by giving my name and contact details I am not obliged to take part ☐

Name: _____

Telephone number/s: 1) _____

2) _____

Best days/times to contact me

_____

_____

Email address (if checked regularly): _____

This personal information will be used ONLY for the purposes of contacting you about this study.

Please return this form to us in the stamped addressed envelope provided

Appendix F: Consent form for Chapter 4

DATE: 2 February 2007 VERSION NUMBER: 2
Participant Identification Number for this study:

CONSENT FORM

RCT of CBT and supportive listening for adjustment to multiple sclerosis (Ref 07/MRE12/6)
STUDY 1: PATIENTS' EXPERIENCES OF MULTIPLE SCLEROSIS:
AN INTERVIEW STUDY

Name of Researcher: _____

Please initial

1. I confirm that I have read and understand the information sheet dated .....(version .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

4. I give permission for the interview I take part in to be audiotaped

5. I understand that when the research is published it may include direct quotations from my interview but that I will not be identified as an individual

6. I agree to take part in the above study

Name of Participant_____Date_____Signature_____

Name of Person taking consent_____Date_____Signature_____
(If different from reseeracher)

Researcher_____Date_____Signature_____

When completed, 1 for patient; 1 for researcher site file

Appendix G: Interview schedule for Chapter 4

- Re-introduce self and purpose of call.
- Check participant is comfortable and okay to talk.
- Chat to build rapport.
- Introduce self and role to the participant explaining role as a student and framing them as the expert.
- Stress confidentiality and anonymity.
- Emphasise that there are no right or wrong answers.
- Remind that they are being recorded and put them at ease with this.
- Ask if they have any questions
- Give following introduction:

Thank you very much for agreeing to take part in this interview. Remember that if at any time you decide you do not want to carry on then just say so and we will stop the interview at once.

We are carrying out these interviews to find out what are the main concerns and problems faced by people in the first few years of having MS, and what they find helpful. We will use these interviews to design a programme of support to help people with MS tackle the issues and problems that may arise. We realise that everyone's experience will be different, and we are interested in finding out what is important to you.

Questions

Section A
Can you start by telling me all about what you thought and felt when you were first diagnosed with MS?

Prompts:
- What were the main issues that concerned you?
- What other problems did you have? (explore symptoms, concerns, feelings, practical problems, social difficulties with family, friends, others)
- What did you do to cope with that? (about each issue identified)
- Was there anything you found helpful/unhelpful? (relating to each issue identified)
- Can you give me an example?

Can you tell me all about what you think and feel about having MS now?

Prompts:
- What do you feel are the main issues that concern you now?
- What other problems do you have? (explore symptoms, concerns, feelings, practical problems, social difficulties with family, friends, others)
- What do you do to cope with that? (about each issue identified)

- Is there anything you find helpful/unhelpful? (relating to each issue identified)
- Can you give me an example?

Section B
What problems or concerns do you think we need to address in our programme of support?

Can you suggest any ways of dealing with these problems/concerns?

Is there anything you wish to add?

- End the interview
- Go through demographic questionnaire
- Turn off tape recorder
- Debrief, offer hard copy of debrief and summary of results.
- Thank them for their help.

Appendix H: Coding manual for Chapter 4

Context The context or starting points from which the adjustment process takes place		
Theme label	**Explanation**	**Illustrative quotes**
The black picture	First/early thoughts of MS are much more extreme than later thoughts. Typically includes fear and horror at thought of being in wheelchair and the loss of independence that brings. Thoughts of death due to MS. Worst case scenarios are imagined. Over time, and with exposure to more information, these initial thoughts and images are altered or toned down.	But it was a bit scary, 'cos you think of MS and you think of, sort of, being in a wheelchair.[P10] I think, well the first thing the consultant said to me was, 'This doesn't mean you're going to end up in a wheelchair', which was very helpful, 'cos that was almost my first thought. [P12] I think he could have given me a little bit more information about MS, because like I say, I mean he asked me 'Do I know anything about it?' and I said 'Well, all I… I'm fairly sure it can be quite debilitating' and he said 'Yeah, it can.' But he didn't say, 'But on the other hand, it might not'. Erm… all I had was the black picture. [P7] when the lumbar puncture results came back, erm, it was confirmed that I had MS. And erm, it was shocking. I, I, didn't actually quite know what to think of it. I, I thought that the world had ended for me. [P15] Well the first thing I thought of when I was diagnosed was, 'Oh God, I'm going to be in a wheelchair', and that was all I could see. And… I think that's what initially concerned me, was the fact that er my life as I knew it would be over and er, that I'd end up in a wheelchair. But er as time went on, I learned that was not necessarily the case. [P31] And I had this picture of me being in the wheelchair and him buggering off out, you know, and leaving me all the time, you know. And I felt like I was gonna, I just had this picture of me being trapped, you know. [P18]
Abandoned at diagnosis	Little formal support, information or direction following diagnosis. People report feeling abandoned by a health system that has little/nothing to offer. This is perceived as impacting on negative emotions and is a difficult start for adjustment.	Because you're sort of left, you know, you go and have your tests, and someone says, 'Yes, you've got MS', and then you're left completely on your own. Erm… you know, they don't sort of follow you up at all then. So, I was sort of left with this, sort of, erm, it was very [crying]……[P9] I said, 'You have to answer some questions for me. I have got an incurable illness which will only get worse, and what's more you don't have any help for me, so we're on our own, is that right?' And he reluctantly admitted that that was true [P1] 'Right your MRI shows you've got erm, multiple sclerosis. Any questions?' And my wife said, 'Well, you know, what about driving? What about work?' 'Well, you know, do whatever you want. We'll

		support you and we'll see you in 4 months'. So that was it. So… it was a very difficult sort of time. [P6]
Feeling overwhelmed	The typical Initial reaction after diagnosis- don't fully understand, shocked, overwhelmed and bewildered. Negative emotions and unanswered questions abound. People sometimes withdraw temporarily from interacting with the outside world, including avoiding information about MS. Time taken before a realistic and accurate picture built up and understanding sinks in. This bewilderment appears to be (to a greater or lesser extent) a short-term experience that dies down as more is found out about MS and how to manage it	But I got it sort of very straight from the consultant. It was very similar to being, sitting on a bar stool and being knocked off backwards really. Disbelief, shock, and erm… before I could recover myself, I suppose, I was quite emotional. P1] Erm… probably a bit of confusion. A bit of, erm… I don't know. I didn't understand it at all. I've never heard, I'd never heard of the disease before and it was just a quick consultation and erm… It just, erm, all he said was, 'Your circumstances will change. Your life won't be completely sure anymore. It'll be fluctuating.' And I didn't quite understand. So I went away and just cried a bit, really and… tried to understand what it was, you know…….[P17] I didn't actually tell my family straightaway because it was difficult enough for me to understand, to fully comprehend what it meant to suffer, or to be diagnosed as, as having multiple sclerosis. [P22] And it's just overwhelming. You're thinking… I mean, this a lot to take in, never mind to try and understand. Take in and then think how it's going to affect you. [P19] Erm… so I just came back here, erm came back home and sort of sat on the sofa and tried to [laughs] take it in really. But it was, it was erm, there were some very dark days for the next few months. I was very low. [P7] I thought that the world had ended for me. And erm, straight, straight away was, you know, the five steps of grievances. You know, I had denial, I had, you know, anger, and eventually I think I got really depressed. Erm… and I mean, I, I'm, I, and then… so I was diagnosed in June, and then by the end of January 2005, my neurologist had put me on anti-depressants. [P15] 'Well okay we've got the knowledge, you know, we've got the background. We know how things work and so on. How the hell do people who don't know these things go on?', you know. So it was horrendous. I mean the first sort of 6 months going along those lines were horrendous. [P26]

Importance of diagnosis	Although shocking and devastating a diagnosis (usually in the context of lengthy unexplained symptoms and long period of seeking medical attention) offers an explanation or answers for what has been going on with one's body. Diagnosis can bring some positive aspects with it including relief, hope for useful medical or non-medical interventions, obtaining more helpful and considerate responses from others. It validates the persons experiences and means that people feel that having and showing symptoms and difficulties is more acceptable Because the diagnosis offers a label for the experience it is often the starting point for exploring management strategies.	And it's also easier in terms of dealing with friends and family, because when you are having a tired day, you're not just being soft. You're not being pathetic. You're not being weak. You're not being stupid. It's very real. And they'll accept it now rather than push you erm……[P8] I didn't know what was wrong with me and it would have been easier if they'd told me what was wrong with me a lot earlier. [P5] I was still in the stage of mystery, so I think it made me [laughs] feel awful about myself really, that I was kind of erm… crumbling a bit and failing to do what I was normally doing [P14] Once I was diagnosed, it meant that I could actually access Disability Living Allowance and get a blue badge and the like, which have been, which are important [P30]

Process

Descriptions of the process of adjusting to MS

Theme label	**Explanation**	**Illustrative quotes**
Takes time	Getting used to living with MS (in terms of the emotional side of things and acceptance of changes rather than practical changes) is a process that takes time. It is taken for granted that this does not happen overnight.	And it did take a couple of years I think, to get to this stage of… of being able to manage practically and being able to manage emotionally……[P6] I suppose since, in the five and a bit years, I suppose, because I've become more, erm……. I, I don't know, I, I'm sort of not accepting of it, though I suppose you have to be accepting, because there's bugger all you can do about it, erm, but more used to it. [P12] [diagnosis] So it was as sort of slow, a bit of a slow business. You know, it was, it wasn't, and then it wasn't, and then it was. So I had a bit of time to get used to the idea, if you like.[P31] Interviewer: How did you cope with that? Erm… I don't know if you do for a while. I don't know… My dad had a stroke and I read that you have to grieve for the person you were. And I kind of adapted that to my illness. I thought, 'Well I have to grieve for that person'. So you go through that process and you kind of realise what you have and carry on. It's kind of an inner strength you kind of get after a while. I don't know… it's one of those… I don't know if everyone has it, it's just something…[P17] I have the confidence now to know that I can deal with it as it comes now. That I have the strength, the inner strength to say, 'Right, okay, whatever happens, we'll deal with it'. Which is pretty much where my husband wanted me to be when I was diagnosed, but er, unfortunately things don't happen overnight, do they, so…… yeah. [P27]

		I think, er the time of diagnosis and follow up for the next year or two, because it takes a lot of time to adjust to it.[P16]
Stages	People express the idea of moving through stages with time. It is deemed inevitability that there will be negative emotions and struggles during some (early) stages, and that people will differ from each other in how and when they move through these stages.	So I've been through everything, relief, depression, feeling sorry for myself, erm anger…[P27] So it happened, yeah, I went through the, sort of like the, the, I think they say you go through different stages of anger and denial. That for me was a very short time, I think. So, sort of yeah, just took the attitude of 'get on with it'…[P4]
Good days/bad days	Adjustment fluctuates from day-to-day. Emotional responses and thoughts about MS are variable from day-to-day, and dependent on shifts in factors such as symptoms and life stresses. Participants normalize feeling low from time to time (bad days) and feeling better on others (good days).	So erm, yeah, at the moment it's erm, having MS is a big thing at the moment with me. But you know, there are some periods where it's not as bad… not as big a thing in my life, so, but at the moment, yes it is…… [P9] You can get depressed with it. But, there are, I certainly have down days, erm……. when, you know, you get this dreadful tiredness, so you know, everything is an effort. [P13] Some of it paints such an awful picture, 'This is the worst that can ever happen', sort of thing. Erm… on a bad that's how you feel. On a good day, you think there's a lot of people worse off than you, you know, and you have to keep reminding yourself of that. [P28] Erm…… I have good days and bad days like everybody else. [P28] I get black, black moments. I mean, who wouldn't, you know. And I get times when I've felt really is life worth going on and then, but they're momentary and they're not depression and I, I do work with people through the [ ] that I know what it is and it's a different thing, you know. [P9]
Critical incidents	Adjustment is often associated with key, memorable incidents which prompt or force making changes by making people realize that some sort of change is necessary in order to accommodate MS problems. People rarely make changes to their behaviour (e.g. using aids, asking for help) until it becomes apparent that it is necessary.	The two incidents of me driving the car [laughs] and falling came in the same week. Erm, and about three weeks later, erm, I, I had a stick, I've got a stick. [P12] Im okay with it now. I think, I think as time goes on it's always going to be a learning curve, because different things are going to happen at different times and… yeah it's a… it's like sort of coming to grips with using a walking stick. [P31] Erm… so yes, when different things happen [sighs] sometimes it's harder to accept some of those aspects than it is others. [P31] I went back to work, carried on working for a while. I had a few falls and trips at work. I ended up falling against a large metal post, I was a supermarket manager at the time, which involved a lot of hours and erm… controlling a lot of staff and whatever else… erm… and cracked a couple of ribs, and so decided there and then to stop work and went sick. And then my area manager was very good, he was my, what they call a sponsor, and put me through for health retirement. [P4] I had to go out at half past eight and try and stop a neighbour to er, put a lightbulb in for me, you know [laughs]. I was plunged into darkness and I didn't know what to do, you know. But it, it can be a bit, a bit worrying. Erm… and I'm wondering now whether I, whether basically, it's hard to get to grips with, but

		whether I'd be better in a, erm, perhaps in a small flat or bungalow for people over, you know, over 55, or over 60 [P16].
Intolerable intrusions	The adjustment process is interrupted/fuelled/made difficult by situations where MS challenges key valued aspects of normal life. Often what is most difficult to deal with are where MS causes a loss of freedom, independence or dignity or challenges the person's view of themselves (e.g. as breadwinner, mother, healthy fit person). This brings about negative emotional reactions- anger, sadness, grief Certain threats or actual losses perceived as unacceptable or intolerable and the patient foresees that he/she would not be able to cope with it or adapt to it - loss of ability to walk, drive, work Interestingly there is no example of where somebody truly is unable to tolerate anything that they come up against, however difficult it is for them	Erm… er… ending up in a wheelchair I think. Erm… that is, and it still is now, that's the worst case, that is. It couldn't get any worse than that. [P7] I won't like that if I'm having to be cared for as it were. Sort of, I won't… yeah, I think I'll have trouble accepting it…[P4] I use a wheelchair. It's out in the garage and I use it… erm. I don't use it locally… erm… to go on holiday or away from home or anything. But if I was having to use it all the time, I'd find that very difficult. And… yeah, it's anything where I wasn't independent. 'Cos I like to be independent. If anything took my independence away…[P4] And I've just lost that post because I'm not practising in the other way. They are, they are kind of married and tied together, if you see what I mean. So, erm, the one thing I could do, that I was holding onto, I've just recently lost, so that's been really hard and really sad for me. Interviewer: I was going to say, how does that make you feel, but…? Devastated. Completely devastated.[P14] Erm… so yes, when different things happen [sighs] sometimes it's harder to accept some of those aspects than it is others. [P31]
Precarious adjustment	Participants suggest that feeling OK about MS and getting on with life in an acceptable way might only be possible in the context of no relapse/severe/permanent symptoms (i.e. precarious adjustment contingent on good current and future health).	It is a practical problem, but if you have a few strategies in place to deal with it then it is manageable. But the symptoms I know are progressing slowly, but it is nothing dramatic and it is nothing life threatening and it's something that I can manage. [P6] I think it's because I've been relapse free for, for so long. Erm… you know, if I'd have had a relapse like that every 6 months, I would be thinking differently, I'm sure. [P7] I've just got used to it and I've just learned to live with it really. I don't erm… I can't really say. Sometimes opening bottles is a pain, 'cos its quite erm, not sore, but its tingly sometimes. I found that quite… But nothing majorly that affected my life, no.[P2] I'm okay with it, I, so long as it doesn't get any worse. Erm… you know I can do a little bit, erm… but I, I… so long as I can keep going, that's all I want really. [P7]
Resources Factors deemed to be helpful/unhelpful in aiding adjustment		
Having help at hand	Beneficial to have people available to offer help. This includes practical or physical assistance and advice. When available this is seen to	Erm… having an MS nurse is brilliant, 'cos you don't wanna bother the doctor. And also my doctor doesn't know a lot about MS, so she relies on my MS nurse. If I tend to have an attack, I phone my MS nurse and then my MS nurse will phone or fax my doctor. [P7]

