

SOCIAL IDENTITY CHANGE IN PEOPLE WITH MULTIPLE  
SCLEROSIS: A SOCIAL IDENTITY APPROACH TO THE ROLE  
OF THE FAMILY IN IDENTITY RECONSTRUCTION

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## **Abstract**

People with multiple sclerosis (MS) undergo changes to their identity and this might have an effect on mood. The subjective experience of this identity change is currently not well understood. Past research highlights that social groups, established prior to diagnosis, might protect against the harmful effects of identity change. No studies have specifically investigated this and the implications this may have for psychological interventions for mood in people with MS.

This thesis first presents a systematic review of the efficacy of group based psychological interventions for low mood in people with MS compared to individual based interventions. Group based interventions were found to be more effective as treatments for depression in people with MS and this may be due to the peer support available. Previous research has highlighted that people may be more willing to accept peer support from people with whom they share a social identity. People undergo changes to identity due to MS, this thesis focuses on identity change following diagnosis. The family is seen as an important source of social support. A meta-synthesis of the role of the family in acting as a secure base for identity reconstruction was undertaken. The family may provide a secure base for identity reconstruction, as long as the coping strategies used by the person with MS and the family are aligned. Sixteen interviews were conducted with people with MS to examine changes to identity over time and what factors might have influenced this. Social support was important for incorporating the MS identity into overall sense of self. A survey study (n = 203) was then conducted to examine whether family identity may have an effect on mood through social support and connectedness to others, as hypothesized on the basis of the Social

Identity Model of Identity Change. Family identity was directly negatively correlated to mood; however, it had an increased effect on mood through the mediators of social support and connectedness to others.

This research in this thesis found that, if coping strategies are aligned, the family provides a secure base for identity reconstruction through social support, which can lead to self reflected appraisals in the person with MS. Identifying with the family group can have a positive effect on mood and can lead to increased interaction with other people with MS following adjustment. The implications of this research are that people do experience changes to their identity following a diagnosis of MS and that social support can help a person to incorporate this into their sense of self. The family can provide a secure base for identity reconstruction. Identifying with the family group can have a direct positive effect on a person's mood, in line with the SIMIC. Family identity can also have an indirect effect on a person's mood through the parallel mediators of family social support and willingness to join new social groups. Group psychological interventions have a greater effect on depression and anxiety in people with MS compared to individual interventions. People may be more willing to engage in-group interventions after an initial period of adjustment. Further research should investigate the SIMIC in people with other chronic conditions. The increased inclusion of the family in support for the person with MS could facilitate the adjustment process.

## **Overview of the work in this thesis**

This thesis was completed between October 2012 and December 2015. The research began with a literature review. In November 2012, work began on the meta-synthesis, this was completed in August 2013. During this time, qualitative interviews were being conducted on participants to explore the subjective changes to identity over time. The participants had recently taken part in a randomized controlled trial in the research division to compare group vs individual cognitive behavioural therapy for mood disorders in people with MS. In April 2013, work began on a systematic review of group vs individual interventions for mood in people with MS, this review was completed in December 2014. The survey study was conducted between August 2014 to August 2015, with data collection running between August 2015 to March 2015.

The interviews in the qualitative study were conducted by two PhD students in the same department who were interested in different research questions. The same interview schedule was used on all participants with each student interested in the answers to different questions. Interviews were conducted by both participants and data were shared before analysis

The survey study was also conducted alongside another PhD students work in the same department, different questionnaires were used in the same survey booklet so that we could examine variables relevant to the different research questions. Both students jointly worked on the ethics application for this project and data entry into SPSS. Analysis of data was conducted independently.

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## **1. Introduction**

### **1.1 Chapter Overview**

Multiple Sclerosis (MS) is an illness that has life changing effects on both the person with the condition and those close to the person (Zajicek, Freeman, & Porter, 2007). The disease can affect a person's physical health and emotional well-being, as well as disrupting the social relationships that person maintains and their economic stability. This chapter describes the symptoms and prevalence of MS, its subtypes and the effect on mood.

### **1.2 Multiple Sclerosis**

Multiple Sclerosis is a neurological condition in which a person's immune system reacts to the myelin sheath, that surrounds nerve fibres, as a foreign body and attacks it (Compston & Coles, 2008; Rog, Burgess, Mottershead, & Talbot, 2010). The immune system damages the myelin and strips it off the nerve fibres, either partially or completely, leaving scars, known as plaques. MS can lead to a variety of symptoms, including problems with movement, vision and balance (Compston & Coles, 2008). There is no cure for MS; instead individuals need to adapt and adjust to live with their chronic disease.