	make coping with MS easier. When lacking it is a frustration and makes day-to-day life harder.	And then they sort of put me on the system and after that it was absolutely brilliant. They, yeah, I couldn't have asked for better people, erm, but that first initial thing was, yeah, was horrendous. Erm, but the other [crying]……[P9] Somehow people have got to be told where they can turn for the day-to-day practical help and advice. Because I must say, as soon as I met [ ] who's our nurse here, I mean, I sort of, a lot of my black cloud lifted, because I thought, 'Well there is somebody there that I can either phone or I can email to', and I've done both of those over the past year. [P13] It's the ones who sort of are over helpful, try to help but end up in the way, interfering or… yeah, just being over supportive. [P4] Well, general public can be very helpful sometimes. I, I have had, when I've been out shopping, they say, 'Oh can we give you a hand', or give up like the bus seats, you know. You get on a bus and they say, 'Do you wanna sit here? [P21]
Having support	Participants think it is helpful, or even vital to have an adequate support system around you. This is typically cited as the most helpful thing in living with MS. Participants refer to support consisting of; talking, being understood and cared about, with the right balance of sympathy (too much can be unhelpful). Sources of contact/interaction are important. The family and close friends often take on this role. The MS nurse is also a key provider of this sort of support. Particularly in the early stages of MS, following diagnosis, many participants feel that something more formal and intensive should be available (e.g. counseling, therapy) in order to deal with the overwhelming emotional impact. Those that lack adequate support from immediate friends and family members often seek out contact and support from the MS Society, internet groups	Being nice to me and being supportive. I appreciate it. [P13] It's like any situation. If you can chat to people who are in the same boat as you, you support each other and help each other. So I certainly think people should join the local MS Society. [P13] Erm… and support really. I had a lot of support when I was first diagnosed and I've got a lot of friends and a lot of people that support me now, but just for being friends and always being there. I think, you know friends and family are paramount really [laughs]. [P2] Quite kind of lost, I suppose, at times. Because I'm a very open person and I'll talk about, I'll talk about people's, you know, I'll talk about my own feelings, and I'll talk about theirs and to me it's very important to be able to do that and, and that erm, that somebody else maybe very different and they might be very closed and that, that does cause me concern because I can't always share what I feel, you know, with, with……[P14] So I think the whole family could have done with some serious counselling at that time, but er it didn't happen so [P27] You must have yourself surrounded with a network of good friends and a support network [P1]
Having money	Money is viewed a resource that makes adaptations in the face of MS possible/easier. If people don't have to work, have decent benefits, and can pay for help around the home	Erm… I work part-time and I'm worried that I'm going to have to stop that [crying]……sorry… Erm, I'm worried about money, you know, if that happens, 'cos being on my own with my son [crying]… Erm, yeah, those sort of things are very worrying I think…[P9] Erm… it seemed eh… the financial side seemed to get

	or relevant adaptations to their environment it gives people the time and the flexibility to manage life with MS in a way that suits them best. Lack of such resources, and money worries (and financially-based job worries) make things much more challenging.	sorted quite well, so there was no financial worries. [P4] the only thing I can think of is giving up work, so that I have more energy to do, you know, to do nice things, but erm, how, how I can do that, I just don't know, moneywise.[P9]
Personal attributes	Background, circumstances, characteristics, personality, skills can be helpful/unhelpful resources in living well with MS (e.g. optimism, resilience, stubbornness, vanity, shyness, self-confidence)	I'm not very good at sort of accepting help, anyway. Although that's got nothing to do with having MS. That's just me [laughs]. [P12] I've always been quite a strong personality so I've always been positive about anything in my life, so erm… having a positive mental attitude really helped me, but everybody's different. [P2] But I consider myself to be quite a strong person. I have a very strong constitution. [P22] Yes it was a bit of a shock, but I'm a very pro-active and get on with it type of person, so erm, although it was quite a shock, I wasn't devastated and in a terrible state or anything. I was just sort of very realistic about it. [P31]
Actions/ Strategies Actions taken and changes made when dealing with life with MS		
Arming self with info	Info seeking is a very common strategy following diagnosis. Initial info given by doctors (and other sources) is perceived as overly negative and extreme and is reported to have a negative impact on the participant. The process of getting/finding information is helpful and provides reassurance that worst-case scenario is not the only way to think about MS. People describe info as a factor that will help them to deal with MS For some, info seeking involves specifically seeking out positive information and avoiding negative. Where health professionals give positive/hopeful info and have a warm and	Erm… but, as I said, when I sort of read about it and realised it might not be that bad and it hasn't been…[P10] But you have to know about it and nobody tells you. You have to go and search this information for yourself. And once you've found the information, then its okay. [P6] Well firstly there was the lack of knowledge about the disease itself and then, well my way of dealing with it was to read up as much as possible. And there is a hell of a lot out there. Far too much information. I know you shouldn't say that [laughing] but for me it was too much. [P27] And the first thing I did was trawl the internet for information and er, I did that endlessly because I wanted to find out everything good and bad. So I was very good like that. [P31] I found it was really helpful to actually erm… eh… get the books from the library and especially reading about other people's experiences. And also, erm the, joining the MS Society and getting the information from them and having their magazine. [P5] I'm gonna write a really positive book about MS [laughs] so that that can be the first thing they read'.[P8]

	collaborative personal style/communication style it gives the participant something to hold onto, and be optimistic/hopeful/positive about. Arming self with info (especially positive info) appears to serve the purpose of making MS manageable and neutralizing the initial fear and horror associated with images of wheelchair/disability/death. People are aware of the varying quality of information and value accurate but positive information Individual differences- A minority want to avoid information. Timing and amount of information is also important and should match what people want.	Erm… I did an awful lot of research about what MS was and I learnt that there were an awful lot of websites that told you all sorts of stuff that was rubbish. So you have to pick out the websites that are good quality and look for information that is, that is really backed up with some sort of evidence. And anecdotal evidence is just not good enough for me. I need something that has been proved. Er… and that, once I found a couple of sources, it was good. [P6] The length of diagnosis, the hardest bit is not understanding. Once you know, you can get your head round it, you can deal with it. [P8] It's the old cliché, people who've known, 'Oh my sister's had it' or 'My sister-in-law had it' and 'Oh she finds this da da da'. You just don't, you kind of want to put the shutters down and you don't want to hear. Unless it's, unless it's that they did really well and they got over it.[P11]
Managing symptoms <u>A set of themes</u> relating to how participants deal with physical MS symptoms		
	Becoming familiar with symptoms Getting to know your own MS, what is going to be 'normal', what needs attention, how it responds to different things	I've got permanent pins and needles in my hands and my feet. And I can't imagine how anybody survives without having pins and needles, because I've had them so long, I think everybody must have [laughs].[P12] Er… and various pins and needles and things, were symptoms I'd never had before. And because they were new to me, I needed to know more about them and I needed to know whether they were, were MS or were they something else on top of it, because it doesn't make you immune from other things. So, eh… you feel a bit of a nuisance, always having to ask is this the MS? Should I be worried? Or should I go to the doctor and get it checked out? Eh… so, it's not knowing quite, quite what a fuss to make of it and whether to do anymore about it or just ignore it…[P6] and now, now when I get all these pains, 'cos I get quite severe pain, stabbing pains down my ears, you know, into my head. Erm, and now I think, 'Oh well, it's probably just the MS', you know. But before, I thought, I mean you start wondering if you've got a brain tumour or something, you know.[P16]
	Putting up with	Like a little while ago I had, it felt like beetles crawling

	symptoms It is possible to just get on with things despite symptoms. Grin and bear it. This appears to be mainly applicable to mild symptoms or those that the participant believes are transient. More serious symptoms are tolerated because there is simply no choice and no successful treatment.	inside my skin [laughs] and absolute pain, you know, these beetles trying to get out and stuff which is really painful, but, erm, I don't, I don't mind that because I know it's gonna get, hopefully, normally it sort of comes and goes. So you can sort of cope with those sort of things. [P9] And … other than that, nothing really, 'cos you can't do anything. There isn't anything you can do with any of the symptoms that I'd got, they're just sort of grin and bear it. [P5] And I suppose I've grown used to that really. I mean, it did burst once, in my teens, that ear. But erm, it's, the pain part, it's erm, it's not very long lived, so luckily, I mean if it was long lived it would be awful, I have to say. But it's not usually. It only lasts for, perhaps for a minute or so. Erm, and it's er, it's something that I've learned to live with really.[P18] Participant: incontinence. Erm… which is a real nightmare…… Interviewer: How do you cope with that? Participant: How do I cope with it? You just have to. [P23]
	Tackling symptoms Do things to help improve or manage or avoid the onset/worsening of symptoms. Includes a range of management strategies including; drugs, medical treatments, pacing, physiotherapy, rest, avoidance of triggers	And I still did yoga at home to sort of help me build it up. 'Cos I think that helps, if you're dizzy, if you're doing things to sort of make yourself sort of feel more stable, I think that helps. And the medication cleared it up quickly so…[P10] Erm… you know just have 10 minutes rest, 'cos that does help. It's surprising just what a 5-10 minute rest does. [P7] But I haven't had the foot drop for a while, 'cos I try not to get myself in a situation where I'm very tired and have to walk.[P13] I don't hear properly and as I say, I don't see properly, but nobody would know that looking at me, or even actually speaking to me, 'cos obviously I make sure I position myself on the right side, so that you know they, you know, I can hear [P5] kind of listening more to my body, trying to be more in tune with it really, rather than fighting it all the time [P14] The neurologist said they might help with the water, I have waterworks problems as well. I have a lot of er, frequency and urgency, erm, and that. And also I had a lot of trouble sleeping. Erm… and these tablets help with the sleep and to a certain extent, they help with the er, waterworks as well [P16]
Good management <u>A set of themes</u> about how participants attempt to manage MS problems in practical ways.		
	Problem solving It is important to be able to see, and achieve, realistic ways to manage the impact of	And not being able to walk, I couldn't see the strategies to manage it and I think that's the crucial thing. Knowing what to do to manage these things, because nothing makes them go away, it's simply good management. [P6] By just getting on with it and finding ways round it. [P4]

	MS on daily living. Problem-solving involves a set of practical strategies (not emotion-focused). Finding alternative ways to do things. Creativity, Compromise. Problem-solving. Initiative. Just doing something.	I have the confidence now to know that I can deal with it as it comes now. That I have the strength, the inner strength to say, 'Right, okay, whatever happens, we'll deal with it'. [P7] I think I've faced it positively and I am sort of a, 'Right what do I need to do now? Where do I need to go? Who do I need to talk to?' and usually I find all these things out, one way and another, and er, then take action accordingly. So I'm quite proactive about that. [P32] Used my, used my left hand. I, I tried to re-train myself to use my left hand, even to the extent of er writing. Er… it's not totally legible but it… at least I could get something done. And luckily for me, with modern technology, a lot of things get done on computers, so it's not half as critical to use the writing skills. In other words, I just try to find other ways of doing things. It wasn't gonna stop me doing things. I just had to be more creative in how I did them. [P28] Er… generally, I, I think I have it managed and I have my life managed. Erm… there are some days that are worse than others, er, and I now know how to manage those days. But it is a series of strategies for management.[P6]
	Planning ahead Looking ahead and planning what might be necessary for short (and longer term) future management. Thinking objectively (rather than worrying/ruminating) and realistically about the future. Anticipating problems so that they can be managed.	Erm… you know, we have to think and plan. We can't easily do things spontaneously because we have to make sure that… you know, wherever we go I can walk the distance or whatever, and that takes a lot of spontaneity out of things that you wanna do.[P30] But I have those strategies to manage. Whether it's transport, I have my list of people I can ask for help. I have a list of charities with volunteers who will come in and help. I have the physical things in the house, like a stairlift and a downstairs [P6] I mean, they're very good with their accessibility now. I mean you have to plan ahead really whatever you're doing, so you know exactly what you're gonna be facing when you get there. [P17]
Adapting social and leisure activities <u>A set of themes</u> about how participants change their social and leisure activities in response to MS		
	Scaling down This involves participants continuing with the sorts of activities they like doing, but in a smaller-scale way. Perhaps doing them less often, or a less physically demanding, less energetic, or less stressful version. This compromise appears to be acceptable to most people; it's annoying but not a devastating loss.	So I have to be, have to pick my holidays much more carefully with the thought, I have to sort of where I, 'cos I think I won't be flogged from dawn 'til dusk. You know, there will be breaks and I can have a rest. [P13] Social life really, is having some friends round, for which I cheat and get sort of Marks & Spencers or Waitrose or something. I don't believe in cooking myself these days if they can do it for me, so… I mean I do small, smaller, smaller things, because it's erm, that can be erm, I mean, I think I can do these things and then I set off and it all gets a bit too much, so I need a helper or if you just have, just have smaller groups of people round. [P13] I do still go on foreign holidays, but I don't go in the height of the season. I tend to go when it cools down and I can like cope, you know, like that really. [P2]
	Replacing	I am learning, and in fact I do get large print books out of the library and I do also get erm… I get erm spoken tapes

	When valued activities become physically impossible or demanding and have to be given up they are sometimes replaced with new sources of pleasure or challenge. Whilst there is distress over being unable to do something they used to love, new activities are useful to prevent people dwelling on what they can't do.	out, spoken cds out, [P5] For many years I've been riding motorbikes and it was my sort of true love and things. Erm… but I found other things to sort of replace it with. [P4]
	Keeping it up Sometimes valued, but difficult, activities are kept up by prioritizing and making special efforts to ensure that they are possible	I'd go, yeah, if it was a particular thing, you know, like, say a wedding reception, or a, or a get together of some people that I, you know, that I haven't seen for a while, or something like that, I'd go to. But I wouldn't actually choose to say, go to the pub anymore, or some of the things that I used to do, erm, no. [P14] I go on days out with the, with our club and erm, I mean I went to Hampton Court Flower Show on Thursday. I managed to get there. My friend she wanted to go, so we drove up, and I had my own scooter and we managed. Admittedly, I got incredibly tired, erm, halfway through the day and could quite happily have turned round and gone back, but sat down, erm, something to eat, settled down a bit and I was alright.[P20] I'm still the same. I still go out. I mean I still like to go out for like a drink. I still like to have laugh. I still, you know, I still, I still go to concerts. I mean, I'm not you know, I can't stand up for long these days, but I still do all the stuff I've always done[P11]
	Withdrawing If activities are difficult and bring more hassle than pleasure they are withdrawn from, or given up. This particularly happens due to fatigue and the symptom management strategy of doing things in small portions. How much upset this causes depends on how much the activity was valued.	That's why I don't really go to pubs and things, because obviously I can't hear in very crowded situations, so I tend to avoid situations where there's going to be a lot of people, because it, it, it just becomes boring because I can't, I can't listen to, to, to conversations in a really busy place, so, it's a nuisance. So it's just easier to avoid it.[P5] I used to quite enjoy that, and I suppose because I've found the last few occasions so difficult, I've found that now I avoid it, so yes, I probably am avoiding more than, than I used to, because I, I, I avoid situations which will make me feel worse. [P5] Participant: I mean I used to go to the gym 4 times a week and since my diagnosis I, you know, I haven't been able to do any exercises, at all, I mean, bar, bar stuff like pilates and yoga… Interviewer: How do you feel about that? About having to give that up? Participant: …….. Well it doesn't actually bother me that much, 'cos I never really enjoyed the exercise in the first place [laughing].[P15] Frustration, erm, [sighs] that's the main thing I think. I keep thinking, well I could do, I mean at one time I used ride my bike. I used to really enjoy that. And now if I try and do that I find I can only pedal so many pedals and then my legs start giving out on me. It's a bit frustrating and a bit sad really. [P16]

		Erm… doesn't bother me actually anymore. No, that doesn't bother me at all. No. The whole… I'm a very much stay at home kind of person. I love to be at home. So that doesn't bother me in particular. In fact in some ways I'm glad I've got an excuse [laughing] to get out of things that I don't really want to do [laughing]. [P27]
Managing others' responses <u>A set of themes</u> about strategies used to deal with MS issues relating to other people		
	Telling people Decisions and the method and timing of disclosing MS seems to be when it is beneficial for the participant. People choose to disclose when it aids understanding or empathy, when it felt to be strictly (legally, morally) necessary, or when they predict a positive response. Because having MS can make people feel ashamed it can be covered up rather than disclosed. Generally speaking participants don't tell people just for the sake of it or where no positive outcomes are expected from people knowing.	I decided not to tell them straight away. But they obviously wanted to know how I was and they knew that… they didn't know anything about MS, but they knew that there was, that there was going to be something that I was going to hear about. And they got home and said, 'Are you alright, Mum?' and I said, 'Yeah, that's fine. It's okay.' And I tried to sort of act it out, but it wasn't very good, and within a few days, I had to tell them. I just can't… I couldn't lie to my daughters anyway, they're sort of very close to me. So I've had to tell them [P11] I sort of like told people on a basis of need to know. As it happened. I didn't keep it as a big secret when I was diagnosed, I just told people as I came across them sort of thing and as they needed to know.[P4] I told him straight from the beginning, before we started seeing each other, erm, and so it was… it was, it was, you know, the impression that you take it or leave it. No skin off my nose if you don't want to go out with me, because I don't know you that well anyway, so I've got nothing to lose. So erm… no, I, no problem. [P15] He is 6 years old and I think I told him about three years ago because, when I first started to self-inject, I had to try and do it when he wasn't around and that was kind of difficult. I had to lock myself in the bathroom, or do it late at night after I'd put him to bed. And I thought, 'I don't like doing this', 'cos I'm kind of like, it wasn't part of my daily routine. [P22] I didn't tell anybody I had MS. Erm… I'm also a diabetic, so if they saw me having a bit of difficulty walking, they just put it down to that. Er… it took me about 3 years before I would actually openly admit I've got it. Er… like a stigma attached to it……[P28] Well my husband, as I say, was with me, so he knew. Erm… we knew that everybody would be at the house when we got back, my sister and my daughter and her partner, so we decided to get, as they were all together, that we would just tell them altogether. So my sister, she had brought her two youngest ones with her from [ ] so we packed all the kids off upstairs and then we just told them all together, 'cos we felt that that was the best thing. [P29]
	Educating others People with MS often have to	I felt like shaking them and saying 'You haven't got a clue, have you?'. Erm… but I had to look at myself as an education project for them, so that I could teach them something. [P6]

	take on a role of teacher where they explain MS (either generally, or their symptoms). The reason that they educate other people is increase their understanding and improve their behaviour so as to make things easier for the person with MS.	I sent him a load of leaflets from the MS Society and had them delivered to his house and he's left me alone since. So hopefully he read them and understood a bit more[P4] Sometimes when you are obviously trying to learn about MS yourself, you end up spending a lot of time educating other people to give yourself a better support base as well. Erm… you know, 'cos you're obviously gonna have to get a) come across other people's reactions and you just have educate them as well to make your life less… not less awkward, or less… I don't know, just make it, make it easier. [P19]
	Displaying disability Participants use strategies to make other people realize their disability and struggles and therefore not judge them badly, and encourage them to make things easier for you. This strategy may involve either making it visually obvious that there is a problem, or using verbal statements to explain one's difficulties and needs. Important given difficulties surrounding it being an invisible illness (e.g. fatigue, numbness, pins and needles).	Again it's because of the fact that it's erm, with me it's such a hidden condition, 'cos I am, there's nothing wrong with me. There's nothing outwardly wrong with me, you know [P22] if you've been to a restaurant or something, you sort of feel, if you're wobbling about a bit, you feel everybody thinks you've had one, one too many [laughs]. I usually take my stick, so that I look as if there's something wrong with me. [P13] I just, I mean the only thing you can do is say, 'I feel like this. I feel like that.' And then you feel like a hypochondriac [laughing], you know. Or you feel like you're moaning, or attention-seeking. But I think it's the only way people can know that you're not 100%. 'Cos otherwise, if you don't do that, they think there's nothing wrong. Unless like with the fatigue, they can see it if you've got it bad. But other than that, like with the pins and needles, erm, nobody can see it [P8] With people I know or judge to, judge reasonably well, then normally I would, I would say, 'Look I've got MS but it's not disabling, it's not really a problem, but if I get tired or I need help…' or maybe, I mean something as simple as getting a tray of cups of tea and coffee. I can't carry a tray of teas and coffees because I don't have the balance anymore, and that's something I would need help with. And if somebody asked me to do that, who didn't know that I had MS, I would probably turn round and say, you know, 'I'm sorry, I've got a medical condition. I can't, I can't balance. Can somebody else help me with this' [P31]
	Becoming assertive People report becoming more assertive in relationships and interactions. Assertiveness is often related to getting the appropriate level and type of help and support from others. It involves telling people what is wanted from them, or asserting one's ability to cope alone.	Erm… I have got so that I now am much more assertive and I ask for more, rather than assuming that they are going to read my mind, and that is quite a big thing for me. Erm… because I, I had assumed that they knew exactly how I felt and, of course, that's not the case, and I have to be very clear about what I think and what I feel to them, and ask for things in a very direct manner, because being subtle does not work. [P6] I've been a nuisance enough with the NHS to move things on. And I've learnt to be a nuisance generally.[P6] So I'll certainly say to people, 'Well could you please move over?' or 'Could you move your bag, 'cos I want to sit down'. And erm… you know, since then I've had to be a, be, erm, I tended to have lived by the motto, 'Put up and shut up', but certainly these days I have to be, I've learnt to be a little more assertive. [P19]
	Rising above it	I mean it didn't make me say anything to my friend, 'cos I know she's acting with the best intentions. It's not her

	Often people have a limited emotional response to frustrating interactions with others whereby they grin and bear it.. They may be a bit annoyed/frustrated/upset but remain relatively calm and taking a reflective/philosophical approach. A few 'incidents' are tolerable because people are generally good and kind but not perfect! They do not blame the other person for their response (see it as understandable) and don't let this negatively effect the relationships or 'make a scene'. Rising above it seems to involve the person not having high expectations of perfect behaviour from others and perceiving themselves as having little power to change the situation (therefore, best not to bother trying). People report becoming thick skinned and not dwelling on unhelpful reactions. Where necessary they mentally or physically distance themselves from the person who is not responding helpfully	fault it's made me feel that way, but I think people should sort of think before they say things like that. [P10] With some of them that… I uh, I now know they are being kind, but they just don't know how to do it in the best way. So I let them say their piece, but I, I don't listen ever so much to it. [P6] Sometimes I think, 'Well sod you', you know. Sometimes I think, well you know, 'If you can't cope with that, that's your problem.'[P9] Half of the time I don't say anything. In fact, I normally don't say anything [P7] And I'm sure I'd be exactly the same, you know. I'd be trying, looking for a way to try to reach out to somebody with this illness and so people do that to me and I, I just, I'm very patient and I smile.[P11] I just cope with it. I don't, I don't really say anything to anybody. I just kind of… I've got used to it, really, [laughs] over time, you know, I've had more of the same. I don't think the public attitude is going to change a great deal [P14]
	Considering loved ones Awareness of negative impact of MS on friends and families. Being considerate and trying to make efforts to minimize/counter-act this.	So, from that point of view, we have always tried to see if from both aspects. I've tried to see what I could do to make life more normal for my wife and obviously she's trying to do the same for me. So that, it's a two-way street, which I'm sure you realise…[P1] I mean the main, the main issues are, you know, it… I don't want my disability to stop the people around me doing what they want to do. Erm… and, you know, as my husband and I tend to do most things together, it's, it does impinge on our life together. Erm… you know, we have to think and plan. [P30]
Joining the cripple club <u>A set of themes</u> about ambivalence about engaging with disabled people and disabled identity		
	Interacting with people with MS Ambivalence is often felt regarding interacting with other people with MS, or other disabled people. It is helpful to get info and advice and support and friendship	But getting together and sharing ideas with other people in wheelchairs or other people with disabilities, they're the experts. Getting a forum of people like us together, we sort all the problems about what we do. We have practical, little practical tips and solutions that we use during the day. Ways of dealing with people, ways of dealing with circumstances. m[P1] I tried to talk to my friends about it and I also kind of went into a few chat rooms in the MS Society, erm, eh, website

	from others in same boat. However, coming into contact with people with MS can be threatening and upsetting.	and sort of talked to a few people that would talk to me. So I kind of found a way of people talking to me about it. [P14] It's like any situation. If you can chat to people who are in the same boat as you, you support each other and help each other. So I certainly think people should join the local MS Society. [P13]
	Feeling stigma Some participants perceive MS as a stigmatized condition. This is particularly the case when it necessitates the use of mobility aids. Avoidance of having to use aids, especially in public as these is felt to be suitable for old, disabled, and inferior people, not themselves.	You all of a sudden feel as if you're actually 10, 20 years older and again there's that social stigma, you know, old people use sticks. [P28] It's like sort of coming to grips with using a walking stick. Some people find it hard to do that because of the so-called label that imposes on you, because if you take a stick out, people look at you and think you're disabled and some people have a problem with that. I grapple with that sometimes, I actually won't take a stick out unless I really, really have to and I suppose it's one of those issues. I think it's acceptance. [P31] He [her boyfriend] says, 'surely that's, you know, a good thing for you, cos then you won't have to struggle as much'. But I am too proud and too vain to, to do it. [P15]
	The spectre of what might happen People have difficulties associated with thinking about and being exposed to disability (e.g. mobility aids, other people, certain information). They can find it too frightening and overwhelming, or too soon. Avoidance is common. Gradual engagement happens as benefits of exposure become more apparent or important (e.g. stick becomes necessary, realize MS Society provides needed support).	It's almost like a different world. You know, which, you kind of know that you'll probably have to join sometime, but you're just kind of thinking well not yet please. [P5] I don't know whether I can cope with like being with a lot of people who are, I mean a lot of them are severely disabled and I don't know. [P5] I can put my hand on my heart, and really say I've not really seen anybody in a wheelchair that's got MS, because I choose not to go down that route. I just don't think I could stand to sit in a room with people that have got MS on the understanding that I could end up like that, but I'm not going to, you know [laughs]. So I don't think that would do me any good. It doesn't do your self-esteem any good I don't think. [P2] It would have been nice if MS sufferers could just get together to sort of like socialize or to talk to each other about their problems, because erm, I don't know, perhaps it wouldn't make the MS sufferers who are suffering severely feel that much more better, but the ones who have mild er, who have a mild condition, I think they need to know that they're quite lucky and they probably need to know what they can do to maintain the status quo. [P22]
	Not relating Not identifying with other people with MS/disabilities, not relating to them or fitting in. Participant may hold negative and prejudiced ideas about disability which are expressed in dislike/avoidance of other	I don't know whether it is the fact that I don't look at all disabled. That I look perfectly okay. [P5] I almost feel as if I'm slightly a fraud, when you get people with wheelchairs and they're struggling badly and I can walk. And I feel as if I'm a bit of a fraud, that I don't really, I don't really count. [P5] But get in with a whole load of 'em. I couldn't. No, I couldn't go to a [name of local club], thank you very much. What it is to announce to somebody, 'Oh what club

	people who are examples of disability- e.g. older, wheelchair-users. Expressing ridicule or looking down on these people. These prejudices often reported to change over time as the person engages more with MS people.	are you a member of?', 'Oh the MS Club, ha ha. Come and join us. You get a badge. Come and get the t-shirt', you know [laughing]. [P23] I try really hard and I mean like they have various outings and things locally, but I just kind of think, 'Am I just making myself part of a cripple club' [laughs] sort of thing. And I don't know whether [laughs] I don't know whether I can cope with it. [P5] I'm not, I'm not dribbling or, you know. It sounds awful, but I'm not a, I'm not classically disabled.[P14]
Learning to accept help	Asking for and accepting help is difficult for many participants. Getting used to not doing things yourself, having other people doing things for you, and having disability aids e.g. wheelchairs, sticks, is hard and is something that takes time. Acceptance of help often related to a critical incident, or final straw where the person sees that accepting help is a way that they will be able to continue with the things that they value.	Er… so it's a bit of a head change for me, not to do things myself er, and it is quite hard for me to have to wait for things, er, and that has been difficult, er, but now I know that the key to it all is to get other people to do the things that I can't do, so that I can do the things I enjoy.[P6] I've had to sort of settle down a bit and admit that I can't always. But I get really annoyed with myself when I can't do things, 'cos I'm a bit of a control freak, keeping it all going. But I've had to, I've had to ease up a bit on that, you know.[P11] I would probably turn round and say, you know, 'I'm sorry, I've got a medical condition. I can't, I can't balance. Can somebody else help me with this', or… you know, I'm not frightened of asking for help. [P31]
Putting on a brave face	Putting on an act of braveness and calmness and robustness is a way of getting strength and keeping going. This strategy can be for one's own benefit, and/or for protecting others.	So I just try and buoy myself up and make out that, you know, okay they know I've got MS. If this is what MS is, you know, it's not that bad [laughs] to them, you know, obviously in my head it is quite scary, but, erm I find that that strengthens me up a bit. If I sort of a put on a, on a, a sort of veneer, really. [P17] I would have liked to have had a good bloody cry over it, you know what I mean, but I felt like I, I had to keep meself together for the rest, for everybody else. [P18] I mean you just have, just have to keep on… put up a bit of a front and, and not let 'em show, or not let 'em see that it's, it's that bad, you know. [P23]
Doing something valuable	Participants describe their efforts to engage in activities that are valuable and productive and give them a sense of worth. There seems to be both positive and negative sides to this. This can be driven by a desire for a feeling of pride, achievement and enjoyment. However it can also be related to guilt, feelings of duty, 'shoulds'. Some people	And grow, you know, grow vegetables in the garden. So I try and be productive, [P5] Erm… once I've achieved it, it will feel good, because I've achieved it. Again achieved something. [P4] And [laughs] from there on I never, ever had to erect my own tent. Someone else always did it. But, people might be very good, but it doesn't stop me from trying and bringing over the bedding stacks and tidying up. [P19]

	describe trying so hard to do things well that they seem to be overcompensating and trying to prove something.	
Keeping a normal life	Daily life doesn't revolve around MS but it is integrated and normal. Participant chooses not to make a big thing out of it on a regular basis. Things carry on much as normal. Ordinary family life. MS is there, but integrated. MS is not the only/main label for the person and the way that they tend to think of themselves. They are the 'same old me' Other things are more important than MS and are more central to the person's life than the illness. This can be a deliberate strategy, or just how things turn out with time	They've sort of got used to me talking to them and not making MS a subject of a conversation. That I now talk to them about their hedges, erm, and how good their, their car is looking at the moment… allsorts of normal things, and they know that it's not a big issue anymore, while at the start, when it was er… it was new to everybody, it was a big issue and it was an item of news, and it's not news anymore. It's just ordinary. And I'm glad for that. [P6] I don't sort of make a big thing of it. I don't tend to talk about it all the time. [P9] Erm… what else?..... I can't really think of anything else. There perhaps are other things but I've learnt to deal with them now and live with them, so I perhaps don't even notice anymore [laughs]… so yeah. [P27] of course, then there's the support through the MS Society, which I, I, I'm not a member of my local group, erm because it doesn't… to me, I don't want it to become the centre of everything that goes on. [P30]
Managing emotions	Engaging in strategies to deal with negative emotions in a way that is felt to be helpful. For some this involves expressing or releasing (e.g. through talking, writing, physical activity) For others, this is a process of calming oneself and regaining control. For some, therapy or counseling or antidepressants are used to bring depression under control.	I had to do a little bit of catharsis. And I had to write about it. And once I'd written about it and I'd made it funny in the, the writing, 'cos I was writing for a magazine, erm… then, if I made it funny, then I was, I was cleared of it. I didn't have to think about it again. [P6] Yeah. I mean, we do yoga, which is brilliant. Just sort of picturing your problems in a bubble and let it float away. It sounds ridiculous but it, you know… I love yoga, it's brilliant, yeah. [P17] Once you get the depression under control, well for me the depression is a big deal, once I've got that under control I can think positively and deal with everything else. So the biggest thing for me is the depression. [P27] I think probably just talking to [counsellor's name] and she sort of trying to put things in perspective, and putting things in perspective has made a big difference. Because you know, you look at the thing and what you think is a mountain is probably only a molehill[P20]
Keeping in good shape	Participants often report taking action to make sure they have a healthy lifestyle and are in the best physical condition. The thinking behind this is that it gives the best chances of fighting off MS and minimizing its impact on the body. Includes diet, exercise, stress management, and following medical advice.	And then I try and live as healthily as I can, sort of, balanced diet and do exercises down at the gym and things. Erm… and just get outside and yeah, do things [P4] When I researched what was wrong with me I thought right heat makes it worse, so I had no hot holidays. I don't have hot showers, I have cold, well lukewarm showers. Erm… I changed my diet to a low fat diet, which is probably most people do that now anyway. Erm… gave up my job because I was a chef. That was too stressful. Stress caused, it could cause the condition to get worse and so I decided the job change[P2]. Erm… keep exercising. Do all things that I can possibly do to keep myself in a good shape. Erm… and then I don't feel like I've let myself down. And my illness will just

		carry on, whatever it wants to do, and all I can do is just keep exercising and just keep doing the things that I can do myself. Keep a healthy diet. Just stay positive, knowing that you can you do all you can do yourself, really. [P17]
Attitudes and thoughts Descriptions of ways of thinking and viewing MS		
Being positive	Positive thinking is a tactic (or personal characteristic) that people believe helps them to cope. Similarly, having a sense of hope is helpful, and it doesn't seem to matter how realistic this is (although there was no possibility of tracking people across time to see what happens if things get worse). An optimistic and positive attitude is seen as helping wellbeing and sometimes the progression of the disease itself. Positive thinking is felt to be protective against depression. For some, negative thinking rather than positive attitude is seen to be the cause of depression and so people can be responsible (and blamed) for whether they are depressed or not). Being positive also involves finding benefits, or silver lining in the ways that MS has changed their life.	So it's quite scary, but you, I think you always just have to stay positive, otherwise I think if you're negative all the time and you sort of let yourself get down, I don't think you help yourself. I think if you stay positive, I do think it can really effect the progression. [P10] Once you slip in to the negative thoughts, it can be really, it can be really quite bad.[P7] Erm… and sometimes you kind of think well yeah, it was a great escape as well [P5] I know what I should be doing. I know I should be more positive. I know I should be more outgoing and I know I should feel better about myself. [P5] I'm quite a positive person and I, erm, 'No it's not going to get the better of me', no I'm not doing it, you know [laughs]. I try and be quite strong and upbeat about it. I refu…, I just refuse to let it get the better of me and up until now it hasn't, which is good. [P2] I think I'd tell them to be positive, you know. MS is not a negative thing. You've got to be positive with it and I'd tell them that. You know, if they can be positive, then, you know, things will be okay. [P20]
Feeling lucky	Positive thinking is a tactic (or personal characteristic) that people believe helps them to cope. Similarly, having a sense of hope is helpful, and it doesn't seem to matter how realistic this is (although there was no possibility of tracking people across time to see what happens if things get worse). An optimistic and positive attitude is seen as helping wellbeing and sometimes the progression of the disease itself. Positive thinking is felt to be protective against depression. For some, negative thinking rather than positive attitude is seen to be the cause of depression and so people can be responsible	So it's quite scary, but you, I think you always just have to stay positive, otherwise I think if you're negative all the time and you sort of let yourself get down, I don't think you help yourself. I think if you stay positive, I do think it can really effect the progression…[P10] Once you slip in to the negative thoughts, it can be really, it can be really quite bad.[P7] Erm… and sometimes you kind of think well yeah, it was a great escape as well [P5] I know what I should be doing. I know I should be more positive. I know I should be more outgoing and I know I should feel better about myself.[P5] I'm quite a positive person and I, erm, 'No it's not going to get the better of me', no I'm not doing it, you know [laughs]. I try and be quite strong and upbeat about it. I refu…, I just refuse to let it get the better of me and up until now it hasn't, which is good. [P2] I think I'd tell them to be positive, you know. MS is not a negative thing. You've got to be positive with it and I'd