Approximately 85,000 to 100,000 people in the UK have MS (Ford et al., 2012). The onset of MS can occur at all ages, however, symptoms are most likely to first appear when a person is in their 20s to 30s (Matthews & Rice-Oxley, 2006). MS affects almost three times as many women as men (Matthews & Rice-Oxley,

2006) and is thought to be more common in white people than people from other ethnic origins (Pugliatti, Sotgiu, & Rosati, 2002).

MS is a chronic condition and is not fatal, however, complications from the condition, such as pneumonia, can be (Cottrell et al., 1999; Sadovnik, Eisen, Ebers, & Paty, 1991). Because of the complications that can arise in people with severe MS, life expectancy in people with MS is thought to be 5-10 years lower than the general population (Zajicek et al., 2007). However due to improving care, this gap is getting smaller (Marrie et al., 2015; Sadovnik et al., 1991). MS is also a costly disease; a recent study used a societal perspective estimate for cost of MS irrespective of who the payer is, and found that MS costs approximately 15 billion Euros in Europe alone (Gustavsson et al., 2011). The cost per person in the UK is approximately £30,000 a year, taking into account direct costs, such as medical care, and indirect costs such as lost work. Whilst these figures cover indirect costs, such as loss of work, they do not cover the cost of comorbid psychiatric problems, such as mood disorders, or the cost to people close to the person with MS, through lost work and time spent caring.

The process of being diagnosed with MS can be quite lengthy. The latest diagnostic criteria for a diagnosis of MS, The McDonald criteria (McDonald et al., 2001; Polman et al., 2011), require evidence of damage to the central nervous system that is disseminated in space (evidence of damage to at least two different parts of the central nervous system) and disseminated in time (evidence of episodes of damage in the central nervous system at different dates) (Polman et al., 2011). Unfortunately, there are also several conditions with similar symptoms

to MS; degenerative diseases, such as cervical myelopathy, and vascular diseases, such as endocarditis, need to be ruled out before MS can be confirmed (Zajicek et al., 2007). There is no single test to diagnose MS and a number of tests may be carried out, including: a neurological examination, MRI, recording of evoked potentials and a lumbar puncture (Zajicek et al., 2007). A blood test may also be conducted to rule out a similar condition, neuromyelitis optica. The type of MS a person has only becomes clear over time due to the varied nature of symptoms in MS. To further complicate the process, a confident diagnosis can only be made once a person has had more than one episode of symptoms. MS is a progressive condition and the symptoms can become more severe, and have a greater impact on a person's life, over time. Severity of MS is often measured by the Expanded Disability Status Scale (EDSS), which was designed to assess symptom severity in people with MS. The scale measures eight aspects of functional performance: pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, cerebral and other, to provide a functional score.

### **1.3 Causes of MS**

The exact cause of MS has not yet been discovered, however there are a number of theories, such as genetic factors (Goodin, 2010), exposure to a virus, such as the Epstein Barr virus (Pender & Burrows, 2014) or a lack of vitamin D (Munger et al., 2004).

Unlike some inherited conditions, no single gene that causes MS has been identified. It is not directly inherited and instead it is thought that a combination of

genes leads to some people being more susceptible to MS than others (Compston & Coles, 2008; Goodin, 2010). However, not everyone with this gene combination will develop MS.

MS is more common in places further away from the equator (Compston & Coles, 2008). It is still unknown as to why this may be, however, it has been suggested that this could be due to exposure to a virus, such as the Epstein Barr virus (Pender & Burrows, 2014) or due to a lack of vitamin D (Munger et al., 2004).

## **1.4 Types of MS**

MS is classified into four types based on the pattern of change in symptoms over time.

### **1.4.1 Relapsing-remitting MS**

Approximately 85% of people with MS are diagnosed with relapsing-remitting MS (Zajicek et al., 2007). This type of MS is characterised by flare-ups of symptoms, known as relapses. Relapses are a period of neurological dysfunction which are attributable to a lesion within the central nervous system, which lasts at least 24 hours (Zajicek et al., 2007). This is followed by a period of remission, in which symptoms become milder or disappear altogether for a period between a few days and a few months. A diagnosis of relapsing-remitting MS can be made if the person with MS has had two relapses more than 30 days apart or symptoms persisting for more than 30 days. Alternatively a diagnosis can be made if the

person has a relapse and an MRI scan shows new damage or scarring three months later (McDonald et al., 2001; Polman et al., 2011; Zajicek et al., 2007).