	(and blamed) for whether they are depressed or not). Being positive also involves finding benefits, or silver lining in the ways that MS has changed their life.	tell them that. You know, if they can be positive, then, you know, things will be okay. [P20]
Don't dwell	Participants say that it is best not to spend time dwelling on difficulties MS brings, becoming bitter, or ruminating about unfairness. Getting on with normal things (or new alternatives) as much as possible is felt to be a good way of coping with difficulties.	I know some people with MS who are very bitter, and erm… they come across as very bitter because of what it's done to them and I, I don't wanna come across like that. So, I think it's best to just button it sometimes and just take it. [P7] Get on with it really, [laughs] you know. Don't make a mountain out of a molehill[P8] It's always like, well I've got, you know, it's like this is my life, so, you know, I'm not gonna sort of fanny around and say, 'Oh God. I can't walk my dog. Oh woe is me', because I don't, I'm just not like that.[P12] And I seemed to get stuck into other things, which I've done ever since. Doing other things and then, I took the attitude of whatever happens, just get on with life. I've only got one life, so get on with it really. And that's what I've done ever since. [P4]
Focus on can not cant	Participants often report thinking about and focusing on what they are able to do rather than concentrating on activities and capabilities they have lost. 'Can not can't' thoughts seem to be something associated with feeling OK about MS and living an acceptable quality of life. Some participants give examples of the opposite pattern- comparing with past performance, and ruminating about their poor current abilities. They tend to also report more distress and dissatisfaction	I read something once, erm, someone was having a bit of a moan on the MS Society message board erm, and, and saying, oh you know, 'They can't do this anymore, they can't do that anymore', and somebody replied saying, 'Yeah, you know, we're, we're sort of all in the same boat and things are taken away from us, but focus on the positive things and not on the negative things, and concentrate on what you can still do'…. And that's kind of stuck with me, erm… and I think it's really important… It is really important… it's erm… and that's perhaps why I think, 'Well okay I can't run on the treadmill, but I can do a bit on the cross-trainer' [P7] I mean if I sit down for 20 minutes or so, then I can get up and I can go again for another sort of half a mile, but obviously that's not very, that's not very far at all is it, half a mile, I mean [laughs]. You can almost throw a ball that far can't you, but…[laughs].[P24] Participant … I used to play, play golf very regular and, before all this started. Erm, unfortunately the walking side of it, that sort of put paid to that. Erm… and last year, back end of last year, I've sort of thought, 'Well I'll go up the driving range. I haven't got to walk anywhere if I go up there', you know. And the distance I was hitting the balls up there compared to what I knew I could've hit them, was pathetic really [laughs]. You know, I was sort of disgusted with myself because I thought, 'Wow, what a feeble effort that is', you know [laughing]. Erm… but there was just not the power there to… to hit the ball the right distance, you know. Interviewer: And what did you do to cope with that? Participant: Er… I stopped playing [laughing]. I thought I've had enough of that.[P24] Obviously I learned to deep sea dive and I had to give that up because of the, you know, the squeeze as you go down

		into the water wouldn't help, obviously, your brain, it doesn't really help that, does it. I focused on the things I could do not the things that I couldn't do. [P2]
Changing priorities	Changes are made to what people think is important in life and what to spend their time and energy on. Pleasure often comes high on the list. People tend to become less rigid about chores and rules and conventions and things you 'should' do. They are less hard on self	And I do now think about if it's a good day, enjoy it. You know, go for it. Go for a walk out. A walk out [laughs], when I say walk, I mean get in the scooter and go in the scooter for a nice walk in the sunshine [P6] it's about the quality to me, I've got now. Live for the moment really. These are the god old days, as it were. [P11] And another issue was, when I found out I had it, erm, I had a list of things in me head that I wanted to do and erm, I thought, there was things like, I thought, 'I'm gonna have the holidays that I want to have', that I probably would have had later on, you know, when I'm older, I'm gonna have them now, 'cos I might not be able to have them, so… I went to the Maldives and I went to Thailand, you know, which I probably wouldn't have done 'til later on in life. And erm, I mean, I haven't done loads of stuff, but I have done a few things. I've thought right, 'I'm gonna do that'. [P18] And we laugh and joke and just saying, things like housework, 'I don't bother to do that. It'll still be there tomorrow.' And you think, 'Well oh this is true. I don't have to worry about it.' No, I think, people do help and support each other. [P13]
Using humour	Humour is used to tell stories about difficult MS episodes. Humour is reported as a helpful strategy to manage upsetting incidents- a case of if you don't laugh you cry. It also appears to be a way of talking about their illness in a way that is socially acceptable and makes others feel comfortable.	I had a phase when I was falling over a lot and of course I can't get up, which is another, it is embarrassing and you just laugh. You have to laugh, otherwise you'd cry [laughs] [P13] You have to be very philosophical and resign yourself to this waiting. And, erm… yeah, humour, and just erm, trying to be, trying to carry on a normal dialogue with the people around you. [P1] And learn to have humour and… the more frustrated and guilty and angry you are, the less energy you have [P17]
Trying to make sense of it	Trying to make sense of why MS happened and what it means. Rumination on why it happened (to me). Tends to be seen early on in the illness/post-diagnosis and remits later on.	I really went round every avenue, and unfortunately, I'm one of those people that kind of goes through it all at an, at an intellectual level and at an emotional level and all those things. You just think, you can't reason it out. There is no reason behind it. [P11] Erm… I think I've accepted it now, fully. I erm, I used to think, 'Why's this happened to me', all the time, you know. And I kept thinking, 'What have I done so wrong that God up there's given me this', you know. And I'm the youngest in the family and erm, I used to think, 'God I'm the bloody youngest out of 5 of us, you know, and I'm the one, other than me sister having a disabled child, I'm the first one to get a major illness', you know. And erm……. so that played on me mind for a long time. For a good couple a year I would say, you know. And, I mean, I still think now, 'Why has this happened to me?', but it just has, I accept that it has now, you know. [P18]

Not giving in	Fighting spirit involving not giving in and letting MS stop you doing things, or get you down. Taking action in order to carry on life whilst minimizing effects of MS. Positive effects on feeling of wellbeing and self-esteem. Can have negative effects on fatigue, symptoms, and lead to getting self into tricky situations where they try to do too much	My wife and I just sat down after the diagnosis over a coffee and said 'Well, we're not gonna let this beat us. We're just gonna erm… It will never dominate our lives. We will just fight it every inch of the way' I think was the words that we used. So that was really sort of right after diagnosis, what happened…[P1] I'm quite a positive person and I, erm, 'No it's not going to get the better of me', no I'm not doing it, you know [laughs]. I try and be quite strong and upbeat about it. I refu…, I just refuse to let it get the better of me and up until now it hasn't, which is good.[P2] I wasn't going to let it, let anything get in the way of my social life, erm, you know. And if I was tired, it was tough, you know I'm just gonna go on and do it. I think I am slightly better at pacing myself, slightly, but erm, I'm not great at it. And I think anybody who says they are, are either very, er, far more self-disciplined than me or erm, very boring [laughs]. It alright, just pace yourself, you haven't got a life [laughs]. [P12]
Take each day as it comes	Due to the unknown prognosis, participants claim to deal with things on a day by day basis. Not particularly planning for the short or long-term future. Approaching MS problems when it becomes absolutely necessary rather than making pre-emptive changes to life. Taking each day as it comes sometimes, but not always, involves suppressing (or not engaging in) rumination about the future. However, it does not involve denial of the nature and reality of MS	I think I'm very much a case of a person deal with it when it happens [P7] and I thought, oh I could end up in a wheelchair or I… But because there's no cure you don't know and I thought, well it's not worth worrying about something that may or may not happen to me [laugh] and if it did then I will cross that bridge if it ever happened to me.[P2] they can't tell me what's gonna happen next, or when it's gonna happen. Er… it's just a case of take it as it comes and, you know [P24]

Appendix I: Mapping Inductively-derived themes onto elements of the model

Inductively-derived themes relevant to "Pre-MS variables" element of the model

Inductive analysis category	Pertinent themes from inductive qualitative analysis
Resources	*Personal Attributes* Pre-existing personality traits and values influence extent to which people find certain critical events challenging. These factors also influence how people respond to critical events (e.g. positivity, optimism)

Inductively-derived themes relevant to "Critical event/s" and "Disrupted emotional equilibrium and current quality of life" element of the model

Inductive analysis category	Pertinent themes from inductive qualitative analysis
Context	*Feeling Overwhelmed* Diagnosis constitutes a major critical event which interrupts emotional equilibrium and poses a threat to current wellbeing
Context	*The Black Picture* Diagnosis as a key critical event: initial extremely negative, fearful response (which changes over time with the presence of "helpful factors")
Process	*A Process that takes time* It takes time before people move away from disrupted equilibrium and towards positive adjustment
Process	*Critical Incidents* Unpleasant and upsetting MS-related events prompt adjustment and demonstrate that changes need to be made in order to have a good quality of life.

Inductively-derived themes relevant to "Factors helpful for adjustment" element of the model

Inductive analysis category	Pertinent themes from inductive qualitative analysis
Context	*Importance of Diagnosis* Links to more social support and positive interactions with others, less uncertainty, more hope, more perceived control and self-efficacy
Actions/Strategies	*Arming self with Information* More information (if it is hopeful/balanced) seems to be linked to better adjustment. Seems to be through reduction of uncertainty and negative, inaccurate illness perceptions, growing sense of personal control and self-efficacy and problem-focused coping
Resources	*Having Help at Hand* Links to importance of social support
Resources	*Having Support* Links to importance of social support
Actions/Strategies	*Good Management* Links to problem-focused coping and self-efficacy for managing MS
Actions/Strategies	*Adapting Social and Leisure Activities* Links to problem-focused coping and self-efficacy for managing MS
Actions/Strategies	*Symptom Managment* Links to problem-focused coping, positive/accurate illness perceptions and cognitive and behavioural responses to symptoms
Actions/Strategies	*Keeping in Good Shape* Links to health behaviours, perceived control, self-efficacy, hope and optimism
Attitudes and thoughts	*Focus on Can not Can't* Links to acceptance, positive re-appraisal coping, hope, optimism
Attitudes and thoughts	*Don't Dwell* Links to acceptance, problem-focused coping, hope, optimism
Attitudes and thoughts	*Being Positive* Links to hope and optimism
Attitudes and thoughts	*Feeling Lucky* Links to benefit-finding,
Resources	*Having Money* Links to social/environmental factors
Resources	*Personal Attributes* Links to many responses: optimism, hope, benefit-finding, self-efficacy

Inductively-derived themes relevant to "Factors unhelpful for adjustment" element of the model

Inductive analysis category	Pertinent themes from inductive qualitative analysis
Context	*The Black Picture* Links to uncertainty, appraisal of MS as threatening, unhelpful illness representations, helplessness
Context	*Abandoned at Diagnosis* Links to lack of social support, high uncertainty
Actions/Strategies	*Adapting Social and Leisure Activities* Links to unhelpful responses to symptoms e.g. excessive resting, avoidance
Attitudes and Thoughts	*Trying to Make Sense of It* Linked to lack of acceptance
Resources	*Personal Attributes* Links to lack of social support and unpleasant interactions with others
Attitudes and Thoughts	*Don't Dwell* Dwelling is related to a lack of problem-focused coping and an absence of acceptance
Resources	*Having Support* Links to lack of social support
Actions/Strategies	*Arming Self with Information* Lack of information links to negative perceptions of MS, appraisal of MS as threatening, uncertainty
Attitudes and Thoughts	*Can not Can't* Links to lack of positive re-appraisal, lack of acceptance

Appendix J: Participant information sheet for Chapters 5,6,7

Supportive adjustment for Multiple Sclerosis

PATIENT INFORMATION SHEET

SAMS (Supportive Adjustment for MS) Trial (Ref 07/MRE12/6)

STUDY 3: A TRIAL OF COGNITIVE BEHAVIOURAL THERAPY COMPARED TO SUPPORTIVE LISTENING FOR ADJUSTMENT TO MULTIPLE SCLEROSIS

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve.

- *Part 1 tells you the purpose of this study and what will happen to you if you take part.*
- *Part 2 gives you more detailed information about the conduct of the study.*

Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information (contact details on page 5). Take time to decide whether or not you wish to take part.

PART 1

Who is conducting the study?
This study is part of a larger research project which is being conducted by researchers at Southampton University, The Institute of Psychiatry at King's College and local MS services.

Some of the data from this study will be collected and used as part of an educational qualification

What is the purpose of the study?
Research has shown that coping with the emotions, lifestyle changes and symptoms associated with a diagnosis of MS can be challenging. Many patients with MS experience periods of feeling down, distressed and/or anxious. It is thought that by providing more support in the early stages of MS patients might be able to adjust better to the diagnosis of the condition.

This study aims to compare the effectiveness of a self-management programme (based on cognitive behavioural therapy) and supportive listening offered by specially trained nurses.

To find out which way of treating patients is best we need to make comparisons between the different treatments. We put people into groups and give each group a different treatment: the results are compared to see if one is better. To try to make sure the groups are the same to start with, each patient is put into a group by chance (randomly).

What is the therapy that is being tested?

Self-management based on Cognitive Behavioural Therapy

Together with a specially trained nurse, patients in this group will look at the ways that their thoughts, feelings, behaviours and physiology all interact and influence how MS affects their lives. The treatment is quite structured and different topics will be covered in different sessions (e.g. dealing with stress or symptoms). Patients will work together with the nurse to set goals to achieve. They will have small tasks or "homework" to do in between the sessions.

Supportive listening

MS provides different challenges for different people and many people feel they do not get the chance to talk enough about their concerns and experiences. Patients in the supportive listening group will meet with a specially trained nurse and have the opportunity to talk freely, extensively and confidentially about their experiences, thoughts and feelings about MS and its effect on their lives.

Why have I been chosen?

We need to recruit about 90 participants in total. You have been approached because you have been diagnosed with MS within the past ten years.

This invitation to take part does not mean that your doctors think you are having particular difficulties or are having problems coping. We are inviting people to take part regardless of whether they feel distressed, down or anxious at the moment.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part? What do I have to do?

You will take part in a screening session over the telephone where a researcher will confirm your eligibility to take part

Our criteria include:

- a definite diagnosis of MS in the past 10 years
- any type of MS
- able to walk for about 20 metres without rest (using aids if necessary)
- if taking beta interferon or glatiramer acetate you must have been on the medication for at least three months
- if taking anti-depressant medication you must have been on a stable dose for at least two months and intend to continue for the duration of the study
- be willing not to try any new psychological treatments during the duration of the study. However, if new treatments are required, they will be allowed and we ask that you inform the research co-ordinator.

We will decide by chance which type of treatment you will receive: Self-management or Supportive Listening. You will have a 50/50 chance of getting each treatment.

You will have eight sessions of treatment (as described above) over about three months. Each session lasts for an hour. For two sessions you will have to travel to Southampton. The rest of the sessions will be done over the telephone so that you don't have to travel.

We will audiotape the sessions so that we can check that the therapists are conducting the sessions in exactly the way that was planned.

We will ask you to fill in sets of questionnaires about your MS and how you are feeling. Each questionnaire pack will take between 30 and 60 minutes to complete. We will give you these on several occasions: before therapy, once your treatment programme has come to an end, six months later and a year later. They will be sent to you by post so you can complete them at home. If you prefer, you can complete the questionnaires through a website.

At the end of the treatment programmes we will interview a selection of participants about their experiences and views about the therapy sessions. If you agree to take part a member of the research team will contact you. They will arrange with you a convenient time to conduct an informal interview on the telephone for about one hour. The interviewer will not be a member of the team involved in your treatment. The interview will be tape-recorded so that the researchers can write it up and study it at a later date.
If you want to take part in the treatment trial but do not want to do this interview you do not have to. You can also change your mind if you agree to do the interview but decide you no longer want to at a later date.