#### **1.4.2 Secondary Progressive MS**

Secondary progressive MS is characterised by symptoms that gradually worsen over time, and relapses may still occur but without recovery from symptoms. A diagnosis of secondary-progressive MS can be made if the person with MS has had relapses of their symptoms within the last six months or if they have become steadily more disabled with or without relapses. Around half of people with Relapsing remitting MS will go on to develop Secondary progressive MS after 10 years (Zajicek et al., 2007). MS never starts out as secondary-progressive, the disease develops to this stage, however, it is possible for a person to receive this diagnosis if they have had unexplained symptoms for a period of time (McDonald et al., 2001; Polman et al., 2011; Zajicek et al., 2007).

#### **1.4.3 Primary progressive MS**

Primary progressive MS is the least common form and presents in approximately 10-15% of people with MS (Zajicek et al., 2007) and is characterised by symptoms, which gradually become worse over time without periods of remission (Zajicek et al., 2007) Primary-progressive MS can be diagnosed if the person with MS has had no previous relapses and has become steadily more disabled over the past year, an MRI shows damage and scarring to the myelin sheath, and a lumbar

puncture shows antibodies in the fluid surrounding the brain and spinal cord (McDonald et al., 2001; Polman et al., 2011; Zajicek et al., 2007).

#### **1.4.4 Benign MS**

Based on the classification of benign MS using the Expanded Disability Scale, a disability score between  $\leq 3.0$  or 3.5 (mild disability) after 10-15 years (Amato et al., 2006) the prevalence of benign MS is estimated to be between 10-20% (Kurtzke, Beebe, Nagler, Kurland, & Auth, 1977; Poser, Wikstrom, & Bauer, 1979; Thompson, Hutchinson, Brazil, Feighery, & Martin, 1986). Benign MS is characterised by no decline in condition or worsening of symptoms following an initial diagnosis. The diagnosis of benign MS can be revised, as symptoms can develop over time. Depending on the pattern of the newly emerging symptoms, the diagnosis can be changed to primary progressive or relapsing-remitting MS.

#### **1.5 Multiple Sclerosis and Mood**

Mood disorders are defined as "a sustained and pervasive emotion that influences perception of self, others and the world, such as depression, elation, mania and anxiety" (Minden, 2000, p. 160). Depression and anxiety are diagnosed when a person meets the criteria set out in either the Diagnostic and Statistical Manual of Mental Disorders or The International Classification of Disease, or other such classification systems. The prevalence of mood disorders in people with MS is high, with people with MS experiencing higher rates of depression (Janssens et al., 2003; Siegert & Abernethy, 2005) and anxiety (Maurelli et al., 1992; Zorzon

et al., 2001) than people with other neurological conditions or the general population. Compared to patients with epilepsy and diabetes, people with MS report significantly worse health-related quality of life on subscales measuring physical functioning, role limitations-physical, energy and social function (Hermann et al., 1996). Whilst depression seems to have the larger impact on quality of life than anxiety, anxiety is also negatively correlated to quality of life (Fruehwald, Loeffler-Stastka, Eher, Saletu, & Baumhackl, 2001). Understanding the factors associated with mood disorders in people with MS may lead to the development of more effective treatments.

### **1.6 Explanations of low mood in people with MS**

Various explanations exist for the high prevalence of mood disorders in people with MS, including reactive explanations in response to living with and facing a chronic illness (Minden, 2000), and other explanations, such as biological effects of the damage MS can cause in the brain (Minden, 2000).

Reactive explanations for mood disorders in MS state that the psychosocial difficulties the disease can cause, such as facing an uncertain future without a known cure, can cause mood disorders. Disease severity can have an effect on subsequent adjustment in people with MS and this may partly explain reactive explanations for mood disorders in people with MS. Adjustment to MS can be defined as maintaining a flexible approach to life, being able to express negative emotions openly but not being overwhelmed by these emotions, and maintaining a reasonable quality of life in the face of the condition (Moss-Morris, Dennison, &



Chalder, 2010). Adjustment is often measured with variables, such as psychological or emotional well-being, quality of life or the subjective impact of the illness on life domains (Dennison, Moss-Morris, & Chalder, 2009). An investigation into the effects of demographic and illness-related variables on psychosocial adjustment to MS, found that physical health status had the greatest effect on seven measures of psychosocial adjustment: personal efficiency and well-being, capacity for independent thought and action, self-confidence, self-reliance, and number of meaningful social contacts (Zeldow & Pavlou, 1984). Life stress was found to be associated with personal efficiency, but sense of well-being and duration of illness and demographic characteristics (age, sex, marital status and social class) had few or no effects on psychosocial adjustment.

Another explanation for mood disorders in people with MS, is that the biological damage or lesions caused by MS interfere with emotional pathways in the brain, leading to changes in mood. MS is characterized by demyelination that appears to be concentrated in the frontal lobes (Filley, Franklin, Heaton, & Rosenberg, 1989), a region thought to be significantly involved in cognitive, characterological, and affective functioning (Rodgers & Bland, 1996).

Depression is usually measured in clinical and research settings using brief self-reported screening measures such as the Beck Depression Inventory (BDI) (Beck, Epstein, Brown, & Steer, 1988) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). There is considerable overlap between the common symptoms of MS and the somatic symptoms of depression and anxiety which may account for the high association between MS and low mood. Due to

the overlap of symptoms, caution has been advised in the use of self-reported screening measures for mood disorders in people with MS (Benedict, Fishman, & McClellan, 2003; Honarmand & Feinstein, 2009; Mohr, Goodkin, & Likosky, 1997; Nyenhuis, Rao, & Zajecka, 1995; O'Donnchadha et al., 2013).

The risk of depression among first-degree relatives of depressed people with MS is low suggesting that the chance of there being a genetic link between mood disorders in people with MS is low (Joffe, Lippert, Gray, Sawa, & Horvath, 1987; Minden et al., 1987; Sadovnick et al., 1996).

Multiple explanations for mood disorders in people with MS exist and the explanation appears to be multi-factorial and complex. The extent that they are direct consequences of the disease process or psychological reactions to it remains unclear (Minden, 2000). Studies investigating the relationship between depression and various disease parameters have found no consistent result. Some studies show a significant relationship between depression and the duration of the illness (McIvor, Ricklan, & Reznikoff, 1984), the degree of neurological impairment (Kikuchi et al., 2011; McIvor et al., 1984; Mohr et al., 1997; Noy et al., 1995; Rabins et al., 1986; Tedman, Young, & Williams, 1997; Whitlock & Siskind, 1980), severity of cognitive impairment (Arnett, Barwick, & Beeney, 2008; Chiaravalloti & DeLuca, 2008; Clark et al., 1992; Moller, Wiedman, Rohde, Backmund, & Sonntag, 1994; Sabatini et al., 1996; Schiffer & Caine, 1991), enlarged ventricles (Rabins et al., 1986) lesions in the frontal and temporal lobes and para-ventricular areas (Honer, Hurwitz, & Li, 1987), left hemisphere lesions (George, Kellner, Berstein, & Goust, 1994) and left acute fasciculus region (Pujol,

Bello, Deus, Marti-Vilalta, & Capdevila, 1997), and regional cerebral blood flow asymmetries in the limbic cortex (Sabatini et al., 1996). Whereas other studies show no significant relationship between depression and duration of illness, severity and type of disability (Gilchrist & Creed, 1994; Minden, Orav, & Reich, 1987; Moller et al., 1994; Noy et al., 1995), cognitive impairment (Clark et al., 1992; Minden & Schiffer, 1991; Moller et al., 1994; Sabatini et al., 1996; Schiffer & Caine, 1991), MRI measures (Barak et al., 1996; Clark et al., 1992; Moller et al., 1994; Sabatini et al., 1996; Schiffer & Caine, 1991; Tsolaki et al., 1994), fatigue (Moller et al., 1994), disease activity (Scott, Allen, Price, McConnell, & Lang, 1996) or course of illness (Minden et al., 1987; Moller et al., 1994), meaning that there are evidence for and against the different explanations for mood disorders in people with MS.

Anxiety in relation to MS has been less frequently studied; one study found anxiety was associated with disease activity but not with severity or duration of MS (Noy et al., 1995), whereas another study found that disease severity was related to anxiety (Hakim et al., 2000). One study found significant correlations with neurological disability but not with cognitive impairment or disease course (Stenager, Knudsen, & Jensen, 1994).