Expenses and payments
Unfortunately we are not able to offer you any payment to take part in the study.
There will be no cost to you for the therapy. The researchers will make and pay for the telephone calls for your treatment sessions. The questionnaire packs you will be sent will contain pre-paid envelopes for you to return them in.
If you need to travel from out of town to get to the treatment sessions (two trips in total) we will make a modest contribution towards your travel expenses.

What are the alternatives for treatment?
Currently there are no similar or alternative treatments available as part of normal NHS treatment.

What are the side effects of any treatment received when taking part?
What you are being offered is a "talking therapy" so it is very unlikely that there will be any side effects.

What are the other possible disadvantages and risks of taking part?
The main disadvantage of taking part is simply the time and effort it will take.
It is also possible that talking about issues to do with your illness may be embarrassing or difficult for you. However, both of the therapies are designed to help people to feel better and we don't expect that people will feel any worse as a result of taking part. If, through taking part in the research, it becomes clear that you are having any major difficulties (e.g. with depression) we will refer you to further sources of support.

What are the possible benefits of taking part?

We cannot promise that taking part in the study will benefit you. However, we do expect that both interventions will be useful for making people less distressed and better able to adjust to living with MS. You will also be contributing to scientific understanding of what help is the best for patients with MS.

What happens when the research study stops?

After the eight therapy sessions you will return to your normal care. We will continue to send out questionnaires for you to fill in six months and one year after the therapy has ended.

Since this is a trial of the two therapies, they will not be available after the eight weeks has finished. Even if the results of this trial show that either or both treatments were very effective they will not necessarily be available in the foreseeable future at your hospital.

If the information so far has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Appendix K: Telephone screening sheet for Chapters 5,6,7

SCREENING CHECKLIST

NAME_____
SOTON/LONDON_____
REFERRED BY_____
DOB_____
DATE OF SCREENING_____-

INCLUSION CRITERIA (MUST ANSWER YES)

Completed and returned a consent form	
Opportunity to ask questions and understand what the trial involves	
Definite diagnosis of MS	
Diagnosed within the last 10 years	
Aged over 18 years	
EDSS score below cut-off of 6.5 i.e. Ambulatory with assistance for at about 20 metres.	
Passed the cognitive dysfunction screening test (TICS-M) i.e. scored 20 or more.	
Can read, write, speak and understand English to an acceptable level to participate in therapy and assessments	
Willing to abstain from new pharmacological and psychological treatment (where possible) and inform the researchers if this is not possible	
Stabilised on MS medication (if using) (i.e. 3 months)	
Stabilised on anti-depressants (if using) (i.e. stable dose for 2 months)	

EXCLUSION CRITERIA (MUST ANSWER NO)

Other serious co-morbid chronic illness	
Medical history shows documentation of serious psychiatric disorder or substance abuse	
Currently in another treatment trial	
Currently receiving other psychotherapy	

SCREENING OUTCOME: ELIGIBLE ☐ NOT ELIGIBLE☐
REFER TO CHIEF INVESTIGATOR FOR REVIEW☐
NOTES:

Appendix L: Consent form for Chapters 5,6,7

CONSENT FORM

SAMS (Supportive Adjustment for MS) Trial (Ref 07/MRE12/6)

STUDY 3: A TRIAL OF COGNITIVE BEHAVIOURAL THERAPY COMPARED TO SUPPORTIVE LISTENING FOR ADJUSTMENT TO MULTIPLE SCLEROSIS

Participant Identification Number:

	Please initial box
I confirm that I have read and understand the information sheet dated ..... version ..... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected	
I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I give permission for the sessions I take part in to be audiotaped	
I agree to my GP being informed of my participation in this study	
I agree to take part in the above study	
OPTIONAL EXTRA INTERVIEW (you can do the rest of the project without doing this) I agree to take part in an interview about my experiences of therapy at the end of my treatment	
I give permission for the interview I take part in to be audiotaped	
I understand that when the research is published it may include direct quotations from my interview but that I will not be identified as an individual.	

Name of Participant_____

Date_____

Signature_____

Name of person taking consent (if different from researcher)
_____

Date_____

Signature_____

Researcher _____

Date_____

Signature_____

When completed, 1 for patient, 1 for researcher site file, 1(original) to be kept in medical notes

Appendix M: Table of intercorrelations between hypothesised correlates of adjustment outcomes

		CBRSQ										BIPQ							
		PVS	BES	ACHC	FA	CA	DA	EM	SF	AL	AV	CQ	TI	PC	TC	ID	CN	CH	EM
CBRSQ	PVS	1																	
	BES	.31**	1																
	ACHC	-.44**	-.24*	1															
	FA	.15	.07	-.04	1														
	CA	.53**	.29**	-.66**	.16	1													
	DA	.34**	.14	-.25*	.39**	.36**	1												
	EM	.42**	.25*	-.46**	.17	.45**	.22*	1											
	SF	.42**	.16	-.56**	.16	.60**	.33**	.34**	1										
	AL	.15	.11	-.06	.43**	.20	.16	.01	.15	1									
	AV	.07	.04	-.04	.45**	.16	.25*	.12	.18	.48**	1								
BIPQ	CQ	.13	-.02	-.23*	.14	.30**	.11	.16	.23	.37**	.32*	1							
	TI	.19	.07	-.05	..02	.27*	.00	-.07	.12	.09	-.04	.01	1						
	PC	.31	.18	-.29**	.01	.43**	.11	.10	.15	.05	-.25*	.05	.08	1					
	TC	.13	.09	-.21	.-.06	.26*	-.07	.05	-.04	.06	-.07	.21*	.10	.41**	1				
	ID	-.12	.03	-.03	.12	.17	.17	-.03	.02	.25*	.29**	.48**	.00	.06	.03	1			
	CN	. .49	.08	-.61**	-..03	.60**	.38**	.31**	.48**	.12	. 03	.37**	.16	.30**	.17	.18	1		
	CH	.183	.20*	-.09	.02	.20	.18	.17	.06	.03	-.04	-.19	-.08	.20	-.02	-.15	.04	1	
	EM	.42**	.22*	-.49**	.04	.62**	.24*	.44**	.45**	.28**	.12	.47**	.19	.29**	.24*	.23*	.58*	.08	1

PVS=Psychological vulnerability Scale, BES=Beliefs about Emotions Scale, ACHC=Acceptance of Chronic Health Conditions Scale , CBRSQ=Cognitive and Behavioural Responses to Symptoms, FA=Fear/Avoidance, CA=Catastrophising, DA=Damage, EM= Embarrassment, SF= Symptom-Focusing, AL=All-or-nothing behaviour, AV=Avoidance/rest, BIPQ=Brief Illness Perception Questionnaire, CQ=Consequences, TI=Timeline, PC=Personal Control, TC= Treatment Control, ID=Illness Identity, CN=Concern CH=Coherence EM=Emotional Representations

*p<.05, **p<.01

Appendix N: Summary of the content of the CBT manual

Chapter 1: Introduction to adjusting to MS	What is MS and what does adjusting to MS mean? Factors which have been shown to affect adjustment in MS. A CBT model of adjusting to MS which includes interactions between thoughts, behavior, biology and emotions. Assessment of current strengths and difficulties.
Chapter 2: Adapting to living with MS	What do we mean by acceptance? Strategies for becoming accepting. Dealing with negative emotions such as sadness, grief, loss, frustration, anger, anxiety, depression, shame and embarrassment.
Chapter 3. Setting goals and problem solving	Exploring values and setting treatment goals where change may be needed across different areas of life. Once problems are identified, developing a stepped approach to problem solving drawing on the patient's strengths and support network.
Chapter 4. Managing symptoms	Helping make the link between symptoms, thoughts and behaviors. May involve a discussion on accepting limitations. The pitfalls of becoming overly symptom focused and avoidant and strategies for managing these. Understanding MS symptoms, and which symptoms are likely to be a sign of relapse, medication side effects, or stress/distress. Diaries of patterns of rest and activity to see how these may influence symptom experience.
Chapter 5. How to tackle negative and unhelpful thoughts	Demonstrations of how perceptions of events can influence coping with illness. Identifying traps or 'errors' in thinking and finding alternatives can help with adjustment and levels of distress. Examples of unhelpful thoughts are covered such as fears about the illness and future, and high personal expectations. Using daily thought records of unhelpful thoughts, challenging these thoughts and coming up with alternative thoughts.
Chapter 6. Improving the quality of your sleep	Basic sleep hygiene including establishing a good sleep/wake routine which encourages natural sleep and addressing factors which interrupt sleep. Goal setting to improve sleep.
Chapter 7**.** Managing stress	Exploring skills to call on in times of stress such as distraction, problem solving, relaxation, prioritising, saying no and planning. Goal setting to improve stress management.
Chapter 8. Managing social relationships	Becoming more assertive. Managing relationships with care providers. Getting the right type of support for one's needs and sharing emotions.
Chapter 9. Preparing for the future	Identifying physical and emotional warning signs of relapse and normalising these. Developing a future management plan using personal strengths, newly learnt skills and support from others in difficult times.

Appendix O: Table of Chapter 6 Participant demographic characteristics

Variable	CBT *n* (%) or *M* (*SD*)	SL participants *n* (%) or M (*SD*)
Site		
London	24 (51.1%)	19 (45.2%)
Southampton	23 (48.9)	23 (54.8%)
Age	40.0 (8.3)	43.7 (10.4)
Gender		
Female	34 (72.3%)	30 (71.4%)
Ethnicity		
White British	37 (78.8%)	31 (73.8%)
Other White	5 (10.6%)	4 (9.5%)
Other	5(10.6%)	7 (16.7%)
Education		
No formal	0 (0%)	1(2.4%)
GCSEs or A levels (or equivalent)	22 (46.8%)	20 (47.6%)
Degree or postgraduate	20 (42.6%)	20(47.6%)
Other (e.g. vocational qualifications)	5 (10.6%)	1 (2.4%)
Marital status		
Married or living with partner	29 (61.7%)	23 (54.8%)
Single	12 (25.5%)	14 (33.3%)
Divorced or separated	6 (12.8%)	5 (11.9%)

Appendix P: Table of Chapter 6 Participant MS characteristics

	n (%) or *M* (*SD*)	*n* (%) or *M* (*SD*)
Time since diagnosis (years)	3.5 (2.8)	4.3 (3.0)
Type of MS		
Relapsing-remitting	37 (78.7%)	33 (78.6%)
Primary progressive	6 (12.8%)	5 (11.9%)
Secondary progressive	4 (8.5%)	4 (9.5%)
EDSS	4.9 (1.4)	5.1 (1.0)
Relapses in 12 months prior to baseline[1]		
None	8 (19.5%)	17 (40.4%)
1 to 3	25 (61.0%)	18 (42.8%)
More than 3	7 (17.1%)	2 (4.8%)
Missing	1 (2.4%)	0 (0%)
Experiencing relapse at baseline[1]		
Yes	4 (9.8%)	3 (8.0%)
No	36 (87.8%)	34 (92.0%)
Missing	1(2.4%)	0 (0%)
Cognitive Impairment (TICS-M score)	26.8 (3.6)	26.5 (3.3)

Appendix Q: Paired sample t tests for pre-post changes within treatment arms

		CBT (*n*=47)				SL (*n*=42)			
	Variable	Baseline *M* (*SD*)	Post-therapy *M* (*SD*)	*t* (*df*)	*p*	Baseline *M* (*SD*)	Post-therapy *M*(*SD*)	*t* (*df*)	*p*
Adjustment outcomes	GHQ	13.96 (5.51)	10.00 (4.39)	4.23(46)	**.000****	15.95 (6.54)	14.01 (6.94)	2.07(41)	**.045***
	WSAS	14.12 (8.26)	11.85 (7.37)	2.37(43)	**.022***	13.79 (8.51)	13.29 (9.61)	.46(41)	.647
Process variables	PVS	16.17 (5.21)	14.68 (4.84)	2.40 (46)	**.021***	16.91 (5.09)	16.68 (5.38)	.50(40)	.618
	BES	21.77 (7.27)	16.95 (6.43)	3.80(46)	**.000****	23.17 (7.37)	20.48 (7.88)	3.52(41)	**.001****
	ACHC	32.30 (7.84)	34.79 (6.40)	-2.77(45)	**.008****	29.82 (7.38)	31.95 (7.99)	-2.80(40)	**.008****
	BIPQ consequences	6.17 (2.33)	5.70 (1.98)	1.86(46)	.070	6.00 (2.19)	6.10 (2.12)	-.35(41)	.730
	personal control	5.96 (2.31)	5.57 (2.41)	1.026(46)	.310	5.38 (2.16)	5.26 (2,12)	.45(41)	.655
	treatment control	4.63 (2.69)	4.37 (2.80)	.67(45)	.508	4.53 (2.20)	4.11 (2.37)	.99(37)	.329
	illness identity	5.89 (2.45)	5.41 (2.04)	1.65(45)	.105	5.52 (1.88)	5.36 (2.01)	.55(41)	.538
	concern	6.68 (2.56)	5.45 (2.03)	2.83(46)	**.007****	7.00 (2.26)	5.36 (2.01)	4.56(41)	**.000****
	coherence	3.13 (2.19)	2.55 (1.87)	2.31(46)	**.025***	2.57 (2.30)	2.19 (2.03)	1.08(41)	.288
	emotional reps.	7.39 (2.44)	5.41 (2.56)	3.26(45)	**.002****	7.33 (1.95)	6.19 (2.92)	3.43(41)	**.001****
	CBRSQ fear/avoidance	9.38 (4.49)	8.36 (3.67)	2.13(46)	**.039***	9.29 (4.07)	8.73 (4.30)	1.26(41)	.214
	catastrophising	8.62 (3.70)	7.13 (3.04)	3.31(46)	**.002****	8.60 (3.26)	8.43 (3.94)	.41(41)	.681
	damage	10.42 (3.00)	9.95 (2.65)	.98(46)	.333	11.32 (3.32)	11.02 (3.12)	.64(40)	.524
	embarrassment	6.13 (3.90)	5.22 (4.29)	1.44(45)	.156	6.52 (4.09)	6.83 (3.94)	-.62(41)	.538
	Symptom-focusing	8.84 (3.44)	7.47 (3.17)	3.04(46)	**.004****	9.05 (3.55)	8.67 (3.57)	.93(41)	.360
	all-or-nothing	7.09 (4.00)	7.19 (3.43)	-.28(46)	.784	7.65 (3.54)	7.26 (3.43)	.82(40)	.416
	avoidance/resting	10.76 (5.30)	9.62 (4.37)	2.53 (46)	**.015***	10.75 (5.02)	10.02 (4.91)	1.35(41)	.183

*p<.05, **p<.01, high scores=worse, except for ACHC

Appendix R: Table of Chapter 7 Participant demographic and disease characteristics

Variable	***n*(%) or range, *M(SD)***
Gender	
Male	7 (23.3%)
Female	23 (76.7%)
Age (years)	24-64, mean 43.5, (9.4)
Marital status	
Single	8 (26.7%)
Married/Living with partner	18 (60%)
Divorced/Separated	4 (13.3%)
Ethnicity	
White British	24 (80%)
Other White background	5 (16.7%)
Asian/British Indian	1 (3.3%)
Type of MS	
Relapsing Remitting	26 (86.7%)
Primary Progressive	3 (10%)
Secondary Progressive	1 (3.3%)
EDSS (at baseline)	2.5-6.5, mean 5.0, (1.1)
Time since diagnosis (years)	0.5-10, mean 2.9, (2.4)
Length of symptom experience prior to diagnosis	
Less than 3 months	3 (10%)
6-12 months	4 (13.3%)
1 to 2 years	4 (13.3%)
More than 2 years	19 (63.3%)

Appendix S: Table of Chapter 7 Participant's intervention characteristics

Variable	***n* (%)**
Site	
Southampton	19 (63.3%)
London	11 (36.7%)
Type of therapy received	
CBT	15 (50%)
Supportive Listening	15 (50%)
Satisfaction with therapy	
very satisfied	10 (33.3%)
moderately satisfied	6 (20%)
slightly satisfied	5 (16.7%)
neither dissatisfied or satisfied	7 (23.3%)
slightly dissatisfied	1 (3.3%)
moderately dissatisfied	1 (3.3%)
Perceived improvement	
very much better	2 (6.6%)
much better	5 (16.7%)
a little better	8 (26.7%)
about the same	14 (46.7%)
a little worse	1 (3.3%)

Appendix T: Interview schedule for Chapter 7

Introduction

- Introduce self to participant.
- Ensure comfortable/uninterrupted.
- Explain purpose of study: what they thought about the therapy they had
- Explain that there are no wrong or right answers and that it is their perspective and their experiences that are of interest to us
- Explain that interviewer is independent of the trial- not involved in its design, the therapy, don't know about the results etc.
- Remind about confidentiality, reason for tape-recording, and ability to stop at any time

---

1. **First of all, can you start by telling me what you were expecting from the therapy sessions?**

What did you think the therapy would be like?
In what ways (if any) did you think it might help you?