### **1.7 Adjustment in People with MS**

Despite the high prevalence of mood disorders in people with MS, not all people with MS experience mood disorders, and in those who do, a substantial proportion manage to adapt well to living with the illness (Antonak & Livneh, 1995; Brooks

& Matson, 1982). Whilst both the disease parameters and the biological basis of the disease appear to be associated with mood disorders in people with MS, individual psychological factors appear to influence adjustment to the presence of the disease. Psychological adjustment to disease refers to the process of becoming aware of, making sense of, and adapting to the changes in a person's circumstances and functioning (Ownsworth, 2014). The cause of mood disorders in people with MS is multifactorial. Understanding adjustment to the disease could provide opportunities to reduce the prevalence of mood disorders in people with MS. Dennison et al. (2009) argued that the disease parameters, such as the severity of the condition, are often only modest predictors of adjustment and are often inconsistently associated, between studies, with adjustment to the disease. Psychological factors are often better predictors of adjustment than illness factors (McIvor et al., 1984). For example, quality of life in people with MS is often reduced, however depression has been linked to lower quality of life independent of the level of physical disability (Janardhan & Bakshi, 2002).

It has been shown, in patients presenting with chronic pain as a primary symptom, acceptance is related to adjustment (Kratz, Hirsh, Ehde, & Jensen, 2013). To test whether the same is true for patients presenting with chronic pain as a secondary condition, Kratz et al. (2013) assessed patients with muscular dystrophy, MS, post-polio syndrome and spinal cord injury. They found that participants who continued with daily activities without letting pain interfere with daily activities reported lower depression and greater quality of life and social role satisfaction than those who let pain interfere with daily activities. Whilst adjustment appears

to be somewhat dependent on the severity of the condition, accepting the condition also seems to be associated with positive adjustment.

In a review of the factors associated with positive and negative adjustment the strongest evidence points to a relationship between perceived stress and certain emotion-focused coping strategies and worse adjustment. Adjustment to MS was measured by psychological or emotional well-being, quality of life, or the subjective impact of the illness on life domains to the psychosocial factors in people with MS (Dennison et al., 2009). Escape avoidance techniques and wishful thinking appeared to be associated with worse adjustment, whereas seeking social support, a problem-focused coping strategy, as well as positive reappraisal appeared to be associated with better adjustment (Dennison et al., 2009).

Cognitive errors and biases and illness and symptom cognitions, specifically with illness uncertainty, are associated with poor adjustment. Social support and interactions with others, control over perceptions, positive psychology factors (such as optimism), and health-promoting behaviours had a positive relationship with adjustment in people with MS.

In regards to early stage adjustment to MS (Dennison, Moss-Morris, Silber, Galea, & Chalder, 2010), illness severity factors accounted for 23.7% of variance and cognitive and behavioural factors accounted for a further 22.6% of the variance in adjustment. Behavioural responses to symptoms were the strongest predictor of two measures of adjustment, illness-related functional impairment and psychological distress. In regards to psychological distress, unhelpful beliefs about the self were found to be the strongest predictor, with other predictors

including unhelpful beliefs about emotions, acceptance, unhelpful cognitive response to symptoms, and illness perceptions. Acceptance of illness and an integration of changes into a person's sense of self and way of life (Stuifbergen, Seraphine, & Roberts, 2000), were thought to be beneficial for adjustment (Dennison et al., 2009). As a person's sense of self has been found to be involved with a person's adjustment to other conditions (Ownsworth, 2014), further investigation of the changes to a person's sense of self in people with MS could allow greater understanding of the adjustment process to the disease.

### **1.8 Sense of Self and Adjustment**

MS can have a devastating impact on a person's sense of self. Body and performance failures can lead to the loss of salient aspects of the self (Boeije, Duijnste, Gryndonck, & Pool, 2002). Positive self-concepts may be replaced by negative self-concepts. The period of time following a diagnosis of MS is described as being "...a period of challenging internal transition; the individual is facing changes in how they see themselves and how others may see them" (Irvine, Davidson, Hoy, & Lowe-Strong, 2009, p. 7). These psychosocial problems can cause a sense of demoralization in the person with MS and are often accompanied by a deterioration in relationships, due to the person with MS and those close to them struggling to adapt with the changed person and circumstances (Mohr et al., 1999). The way a person thinks about their self is linked to psychological well-being (Haslam et al., 2008) and adjustment to the disease (Dennison et al., 2009).