2. **How did you find the therapy overall?**

Tell me how you found your first session
Tell me about the other sessions
Tell me how you found the homework tasks [if appropriate]
Tell me about your partner's involvement [if appropriate]

3. **Can you tell me what you liked about the therapy?**

What was helpful? Why? How?
Were there some sessions/some aspects that were more helpful than others?

4. **Can you tell me what you disliked about the therapy?**

What was unhelpful? Why? How?
Were there some sessions/some aspects that were less helpful than others?

5. **Tell me about anything that you feel has changed from having the therapy?**

Can you tell me what changed? (anything different in your day-to-day life with MS, the way you are dealing with your illness?)
Can you tell me how you came to notice things changing?
Why/how do you think things changed?

6. **Do you have anything else you would like to tell me about your experiences of this therapy that we haven't already covered**

What would you feed back to the people who designed this therapy?
What advice would you give to people thinking about having this sort of therapy?

Appendix U: Coding manual for Chapter 7

	Theme label	Subtheme labels and definitions	Examples/locations
1	EXPECTATIONS & MOTIVATIONS	**Not knowing what to expect** Having little or no knowledge of what the therapy would be like. Yet, open-minded and willing to give it a go as there is nothing to lose. Content to do this as health professional had mentioned it.	I didn't know anything about CBT so I just thought oh well, it certainly won't do me any harm, erm so I that's why I volunteered and I didn't know anything about it, or or what to expect really. Participant 13, (CBT) Page 1, Line 13
		Having a basic grasp A basic, general understanding that sessions would be talking about impact and emotional aspects of MS in order to improve how you feel. CBT seen as goal-focused, structured, skills and learning-based and to do with thinking. SL seen as a counselling method where patient will talk about whatever they want or need to and be listened to. Some showed preference towards being allocated CBT if they had heard of it – more likely to think it would be useful.	sort of in the now and what sort of I can do really to help myself and how to get through things myself you know rather than ermm giving me the sort of tools if you like to work through things Participant 24, (CBT) Page 1, Line 8 I was expecting erm… to well very much really what happened, you know erm… someone the that listened and sort of reflected and summarised some of the things and prompt you know prompted me but without actually giving advice Participant 14, (SL) Page 1, Line 13
		Curiosity Interested in what the approach would entail. Motivated by curiosity. Especially in those with relevant jobs or education (nurses, those who had studied psychology)	So I was intrigued, you know because I did as I say I studied psychology so I was interested to see what what was em you know what what angle they were coming from Participant 18, (CBT) Page 1, Line 27

	Theme label	Subtheme labels and definitions	Examples/locations
		Hope for improvements Hopes and expectations that therapy would be constructive and lead to improvement in some aspect of life. Specific expected gains are not always described. Includes: learning new ways of coping, being more accepting, feeling less burdened by negativity and feeling better physically. Hopes and expectations may pre-exist but can be solidified during/after first (introductory) therapy session.	I s'pose ermm what I was expecting was ermm to be able to deal with my diagnosis of MS in a a in a better way Participant 20, (SL) Page 1, Line 11 for… three years really since I was diagnosed I was just… I felt like my life was … you know over really. It was… bizarre thinking but I couldn't … I couldn't get out of that mindset of thinking and I was just hoping that… the with the CBT it would help me break that cycle of thinking Participant 8 (CBT) Page 1, Line 21
		Low expectations Low expectations or scepticism. Not expecting therapy to be very good, or any/much change to come about through participation	I went through it not thinking necessarily that it was gonna help me, and I got a huge benefit out of it Participant 28, (CBT) Page 9 Line 21
		For the greater good Motivation to take part in order to help others in the future, contribute to science and understanding. The ability of the research project to contribute towards helping others newly diagnosed with MS was valued. Not necessarily just (or at all) for personal gain	The reason why I decided to do this is because I thought it might help other people who's in the same situation as me. **Yeah**. In long so long term other people might be diagnosed with M.S. and it can help them Participant 12, (CBT) Page 1, Line 6
		Concerns Worries that therapy might be difficult or unpleasant in some way. Includes worries about having to put in a lot of effort, getting upset, or having difficulty engaging in telephone-based interaction.	I was a little bit apprehensive that it would be quite emotional and I would end up sort of crying which ermm isn't a bad thing but ermm Participant 20, (SL) Page 1, Line 10

	Theme label	Subtheme labels and definitions	Examples/locations
2	SPECIAL OPPORTUNITY TO TALK	**The neutral listener** The value of having the opportunity to talk to and be listened to somebody specifically there for that purpose. Importance of this person being neutral and uninvolved. Also includes discussion of lack of other people in the participants' life who are available or appropriate to talk to.	It was just nice to have someone there to talk with because I spend a lot of lot of time on my own Participant 1, (SL) Page 3, Line 25 I think it was nice to have someone to listen to my woes. And eh the fact that they were objective, someone that it wasn't emotionally involved with my life **Yeah** It was very useful for me because I was able to tell her things I probably wouldn't tell other people. Participant 18, (CBT) Page 3, Line 43
		Offloading The process of offloading or releasing thoughts and feelings through talking as being therapeutic. Both significant emotional issues, and day-to-day issues and concerns.	it did release some anxiety and some anger Participant 20, (SL) Page 1, Line 27 And it was just really good to be able to you know, get rid of some of your worries and anxieties about things in life. Participant 27, (CBT) Page 1, Line 8
		Filling the silence Finding it difficult and burdensome to find relevant things to talk about. Silence filling ending in repetition or talking about unrelated and insignificant things which was not very useful. This tended to get worse after the initial few sessions	I found it sometimes hard work because…… [sighs] …… you know pauses are very effective in a conversation and no-one likes to have too long a pause and if, if the pause ended up being too long you'd quickly have to think of something else to to talk about and that was the hard bit to try and think of something new to talk about all the time. Participant 1, (SL) Page 1, Line 23 err sessions drew on, ermm I really felt like we were just going around in circles. And saying, covering the same ground over and over again Participant 26, (SL) Page 3, Line 1
3	HEIGHTENING AWARENESS OF THOUGHTS AND FEELINGS	**Setting aside time to think** Usefulness (and unusualness) of having a specific time and place set aside to think and reflect	it carved out time where I had to stop and thinking and take you know take time out form the rest of life and work from home from you know anything else in life em and to stop and think about me and what was going on Participant 19, (SL) Page 3, Line 20

	Theme label	Subtheme labels and definitions	Examples/locations
		Increased clarity The therapy process led to the recognition and/or clarification of problems. Growing awareness and clarity. Understanding of own thoughts, feelings and responses to people and situations is heightened.	she was able to sort of reflect a lot of that back so it sounded clearer to me and yeah so that was good. Participant 14, (SL) Page 2, Line 24 I felt it was very therapeutic and it allowed me for the first time ever really to develop my own thoughts Participant 30, (SL) Page 2, Line 7 you really did get to some deep kind of areas of understanding about your thought life, about your personal life, about how that had affected your thought life in in the you know as years have gone by Participant 15, (CBT) Page 2, Line 20 you know organise my thoughts a little and helped me sort of understand how I did feel about it all a little bit better. Participant 26, (SL) Page 2, Line 24 As I was a more aware of everything. I I had a habit of walking around with my eyes closed I suppose, being very insular… erm and not taking notice of things, which now I tend to do more. I, you know, I notice how I'm thinking how I'm feeling how I'm acting what what time of day it is compared to how I'm feeling or… erm what I've been doing and how I'm feeling. So I tend to try, you know I I'm actually thinking more about what's going on Participant 5, (SL) Page 5, Line 7
		Saying it or writing it The process of saying things out loud as being useful in enhancing awareness, reflection and clarity about what you think, feel and future courses of action.	it felt really quite powerful for me… erm… you know to hear, it was just like, wow I said that now, it's out in the open… dealt with, you know Participant 3, (SL) Page 4, Line 23 I write it down and think OK, that's what I need to think about, how can I get round that. Do you see what I mean? Participant 24, (CBT) Page 24, Line 22

	Theme label	Subtheme labels and definitions	Examples/locations
		Questionnaires and interviews Trial data collection processes as providing an opportunity for reflection.	mid-therapy questionnaire I think made me...think more about MS Participant 20, (SL) Page 5, Line 19 it's ermm enabled me to revisit some of the feelings and experiences that I went through over the eight week trial Participant 20, (SL) Page 8, Line 26
		Getting upset Difficulty having to talk about upsetting things, or digging up upsetting or difficult experiences from the past. Wanting to avoid getting upset. Different views of whether becoming upset was therapeutic or unhelpful, dependent on how the upset was dealt with (or not).	the only one I didn't like it was when I was upset but again its because I had to go into work eh and that did really get to me Participant 17, (CBT) Page 7, Line 40 there's something quite draining about just pouring everything out and then you're just left, you know ermm..... Participant 32, (SL) Page 6, Line 26
4	PROMPTING ACTION	**[no subtheme]** Therapy process prompts action towards goals. E.g. problem solving, decision making, initiating behaviours. Through both reflection, specific strategies, and having to report to the therapist. .	it gave me a sort of bit more confidence to go and talk to various people about er like friends and … a an accountant and 'cause I'd got my thoughts clarified Participant 14, (SL) Page 9, Line 7 I think I promised oh I wrote down I would start doing some swimming which I've never done actually but I need to do that. … Well, yeah I did I did it did come and set me things to do which I probably wouldn't have done without it. Participant 18, (CBT) Page 3, Line 36

	Theme label	Subtheme labels and definitions	Examples/locations
5	LEARNING STRATEGIES	**Picking up a toolbox of skills** Many people were quite general about what they have learned e.g. coping skills, ways of dealing with things, a toolbox of skills. Some people just named chapters in the CBT manual, stating they were helpful but giving little detail about what specifically they learned and put into practiced. This theme captures general comments regarding learning of self-management strategies for now and the future.	of course you have good days and bad days so but it has given me some tools to work with. Participant 18 (CBT) Page 5, Line 37 but it gave me the sort of skills if you like to actually think oh right, OK yes I am doing that, but I can see why and certainly it gave me sort of the as I say the tools and the skills to sort of carry on with that and to actually in areas where I wasn't sure how to sort of cope with things Participant 24, (CBT) Page 1, Line 27 this certainly gave me the tools to ermm [?offer?] for the ongoing care of my MS if you see what I mean, to actually help me help myself I suppose Participant 24, (CBT) Page 28, Line 33
		Lifestyle changes to manage symptoms Participants learned ways of dealing with symptoms such as fatigue or pain, through changing aspects of their lifestyles, particularly adjusting levels of activity and pacing themselves.	You know it it taught me a lot of things it you know, simple things like doing housework, pacing myself. Participant 27, (CBT) Page 1, Line 32 it was good to be able to learn things to deal with when I'm thinking right, I'm tired, I'm not gonna bother doing that 'cause I'm tired. Ermm and learn little strategies for how to sort of cope with that and plan, I almost plan my week now, and I don't always do everything that I say I'm going to do but I also don't beat myself up if I don't do everything so you know to have time set aside to teach me ways like that ermm to do err however unpredictable my MS decides to be day-to-day was great. Participant 28, (CBT) Page 4 Line 25
		The power of thoughts Participants gain an insight in how thinking influences mood and behaviour and symptoms. . Sometimes the process simply reduced to positive thinking, positive mental attitude. Sometimes details and examples given which shows they	So she helped me to go over it and she said ok which part of that is catastrophising catastrophising, which part was personalising and so I picked out that when I said it's always gonna be like this, that was catastrophising it all **Yeah** and then when I don't want er not want to I don't want to not be able to walk… and how can I stop these symptoms from happening I was personalising them to me and it isn't always gonna be like that **Mmm** erm… er I also on one of my other situations on that

	Theme label	Subtheme labels and definitions	Examples/locations
		understood and implemented the CBT strategies. This includes understanding your thinking patterns and being able to identify unhelpful thoughts and then adjusting thinking to something more positive, balanced or realistic Participants report CBT thought management strategies to be helpful but can be quite challenging to learn as it is fairly complex, new to people and negative ways of thinking can be deeply entrenched. More time may need to be spent on this, and more therapist input may be needed. However, some people seem to have internalised the skill and are now able to do it automatically and naturally without writing it down or doing it systematically.	I used the word 'should' all the time. **Right**. I 'should' and I 'could' and 'have to' and [laughs] and so we looked at the use of those words and how that kind of effects erm thoughts… And again it er just made me realise that erm when I say those things to myself actually it makes the pain worse and I really didn't know that er and the book verified that as well **Mmm** and er your thinking can actually make your pain feel worse at the time as well… Participant 15, (CBT) Page 7, Line 6 the overwhelming thought is when you're first diagnosed is 'oh no this disease is just going to take over and I'm going to end up in a wheel chair and that's it' you know and I and you do have those thoughts come flooding over but its its learning what to do with those thoughts and I think I think the course has helped to erm underline that. Participant 15, (CBT) Page 8, Line 24 also with the positive thinking thing was really good because eh you know I think its very very useful to try and turn round a negative into a positive every time Participant 18, (CBT) Page 4, Line 25
		Challenging your current ways Part of the learning process was having your current ways of doing things challenged. Another person's point of view or a different angle is introduced and there may be resistance to change and trying new ideas and strategies.	she pushed me on some things in a very kind way, erm… to to sort of break down my resistance to various concepts… erm and I'll give you one example of that. Some of the some of it was about erm dealing with… [sotto voce] what were they called… unhelpful emotions. Right. And erm…at first I didn't want to look at that… at all. I didn't want to look at that section Mmm but when we talked it through again… I realise that actually it could be very useful Participant 11, (CBT) Page 2, Line 32 but it was sort of like… not as much challenging, it… it was a case of oh why aren't you doing it this way or why aren't you doing it that way. Participant 4, (CBT) Page 2, Line 20 what I liked about it was that it's not it

	Theme label	Subtheme labels and definitions	Examples/locations
			wasn't at all aggressive saying "why haven't you done that?" or "have you thought about that but what have you done about it?". It's absolutely completely on the level, ermm and it therefore with somebody not in you know immediately in my life, ermm it was fantastic because therefore it's somebody else's point of view, which I needed. Participant 29, (CBT) Page 2, Line 6
6	BUYING INTO IT	**Putting in effort** The participant puts in effort in order to get gains from therapy. This includes making time for it, doing stuff outside of sessions. In CBT this is usually homework. In SL this is preparing for the session and/or reflecting on what happened in the therapy. The effort can be perceived as burdensome, but also as enjoyable.	I just didn't want to be starting doing these telephone interviews each week and I I would sort of, we did them on a Thursday morning and I would ignore the manual until possibly Wednesday night or even early Thursday morning and think oh no I've got to do that. It became a chore and I didn't like it all. Participant 13, (CBT) Page 2, Line 18 I think it like most things in CBT it's if you what you put in, you get out of it, you know and I was honest and open and ermm I think really sort of worked on it to the best of my ability throughout the whole session and afterwards sort of the the ongoing things and sort of kept to it if you like Participant 24, (CBT) Page 1, Line 15
		The right approach A helpful approach to therapy is open-mindedness and willingness to engage and give it a chance.	be open minded, go for it and just just say how you feel Participant 16, (SL) Page 9, Line 1 some people may be a bit sceptical about counselling and say oh you know I don't I will work things out for myself and I can do it but you know I'd say go for it and try it and see how it you know how it can help you Participant 14, (SL) Page 16, Line 7

	Theme label	Subtheme labels and definitions	Examples/locations
		Relating/Resisting Extent to which a person reports finding therapy useful and puts in effort is related to whether they understood, related to, resisted or liked the therapy approach, rationale, and materials (manual, quotes). May change over the course of therapy.	I still don't understand it really and that [coughs] wasn't the fault of the person doing it. I just looked at the manual and saw these flow charts of you know this leads to this and you can do this to sort that you and it's just not, as I keep saying, it's not my sort of thing Participant 13, (CBT) Page 6, Line 26 when it was she was going through it I thought, that's, do you know that makes sense. Participant 23, (CBT) Page 1, Line 32 I could really you know you could relate to to all of them and how you know that you I thought it was well you know it was very well done, the different like sections Participant 23, (CBT) Page 9, Line 6 Rubbish [laughs]. Erm it didn't, it wasn't my sort of thing at all. Er just didn't do anything for me and about half way through I said that I didn't want to continue Mmm 'cause I didn't think I was sort of the right person for it or or you know agreeing with it o, I didn't like it at all. Participant 13 (CBT) Page 1, Line 18
		Needing a positive approach A conviction that talking about or dwelling on negative or upsetting things is not helpful. Therefore, therapy that pushes you to talk or think about difficult things is not appropriate and may be resisted, or found unhelpful. Need to concentrate on positives and be reassuring	It didn't seem positive. Mmm. It all seemed to be based on negative things. One thing that I kept getting asked was negative thoughts. Well I don't have them and the people I know who have also got M.S. ... don't seem to have them. So it seemed to be, so it seemed to me... everything was always basing everything on negativity **mmm** which doesn't seem right.... Participant 4, (CBT) Page 1, Line 12