Investigating the changes to a person's sense of self-following a diagnosis of MS may provide a greater understanding of adjustment to mood disorders in people with MS.

### **1.9 Chapter Summary**

This chapter has described MS, the prevalence and causes of the disease, and the prevalence of mood problems in people with MS. The possible underlying causes of mood disorders in people with MS were then discussed and it was concluded that due to the multi-faceted nature of this, it would be difficult to predict or prevent mood disorders in people with MS. Instead, understanding adjustment to the disease could provide a means of reducing mood disorders in people with MS. A greater understanding of the changes to a person's sense of self could provide opportunities to increase adjustment. In the next chapter I will examine the literature on self and identity and how this may relate to the changes experienced to the sense of self in people with MS.

## **2 Literature Review**

### **2.1. Chapter overview**

This chapter will cover the existing literature on identity loss following a diagnosis of MS. It will focus on the definitions of the self and identity, the current research on loss of self in people with MS and how these changes to a person's sense of self are related to mood, and the social identity model of identity change. Research on the family and how a person's family identity and support from the family could be linked to identity reconstruction was examined, the implications this could have on the format of psychological interventions for mood disorders in people with MS is discussed. The gaps in the literature were identified and a hypothesis regarding the role of the family in identity reconstruction in people with MS, and the implications for psychological interventions, was formulated.

### **2.2 – Self**

Several definitions of the self exist. The self has been defined as a conscious agent in control of unique actions and thoughts, or the essential essence of a person that endures over time (Brinthaupt & Lipka, 1992). The self has been defined as a cognitive structure that relates to characteristics that a person thinks of as their own, including bodily processes and psychological states (Dumont, 2013; Ownsworth, 2014). Others have argued that the self is a narrative sequence or language-constructed metaphor (Freeman, 1992), which possesses consistent characteristics about the self, as well as characteristics that are under construction.



In this sense the self reflects a person's past, present and possible future selves (Markus & Nurius, 1986).

A person's sense of self encompasses a number of inter-related concepts, including self-awareness, self-concept, self-esteem, self-efficacy and identity (Ownsworth, 2014). The self refers to a person's ability to experience themselves as distinct from others through self-awareness, thoughts and feelings about their self-based on stable characteristics values and behaviours (Existential self-concept). The self also allows comparisons with others (Categorical self-concept), through self-concept, an evaluation of their self-concept, through self-esteem, and beliefs about their ability to perform at certain tasks, through self-efficacy.

Self-Comparison Theory (Eisenstadt & Leippe, 1994) proposes that people think about their self in different ways and hold beliefs about possible selves. People have a sense of actual self, how they currently see themselves, an ideal self, who they would like to be and ought self, who they feel they ought to be. Self-Discrepancy Theory (Higgins, 1987) extended Self Comparison theory to state that the way that a person thinks about these selves can have an emotional impact. The level of discrepancy between a person's actual self and ideal or 'ought to be' self can have an effect on a person's mood (Higgins, 1987). People can also observe discrepancy between their actual, ideal and ought to be self by receiving feedback on who they feel others think they should be (ideal-other self) or who they ought to be (ought-other self). Feedback from others or events that can lead to a change in perception of self, such as a diagnosis of MS, can lead to self discrepancies which can have an effect on a person's emotional state.

Self-identity refers to a person's unique and persisting qualities about the self that distinguish the self from others (Dumont, 2013). This includes typical ways of feeling, thinking and behaving. However, a person's self-identity is not separate from the social setting that they find themselves in. People can derive a sense of identity from the groups they see themselves as part of or separate from. Social identity has been defined as "the sense of self that people derive from their membership in social groups" (Jetten, Haslam, & Haslam, 2012, p.4). This means that a person's social identity is changeable depending on the social setting that they are in, and a person could have multiple selves depending on the situation they are in (Linville, 1987). A person's sense of self-identity and their sense of social identity are closely related aspects of the self. The self is continually both socially and subjectively constructed. The self, self-concept and identity can be considered as related concepts (Carver, 2012). Identities are traits, characteristics, social relations, roles and social group membership that define who a person is. A person's sense of self is also used as an orientating tool by providing a meaning-making lens, which can focus a person's attention on some features of an immediate context and identities but not others (Oyserman, 2007, 2009a, 2009b). Together, the different identities that a person has make up a person's self-concept, what comes to mind when they think of their self (Neisser, 1993; Stets & Burke, 2003; Stryker, 1980; Tajfel, 1981). Identities can either be forced on a person, as in the case of chronic disease, or something that the individual feels motivated to seek out and become, due to their guiding sense of self.