	Theme label	Subtheme labels and definitions	Examples/locations
		Things you would naturally do anyway The issues being raised within therapy had already been dealt with to some extent by the participants on their own. Some of the therapy content was felt to be basic- just common sense. Some participants felt they therefore had little to gain. Others appreciated the reminder and structure available for looking at these issues, or benefited from reassurance that they were doing well.	I've been working on that myself personally so I think that that does actually affect the way you live your life, it can be life changing I think so em as I said if it wasn't for the fact that I'd come across that in yoga I would say that it was enlightening Participant 18, (CBT) Page 3, Line 46 I had started doing some of those things ermm prior to actually the course starting and before I knew it's content anyway. Ermm but it all just reaffirmed and err really from my point of view helped me with each of the sections that we covered, in whether I wasn't doing something maybe as err maybe as organised as I could do or things that gave me ideas of how to deal with things or if I was doing them in a in a way that almost was what the chapter and verse was saying I should be doing then I was I was quite pleased because I'd already started doing it. Participant 25, (CBT) Page 2, Line 32
		Enjoyment and interest Therapy as a nice, fun or interesting experience i.e. enjoying and looking forward to the sessions regardless of whether they were perceived as helpful.	I loved it, I loved every bit of it. Participant 27, (CBT) Page 2, Line 24 homework that was being expected from you and I actually found that quite exciting 'cause I er actually like personal development stuff anyway Participant 15, (CBT) Page 1, Line 36
		No criticism Unable or unwilling to find an aspect of the therapy to criticise. Appeared to find therapy ideal/perfect.	it was very good, very good so I I wouldn't I'd say there well there was nothing that I would say that would still needed changing about it at all, nothing. Participant 23, (CBT) Page 9, Line 1 **That's good. So what was helpful?** What talking to her? **In in the sessions, anything you like, what was helpful?** Every single thing. **Mmm.** Every single thing. Participant 27, (CBT) Page 6, Line 16

	Theme label	Subtheme labels and definitions	Examples/locations
7	TARGETING THE RIGHT PEOPLE AT THE RIGHT TIME	**The right sort of person** Patient perceives that there are certain types of people who suit therapy (or parts of the therapy) better than others; matches and mismatches. The extent to which the individual is the right sort of person influences how relevant and useful the therapy is.	But I'm a very strong personality and I…I, I don't really have that great need and I did say that I might not be quite the right sort of person for this Participant 1, (SL) Page 1, Line 5 it's good, I would say, for people who are worried and anxious about M.S. For those people I think it's just the thing. For people like me who… [sighs] who don't really need to to talk about it, then I think it doesn't make so much difference to them Participant 1, (SL) Page 6, Line 21 I find it all woolly and it it's not me, I'm quite a practical person and I'm not I don't sit pondering Participant 13, (CBT) Page 3, Line 4 I presume it might be helpful to somebody who's ermm I don't know, unstable, depressed Participant 21, (SL) Page 9, Line 13
		Disease status MS status influences whether therapy is useful or relevant at that time; relapse, progression, type of MS, severity of disability, time since diagnosis. NB- little consistency between patients about what disease factors are relevant.	I already had been, had M.S. for for a few years, so it's not like I was just diagnosed the previous months, in which case it would have been… maybe a whole lot more helpful. Participant 1, (SL) Page 5, Line 38 I found that quite difficult because I didn't really know, I didn't really have a lot to say on it as I haven't had regular relapses and I haven't experienced sort of difficulties erm that I could talk about at first hand. Participant 16, (SL) Page 1, Line 27 Although not now relevant to my actual condition at that time so you know that was but obviously it prepares you for a worse situation maybe Participant 18, (CBT) Page 1, Line 49 it is too general… that it doesn't 'cause I've got one type of M.S. and to me it dealt with another type… and it… that's what I

	Theme label	Subtheme labels and definitions	Examples/locations
			was finding. It only seemed to be dealing with relapsing remitting type… **Right**. And I've got progressive so a lot of it, I found, it didn't necessarily apply to me. Participant 4, (CBT) Page 3, Line 37
		Suitable state of mind Participants need to be in an appropriate state of mind in order to benefit from therapy. Includes level of acceptance of MS diagnosis, ability to concentrate and reflect etc. Readiness to tackle MS-related issues.	through the fear your universe has become extremely narrow and there is its its like there's no peripheral vision there is only focus. **Mmm** and talking about anything even what it is that you are scared of is essentially peripheral vision **Right** its not focused. Participant 7, (SL) Page 6, Line 16 but the first year, people are finding out about themselves and how they're dealing with M.S. so it don't work. Participant 4, (CBT) Page 2, Line 12 in June will be nearly five years ago with my MSand during that period of time, ermm I basically didn't really accept my diagnosis, you know it sort of was one of those things I just tried to get on with life and sort of brushed it to one side, and it really wasn't until early part of last year, where my health generally deteriorated, ermm and also obviously it was becoming more difficult for me to cope ermm on a day-to-day basis, particularly at work, and it wasn't then until early May that I realised ermm how serious my health had been where I'd been trying to struggle on Participant 25, (CBT) Page 2, Line 5
		Life events and stressors Therapy as particularly useful when it coincides with 'material' to work on in the form of important or stressful life events, or day-to-day stresses. Although if you are particularly stressed, therapy can also be an extra burden	quite a lot had happened to me emotionally since then erm and so as I said to you earlier, this kind of came along at the right time for me or a very good time for me. Participant 11, (CBT) Page 3, Line 34 I got made redundant in the middle of it all.So err and luckily having just said that during the therapy, made me realise that ermm maybe I didn't want my career anymore, being made redundant didn't

	Theme label	Subtheme labels and definitions	Examples/locations
			actually become the devastating blow it might have been Participant 28, (CBT) Page 5, Line 9
		Wide applicability Therapy as useful to a wider range of people than just those newly diagnosed. Includes people with other chronic diseases, later in disease trajectory, people without MS.	I really think it is something that people with MS and other chronic conditions could really benefit from. Participant 28, (CBT) Page 9, Line 12 Don't let it just be for the introduction erm you know to those people who've been newly diagnosed… Participant 15, (CBT) Page 10, Line 39 I think regardless whether people have MS or not just ermm recommend it...to everybody. Participant 29, (CBT) Page 17, Line 6
8	QUALITY OF INTERACTION	**Bonding with therapist** Building up a comfortable and trusting relationship with the therapist was important to people. Tendency to like the therapist and perceive her to possess positive characteristics e.g. kindness.	the therapist was erm… extremely er friendly and helpful and erm very, I felt very comfortable with her from the beginning erm so that was that was good Participant 11, (CBT) Page 2, Line 5 Sarah was lovely ermm from the first time I met her so that was really reassuring Participant 20, (SL) Page 2, Line 27 she's very nice, very lovely lady, easy to talk to Participant 21, (SL) Page 9, Line 25
		Warming up Initial awkwardness which eases within first session, or within few minutes of starting each session. First session as an introduction that made participant feel comfortable.	Erm well at the beginning it's erm well you do feel a bit nervous… because well, it's like I said you are unsure, you don't know what's gonna be… happening erm. Participant 2, (CBT) Page 2, Line 40 difficult to keep talking **mmm** all the time, all the time, all the hour through, but then… that was more in the beginning and once I got going then, then suddenly the

	Theme label	Subtheme labels and definitions	Examples/locations
			hour had gone Participant 1, (SL) Page 6, Line 16 once once we had to into our stride then then actually I began to really look forward to them Participant 19, (SL) Page 2, Line 34
		Naturalness of communication Extent to which interaction is natural. The one-sided nature of SL communication.	I would have preferred something that was a bit more ermm ermm interactive. Participant 32, (SL) Page 5, Line 8 don't mind talking, I talk quite a lot I do [laughs] I do it for a living almost, but the fact that you're talking about yourself… and you're not getting a a response almost, you're just literally just keep talking Participant 5, (SL) Page 5, Line 24
		One to one format Pros and cons of the one to one format versus a group meeting	Sometimes I think if you're in a group of people you'd be bouncing off each other all the time, Participant 22, (SL) Page 2, Line 21 it was good that I was one on one with the person you know and not a group. Participant 9, (SL) Page 8 Line 39 I don't know if you'd be able to, well I talk so much that usually err nobody else would be able to get a word in edgeways when I'd started so yeah. I don't know about that seeing other people might be be quite therapeutic Participant 22, (SL) Page 2, Line 22
		Telephone vs face to face Impact of telephone and face-to-face formats on interaction and therapeutic relationship	I was sort of thinking well it that would be really strange because it will be an anonymous person on the end of the phone. I won't have made a sort of sort of link with them, but in fact I think it worked really well Participant 14, (SL) Page 1, Line 30 I think if you were just in a room and you were like face to face with someone I think its better its more personal and its yeah I think a couple of more face to face

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			Participant 17 (CBT) Page 9, Line 37 there were a couple of occasions where I did cry again on the telephone and that tended to be a little bit difficult...ermm not only for me but for the counsellor as well counsellor because ermm you know a lot of it is to do with empathy isn't isn't it and I think you can get that better with the one to one Participant 20, (SL) Page 3, Line 12 Maybe it would have been better if ermm it wasn't done on the phone, I hate talking to people on the phone, Participant 21, (SL) Page 9, Line 27
		Expertise and professionalism Perceiving the therapist or therapy design to be professional and show expertise in dealing with MS	[therapists name removed] was obviously very patient and very em enthusiastic and eh very very what's the word when someone really really follows the book. Em she was very focussed on on the what we were going to do together. So I think it was good, it was well planned out and well thought out Participant 18, (CBT) Page 4, Line 3 I think they knew what they were, they'd obviously done a lot of research in well they knew the thing beforehand because there's you know when you think oh someone, they know what they're talking about? And that was very very ermm obvious when you're doing it 'cause you're not having to explain it to somebody who's teaching you, do you know what I mean? Participant 23, (CBT) Page 8, Line 31
		Attributing gains to therapist Extent to which the therapist was described as being the source of any change or improvement in adjustment, rather than specifics of the therapy	the counsellor was absolutely brilliant I mean you know she was a very very good counsellor and being that I've met counsellors, had counselling before, trained done some training in counselling ermm I know that what she did was a hundred percent to get me to where I got to. Participant 20, (SL) Page 5, Line 30

	Theme label	Subtheme labels and definitions	Examples/locations
9	PRACTICALITIES	Doing therapy when you have MS Symptoms and impairment from MS as important considerations in delivering a therapy	partly it's to do with physical comfort because I actually find holding the phone for an hour very very tiring Participant11X, (CBT) Page 2, Line 12 everybody accommodated me trying to park and ermm...you know I was able to go to the the loo was upstairs but I mean I can still do stairs Participant 20, (SL) Page 2, Line 25
		Convenience Importance of flexibility with scheduling and being able to fit it easily into work/family routine	I liked the fact that it was It was flexible around me and when I had time so, I did it in the evenings because of the kids. Participant 3, (SL) Page 4, Line 2 it wasn't inconvenient, if it was inconvenient I wouldn't have agreed to do it you know Participant 17, (CBT) Page 7, Line 11
		Trial procedures Procedures such as filling in questionnaires or being recorded can lead to a degree of uncomfortableness, frustration or burden.	if there was one criticism I'd just say was a bit long winded at times but you know that's you know, that's normal. Kind of questionnaires Participant 18, (CBT) Page 4, Line 42 it just made me cross…. I don't think the questionnaires were made up specifically for people with M.S. Participant 13, (CBT) Page 5, Line 1
10	INVOLVING LOVED ONES	**Deciding whether to involve them** Deciding not to involve them because therapy is your own, special thing done on your own, lack of time, whether they would buy into it or not	I didn't really want Mum and Dad there really er 'cause I could do it all by meself you see Participant 12, (CBT) Page 3, Line 90 unfortunately that specific time, we couldn't get her to come along, she was actually doing something else. Participant 25, (CBT) Page 7, Line 2
		Keeping them in the loop Discussing what went on in the session, reading the materials. Generally supporting attempts to deal with MS/adjust	he didn't come along but I was telling him about it and that so it was it was good to speak to to talk to him about it and running you know going saying oh what had happened, going through what I'd done that day so so he didn't come with me but and also there was some booklets and

	Theme label	Subtheme labels and definitions	Examples/locations
			everything that I brought back, he was reading through those which it was I felt it really got support from him as well which was good. Participant 23, (CBT) Page 6, Line 29 in between times, I'd updated my wife on all of these ermm sessions after each conversation, generally what we'd talked about here and there. Not in great detail I admit but you know sort of updated [?as?] she had the opportunity of reading the the large booklet and ermm the support supplement that was given to us at the start as well. Participant 25, (CBT) Page 7, Line 5
		Benefits and drawbacks for families A variety of potential benefits and drawbacks as a result of involving a family member. Benefits include increased understanding of MS and its effects on both partners which improves relationships. Another benefit is opening up communication- bringing issues to the foreground (sometimes but not always resolved). But one family member had regrets about opening up about feelings and getting upset	it was it was a good chance to see how [**partner's name removed**] really felt about my diagnosis 'cause I think he was always quite wary of saying stuff in front of me… **mmm** but actually I think it just provided a safe environment to be really honest… **mmm** about how he was feeling, how I was feeling and… yeah it was it was good… Participant 8, (CBT) Page 4, Line 17 to be able to talk about some specific iss- not issues is probably a strong word but ermm you know to be able to say the things that he found hard and he was able to say he found it hard when I'm emotional ermm Participant 28, (CBT) Page 3, Line 18 So that helped me as well because during the therapy, I'd actually spoken to my daughter, sat her down, I'd give her the manual to go through and look at and you know now we're sort of hunky-dory, she's actually accepted the MS, she's actually understanding more about it... Participant 27, (CBT) Page 4, Line 23
11	TAILORING	**Matching CBT to relevant problems** Not all the CBT manual was relevant to everyone (which was accepted as most people as being	you're really not expected to go through this with a fine tooth comb and fill in every page er and answer every question if it's feeling like it's too much for you. Participant 11, (CBT) Page 9, Line 24

	Theme label	Subtheme labels and definitions	Examples/locations
		inevitable but some thought the manual was too broad and didn't suit their type of MS or personality or was overwhelmingly thorough). However, between the therapist and the patient, useful areas were picked and chosen and patient had input into agenda. Therefore relevant issues were covered and useful homework tasks chosen. Different individuals had favourite chapters, or most useful chapters and those that were not so helpful for them.	I think I picked and chose the ones that I felt would help Participant 17, (CBT) Page 6, Line 13 there was ones that were more helpful than others because they were only because I thought they were specific to like my sort of like side of the illness but I didn't think there was any that weren't ermm there was one ahh do you know, there was one session which we said well we won't need to go through that as much because but we which we didn't cover but I can't think what that was to be honest Participant 23, (CBT) Page 7, Line 3
		Directing the sessions Being in charge of what was talked about in SL and how sessions progressed made it tailored but this was not necessarily always good. Could be a burden and an unwanted responsibility. Total patient direction was perceived as not the best ways of doing things as therapist would have had the skill to direct conversation more usefully. In both therapies, prompting and direction and structure was appreciated.	what I did find… a little bit awkward… was the beginning of each session… what to talk about, because it was just my choice Participant 3, (CBT) Page 3, Line 11 in a way you need more guidance, you need someone who's sort of, I find, you need someone who's asking you, sort of guiding you in a certain direction Participant 32, (SL) Page 2, Line 32
		Inflexible length Therapy was felt to be inflexible in the number and length of sessions. It did not take into account the need of the patient to have few or more sessions (in total, or on particular topics e.g. negative thoughts).	in the study it was done but generally I think the NHS does do that erm they get they they give you and they certainly did give me eight sessions and and then that's then that's it, rather than seeing whether how things go and whether you could actually then have extra sessions until you resolve something Participant 14, (SL) Page 10, Line 32 I appreciate the opportunity and I really appreciated the first few sessions but as I say it went on a little bit too long for

	Theme label	Subtheme labels and definitions	Examples/locations
			me. …… Participant 16, (SL) Page 4, Line 10 I think possibly I could have fitted everything into I would say four or five sessions. Participant 30, (SL) Page 6, Line 25
12	ONGOING IMPACT	**Continuation of what was learned** Participants have continued to make changes and improvements with skills or insights developed in therapy sessions	the supportive listening now it feels as though it's done, gone, forgotten Participant 20, (SL) Page 4, Line 4 but certainly by using the stuff which I learnt at that therapy session I think really do think that that's probably a lot to do with how I'm why I'm feeling so much more sort of like better in myself Participant 23, (CBT) Page 7, Line 25
		Managing without therapist Difficulty managing to continue progress without ongoing therapy	then all of a sudden… well that's it then. And you sort of where do you go from there? And you know you've not resolved some of the things you wanted to resolve so it's all it is quite difficult to do things in… in blocks but I don't know how else you sort of allocate it, I suppose according to need or… erm… 'cause they just say oh you're sometimes half way through things and then you, that's it then… you've had your bit of counselling and that's it [laughs] Participant 14, (SL) Page 10, Line 18 the first two weeks after not having the nurse at the end of the phone, I actually started losing confidence in myself again. Participant 27, (CBT) Page 7 , Line 20
		Forgetting it Difficulty remembering what was covered during therapy (latent theme- therefore not remembering and putting into action what was taught)	I can't remember that much about it to be honest now which it just goes in and er yeah I've forgotten a lot of it Participant 17, (CBT) Page 1, Line 35 I haven't been fantastic recently and I think em some of those things I've kind of forgotten about now Participant 18, (CBT) Page 6, Line 5 no I honestly can't I have been trying to