In line with Self Complexity Theory (Linville, 1987), people can have multiple identities to represent themselves in different situations. People cannot take on and integrate every identity that they have; Self-Determination Theory (Ryan & Deci, 2000) provides a more detailed account of how identities become a part of a person's sense of self. A person can respond to these identities and either incorporate them into their sense of self and think and act accordingly or have a complete lack of interest or motivation in an identity (Pelletier, Dion, Tuson, & Green-Demers, 1999). This refers to an identity in which a person sees no motivation or value (Ryan, 1995; Ryan & Deci, 2000). As the self provides a meaning-making lens through which a person's identities are either assimilated, and therefore become a part of a person's sense of self, or compartmentalised (Linville, 1987), it is possible that a person could have an identity which they have not internalised to their overall sense of self. As MS is externally forced upon a person and causes changes to a person's identity and sense of self, it is possible that this identity may not be incorporated into a person's sense of self, which could lead to negative effects of identity change (Jetten & Panchana, 2012) and an unwillingness to seek social support with others who share the MS identity (Ryan & Deci, 2000)

The concept of integration has been discussed in the healthcare literature. Integration has been defined as a complex person–environment interaction whereby new life experiences (e.g. transitions, illness, self-management) are assimilated into the self and reconciled with past activities and roles (Whittemore, 2005). Results of theoretical and empirical research (Dungan, 1997; Fleury, 1991; Hernandez, 1995, 1996; Medich, Stuart, & Chase, 1997; Whittemore, 2005;

Whittemore, Chase, Mandle, & Roy, 2002) suggest that the process of integration might be an important aspect of adjusting to and learning to manage chronic illness. Successful integration of new experiences into the self has also been proposed to be associated with psychological well-being (Reed, 1997). The process of integration appears to be difficult for individuals (Showers & Kling, 1996; Whittemore & Dixon, 2008) and can be distressing requiring significant attention, time, and effort. The ease of the process could depend on the cognitive ease of integration. However, the majority of research into the topic of integration has focused on people with diabetes, and it is only recently that this theory has been examined in people with other chronic illnesses (Whittemore & Dixon, 2008). Further research will be needed to investigate whether the process occurs in people with MS.

### **2.3 - Social identity**

Social identity theory states that because humans are social in nature, they will define themselves according to their sense of social identity, the groups a person belongs to. A person's mood state may be dependent on the state of the groups that define the person (in-groups). A sense of social identity can be beneficial for group members psychologically by providing a sense of belonging and purpose. A compromise in a sense of social identity, such as becoming ill or moving house, can have a negative impact psychologically and require some adjustment on the part of the individual (Iyer, Jetten, & Tsivrikos, 2008).

As stated in chapter 1, MS can have a devastating effect on a person's sense of self. People with MS often report decreases in the number and quality of social relationships (Thomas, Thomas, Hillier, Galvin, & Baker, 2006). These changes to a person's social role can affect their sense of identity (Jones et al., 2011). The changes to the person's identity due to a diagnosis of MS can have a negative psychological effect on the individual (Haslam et al., 2008). Chronic illnesses, such as MS, can lead to biographical disruption. MS, like other chronic illnesses, "involves a recognition of pain and suffering, possibly even death, which are only seen as distant possibilities or the plight of others" (Bury, 1982, p.169). In this sense, chronic illnesses, such as MS, can be seen as a major disruption to people's lives. The experience of symptoms in everyday life can result in a process of restructuring personal and social resources in an attempt to deal with the uncertain disease progression. Increasing conscious recognition of functional limitations can lead to embarrassment, resulting in social isolation (Bury, 1982). Instead, individuals begin to restrict their social environment to local and familiar territory (Barker & Bury, 1978; Goffman, 1968). These psychosocial problems can cause a sense of demoralization in the person with MS and are often accompanied by a deterioration in relationships due to the person with MS and those close to them struggling to adapt with the changed person and circumstances (Mohr et al., 1999). The way a person thinks about their self is linked to psychological wellbeing (Haslam et al., 2008). Whilst MS can cause disruptions to social functioning and changes to a person's sense of self, maintaining social relationships can be good for maintaining emotional well-being in people with MS (Till et al., 2012). This implies that the individual reaction to a change in self and social identity may

have implications on a person's psychological well-being following a diagnosis of MS.