	Theme label	Subtheme labels and definitions	Examples/locations
			think if I can find the book the stuff which was given to me but I can't remember where what the ermm the topics were but ermm Participant 23, (CBT) Page 9, Line 16
13	LIMITATIONS OF THERAPY	**Something missing** Therapy is missing a key ingredient. Particularly input on /help/advice with making changes, addressing the problem/s raised.	I would have liked something that was more...yeah just more more of a...you know a therapist's thoughts on how I respond to things or how, you know what would be a helpful way. Just just more suggestion of...support Participant 32, (SL) Page 5, Line 15 I think something just err more input from the therapist. More than just kind of sympathy or sympathetic noises, I think you know it's it's just more constructive input. Participant 32, (SL) Page 6, Line 29 its not going to teach you any kind of technique or skill or habit or whatever that you can then apply to make it useful in the times when you are not having it. Participant 7, (SL) Page 12, Line 14
		Not a therapy The sessions were not perceived as being something that could/should be labelled an intervention or therapy	I don't even think there was a ther-, there's no therapy there I mean there's blimming just talk talk talk Participant 21, (SL) Page 7, Line 3
		Not enough Therapy was not extensive enough in terms of either scope or type of approach. (NB- not enough lengthwise is coded at 'Inflexible Length')	I did explore I did explore some stuff that I wouldn't have done normally and I think it in in actual fact it's helped me to want to pursue further counselling 'cause I know I do need it, I don't think the eight sessions were enough Participant 20, (SL) Page 3, Line 28 Erm so… on the whole… yes erm it had something… but I would say it needs something to back it up, to substantiate it because it wasn't enough to carry on with Participant 3, (SL) Page 1, Line 39

	Theme label	Subtheme labels and definitions	Examples/locations
14	WIDE RANGING OUTCOMES	**Achievement** Therapy leads to or encourages the achievement of various goals or tasks. For some, keeping this up is difficult without the 'crutch' of ongoing therapy	I think I was sort of lacking motivation to do things so we sort of worked on setting some goals to to get things done and actually one of the things that … what I wanted to do was that erm… I'm claiming on my life insurance because of the M.S. I've got critical illness cover **mmm** and it was something that I kept thinking I should do I should do I should do and then… it just never got done and I set some goals with [therapist name removed] when I was doing the course and actually that's all in process now. Participant 8, (CBT) Page 2, Line 30 I remember that was a nice session when we talked about my plans for the future and ways in which I could change my life and I think that actually did affect my life. I think someone said that if you write things down you're more likely to achieve them **Mmm** and I think [therapist's name removed] proved that to me because I ended up getting a job. Participant 18, (CBT) Page 2, Line 50 I started to implement some of them but I'm afraid I've got a bit lazy [laughs] Participant 15, (CBT) Page 2, Line 36
		Attitude change Optimism and positivity Feeling more positive and optimistic about life	I think eh you know the core of it was basically trying to make me feel more positive about my situation and I think em that was that was kind of achieved Participant 18, (CBT) Page 4, Line 30 noticed a kind of more positive optimistic. **Yeah**. Yeah, I was optimistic and I'm a natural pessimist so… there was a definite hint of optimism there lingering around. …… Participant 3, (CSL) Page 7, Line 40

	Theme label	Subtheme labels and definitions	Examples/locations
		Easier on self Lowering standards for own behaviour and being kinder and easier to self	it...helped me to see ermm it helped me to look at the way I behaved and my reactions in situations and [?thought?] the times I suppose when I am vulnerable and don't deal with things ermm as well. Usually when I'm tired I discovered so if I'm fatigued I sometimes can lose objectivity and beat myself up Participant 26, (CBT) Page 2, Line 4
		Changes to goals and priorities. Becoming more realistic and flexible about goals and achievements. Changing priorities or standards.	the other thing certainly one of the homework tasks managed to do for me was make me totally ermm reassess my priorities and what I was actually doing in life which was totally unexpected ermm but having to sit down it was around goals, goals and err targets I think, goal setting, and then [?it was then?] thinking about career goals, I never really set any ermm in the jobs that I was in, and it dawned on me that's because I maybe I didn't really like doing the jobs that much...so ermm yeah I learned some unexpected things there as well and ermm I found doing those homeworks useful and valuable Participant 28, (CBT) Page 4, Line 9
			whereas before, if I hadn't done all the things on the list, I'd be oh gosh you know and yet now I'll often find that I'll probably tick a few things off and then think ok, but I'll you know, I'll do those tomorrow, whereas before I would have got myself in such a pickle Participant 24, (CBT) Page 25, Line 28
			like long term and short term goals, you know, again, I think sometimes we do all set them in stone, ermm but it was sort of it was helpful to think that well OK, they might not be set in stone now, you know we might have to alter this and and certainly it's a different way of looking at things I think. Participant 24, (CBT) Page 18, Line16

	Theme label	Subtheme labels and definitions	Examples/locations
		Realistic acceptance Therapy helps to develop a more complete and realistic acceptance that MS will be with you forever/long term and that it is going to affect aspects of life and need to be managed. Importantly, this appears to go alongside increasing skills and confidence in dealing with MS symptoms/limitations. Altered perspectives on MS reporting changing ways of thinking about MS; not otherwise/better captured by alternative themes	I think that's that's what it is good for, to make you realise that actually, it is just part of your life ultimately Participant 24, (CBT) Page 30 Line 8 I've had to accept that I've got the condition and I've had to get on with it **Mmm** You know, and the sessions have helped me to accept that if you like and if I've got anything from it its help in acceptance of the condition in the first place and accepting it into my life. Participant 16, (SL) Page 7, Line 18 think my attitude, my whole attitude to the ermm...my...well sort of maybe towards like the illness and maybe even towards how I look at things, Participant 23, (CBT) Page 7, Line 22 I think it might be that it's helped me to ermm look at things from a different point of view sometimes, yeah...and err just see as we go from there so I don't know but I think it was quite did help me to look at things from a different viewpoint in general because I think you become a little bit ermm tunnel vision when you've got MS, you can't see any other vision and if you talk to somebody else, you talk it over, it does help to get rid of the tunnel vision I think. Participant 22, (SL) Page 8, Line14

	Theme label	Subtheme labels and definitions	Examples/locations
		Communication Therapy leads to improved communication. More thoughtful, confident or comfortable communication. Appear to be many different mechanisms including, positive experiences of sharing during therapy, reflection and clarity leading to confidence in talking about things, strategies to improve communication and emotional responses	I mean it helped to open up channels of communication with my partner as well, which I don't talk about erm my feelings in relation to anything, let alone MS erm I didn't before and it sort of made me realise that I can talk about it without getting upset I can talk about it erm openly and you know its not, maybe it isn't as taboo as I thought it was, I thought it was in my life. Participant 16, (SL) Page 2, Line 19 by er talking through it I I was then able to go and talk to a few other people and get get things clear in my head and…tackled it with with my erm… with my brother. Participant 14, (SL) Page 9, Line 13 well here is a good example of one of the strategies of of problem solving and erm it was the erm er pros and cons one… **Mmm** and erm what we did what I did was I sat down and for [therapists name removed] I did all the pros for having a baby and what the cons were and then she said well how about involving [husband's name removed] in that and so I did and actually it really helped me to see that if you use that strategy it actually opens up the door for more conversation Participant 15, (CBT) Page 4, Line 29
		Boosted Confidence **Confidence for dealing with MS** New or renewed confidence in dealing with MS. Feeling more in control of MS and feeling more self-efficacy for having a pro-active role in managing it and dealing with challenges successfully. Confidence about managing in future.	an even more deeper realisation that on the journey adapting to MS erm I can do something to erm contribute to it it doesn't control me but I actually have a bearing on what happens. Participant 15, (CBT) Page 8, Line 22 it give me my confidence back, you know things that I was doing you know, the way I was handling my life with the MS was good Participant 27, (CBT) Page 2, Line 27

	Theme label	Subtheme labels and definitions	Examples/locations
		Confidence for managing social situations More confidence in social situations. In particular, dealing with peoples' reactions to MS.	confidence to deal with people when they ask direct questions which so many people do Participant 18, (CBT) Page 5, Line 8 I am more ermm direct in accepting my multiple sclerosis and talking to people about it. It was one of the things that I had great difficulty in talking to people about and confirming to them that I had it, ermm and that definitely at the end of the the sessions, there is no doubt that I will now talk to anybody and advise them if they either ask me how my health is or if I need to clarify what my health is, I will I will tell them about it Participant 25, (CBT) Page 10, Line 22
		Feeling more normal Feeling reassured that other people in similar situations think and feel in the same way. Feeling less isolated by experience of MS. Self-esteem improved due to feeling more normal and 'sane'.	I end up telling myself and convincing myself of really strange things [laughs] and… and in the end I just decided that I was loony bin erm… in a normal person disguise, you know. And er, when I had these sessions in the therapy erm… er… then it made me feel saner… that, what I'm thinking is quite normal… Participant 3, (SL) Page 6, Line 22 at the point where you're reading through it you realise that a lot of people have the same same thoughts that you have an before that I I didn't know that that other people felt the same way about things that I did…. So that was very very erm useful to me because it made me feel better that I sort of wasn't the only one that was feeling that way. Participant 6, (CBT) Page 4, Line 13
		Lack of change No change Perceiving that no substantial change or improvement occurred as a result of therapy .	PERSONALLY I don't think I got anything out of it. Participant 21, (SL) Page 1, Line 21 I just thought you know nothing really changed over the ermm the the period of three months or whatever it was I'd I'd done the therapy for. Participant 21, (SL) Page 4, Line 15

	Theme label	Subtheme labels and definitions	Examples/locations
			I mean the the strides that I've made have been because I've made them, nothing related to the therapy because it was just and I sort of forgotten about it now Participant 13, (CBT) Page 6, Line 3
		No physical change Disappointment that the therapy did not improve physical symptoms of MS	don't think it's done very much for my MS...ermm I don't think it's it's either ermm improved or or anything like that, I don't I don't think my MS has changed in any way, Participant 30, (SL) Page 7, Line 6
		Already doing well Participant was already very well adjusted and had little to learn or gain. Didn't really need to do therapy	I'm making changes as I go and I I try and stay positive anyway so there wasn't really anything for me to change… except to get better [laughs]. Participant 1, (SL) Page 5, Line 28 nothing major that I've noticed, I mean I've always just sort of got on with it. Participant 28, (CBT) Page 7, Line 19
		Mood control Participants describe being better able to manage negative emotions and reactions and having better control over their moods. This includes being upset or down, wound up or stressed, anxious, angry or having a short temper. These mood states still occur but are easier to nip in the bud or attenuate. For many, these improvements are linked to strategies learned in therapy, particularly awareness of and challenging of unhelpful thoughts and being more reflective; thinking before reacting.	It it did help me to actually rather than react ermm.....you know in a negative way, it's actually it's been great for me to think about things before I react... Participant 29, (CBT) Page 10, Line 32 It's nothing like erm suddenly I decided that I would jump up and down for joy in the living room or something, you know, it's erm… er…… I don't, I really don't know er. You just know when… erm… sh, I just felt that I wan't… I wasn't… so burdened as I used to be Participant 3, (SL) Page 22, Line 7 I I think I know how to to manage stress a bit better, definitely how to relax a bit more… rather than getting very sort of, I was very anxious before… I I think that has improved… So that was very good. Participant 6, (CBT) Page 3, Line 19 I think about my M.S. every single day and

	Theme label	Subtheme labels and definitions	Examples/locations
			that will never change but I don't … a thought will come into my head now and I can get rid of it as quickly as it came in I, I'm not in that same dreadful thought process that I was before Participant 8, (CBT) Page 1, Line 32
		Less fatigued Noticing less fatigue, or fatigue under control	I've haven't had any fatigue wow. Yeah I had that for like a couple of months so may be I'm not stressing out so much. Maybe yeah that's good. **Excellent** so yeah I think yeah I haven't been fatigued. The fatigue like kind of hits you like a brick wall. You've got to sleep wherever you are you've just got to sleep. **Right** and I've not had that Participant 17, (CBT) Page 9, Line 1
		Noticing benefits Difficult to detect change Change from therapy is subtle, gradual and not easy to spot or distinguish from change from other factors, especially at the time of change	I mean sub-consciously I think it it benefited me more than I appreciated at the time Participant 16, (SL) Page 9, Line 11 Again I don't know if its down to therapy or the injections or you know anything like that Participant 17, (CBT) Page 7, Line 15 maybe I am dealing with yeah Sorry as I say its not until you look back that you think em **Yeah** and I haven't been looking back I just look forward. Participant 17, (CBT) Page 9, Line 6
		Others notice Other people notice change in the patient.	Err friends, friends noticed it. They'd noticed, when I was having the therapy they noticed that I was more confident... Participant 27, (CBT) Page 8, Line 11

	Theme label	Subtheme labels and definitions	Examples/locations
		Questionnaires and interviews Trial procedures have acted as points of reflection where benefits are noticed Test situations Difficult/stressful circumstances, including relapses, are situations where benefits are tested.	**how you came to notice things changing at all?** Only you talking to me Participant 17, (CBT) Page 8, Line 33 I think the test will come when there is a relapse I think. When things are like they are now which is I can get out and about and and you know things are pretty good although I still have to deal with pain and some eh very annoying symptoms that're coming and going all the time erm things are alright but as the disease progresses that's when I will be able to tell how much of this is going to have an affect on me really Participant 15, (CBT) Page 9, Line 1 I think it just comes about from some- err something actually happening Participant 25, (CBT) Page 12, Line 8
		Relationships Therapy has improved interactions with other people and relationships. Closely linked to communication.	It er helped me go work through that and relate to my family better on maybe sort of made me think about how difficult it was for them, even though I thought they wouldn't understand me and what I was going through I sort of maybe had been a little bit I don't know whether it would be selfish but a bit self over focused on myself and not realised what it was doing, what it meant for them really. Participant 14, (SL) Page 8, Line 19 I've been able to… sort of relate to the family better really. Erm… on some issues erm I'm tried to see their side more Participant 14, (SL) Page 12, Line24 I am more comfortable about meeting people and talking about it now than I was before may be. So I think that's em, that's that's changed my daily life Participant 18, (CBT) Page 4, Line 49 every time I went to the hospital I wasn't very good at talking with doctors, and I

	Theme label	Subtheme labels and definitions	Examples/locations
			didn't really understand their ermm you know doctors, I don't know, they don't really explain things properly to you. You know and it, that was really making me frustrated and angry...and I didn't really have a good relationship with my doctor, until after I had the therapy and I've gone back to the hosp- hospital and we've actually shake hands and sort of you know, made friends.**Mmm.** And he is a lot better towards me... Participant 27, (CBT) Page 3, Line 12

Appendix V: Initial themes and subthemes from thematic analysis in Chapter 7

Theme	Low level Subthemes
1. Expectations and motivations	1. Not knowing what to expect 2. Having a basic grasp 3. Curiosity 4. Hope for improvements 5. Low expectations 6. For the greater good 7. Concerns
2. Special opportunity to talk	8. The neutral listener 9. Offloading 10. Filling the silence
3. Heightening awareness of thoughts and feelings	11. Setting aside time to think 12. Creating clarity 13. Saying it or writing it 14. Questionnaires and interviews 15. Getting upset
4. Prompting action	N/a
5. Learning strategies	16. Picking up a toolbox of skills 17. Lifestyle changes to manage symptoms 18. The power of thoughts 19. Challenging your current ways
6. Buying into it	20. Putting in effort 21. The right approach 22. Relating/resisting 23. Needing a positive approach 24. Things you would naturally do anyway 25. Enjoyment and interest 26. No criticism

7. Targeting the right people at the right time	27. The right sort of person
	28. Disease status
	29. Suitable state of mind
	30. Life events and stressors
	31. Wide applicability
8. Quality of interaction	32. Bonding with therapist
	33. Warming up
	34. Naturalness of communication
	35. One to one format
	36. Telephone vs. face to face
	37. Expertise and professionalism
	38. Attributing gains to therapist
9. Practicalities	39. Doing therapy when you have MS
	40. Convenience
	41. Trial procedures
10. Involving loved ones	42. Deciding whether to involve them
	43. Keeping them in the loop
	44. Benefits and drawbacks for families
11. Tailoring	45. Matching CBT to relevant problems
	46. Directing the sessions
	47. Inflexible length
12. Limitations of therapy	48. Something missing
	49. Not a therapy
	50. Not enough
13. Wide ranging outcomes	51. Achievement
	52. Attitude change
	53. Awareness
	54. Communication
	55. Boosted confidence
	56. Feeling more normal
	57. Mood control
	58. Less fatigued
	59. Relationships
	60. Noticing benefits
	61. Lack of change

14. Ongoing impact	62. Continuation of what was learned
	63. Managing without therapist
	64. Forgetting it

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