One explanation for how individuals acquire their sense of self is through reflected appraisal. Reflected appraisal refers to the process through which people's self views are influenced by their perceptions of how others see them (Wallace, 2012). The role of others opinions helping to form a person's sense of self has long been acknowledged in psychology (e.g. James, 1890). Self reflected appraisals can have an elevated effect if a person has stigmatised features (Cioffi, 2000; Khanna, 2010; Santuzzi, 2002). Due to the negative changes in identity a person with MS experiences, they may be more willing to be affected by self reflected appraisals and come to see their changed identity faster. In this way the previously established social groups could facilitate identity reconstruction through self-reflected appraisals. Reflected appraisal outcomes also depend on the person's perceptions of the other person's characteristics. As predicted by Cooley (1902), perceptions of others' appraisals are more likely to be assimilated into the self concept if the other person is considered important, relevant, desired, valued and an in-group member (Cast, 1999; Rosenberg, 1973; Sinclair, 2005; Turner, 1999). Based on this information, the family could provide self-reflected appraisal, which could explain, why they are seen to be a salient factor in adjustment to MS (Wineman, 1990; Dennison, 2009).

Whilst research suggests that individuals undergo a loss of aspects of identity following a diagnosis of MS, the individual's change to this identity over time and the subjective experience of this change is less understood. There are also

differences in the extent of detrimental effects that people with MS experience and how they live with an unpredictable disease (Wilkinson & das Nair, 2013), suggesting that some factors may prevent the negative effects of identity loss. This suggests that a person's individual response to the disease could have an effect on their adjustment.

#### **2.4 The Social Identity Model of Identity Change (SIMIC)**

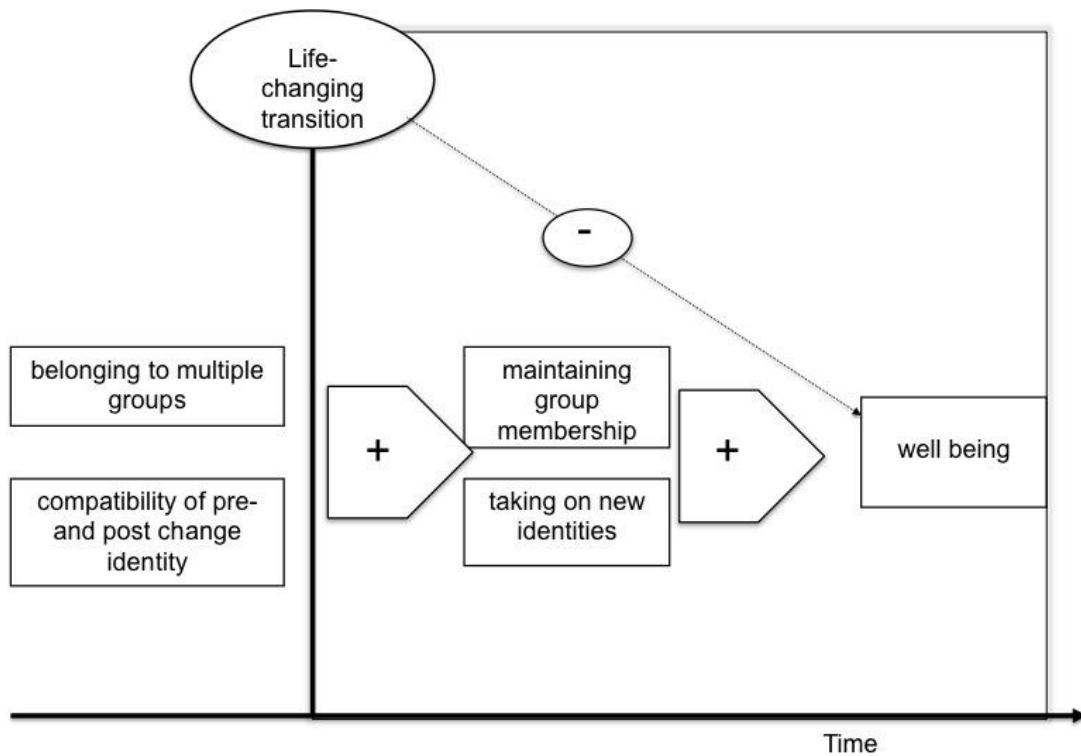
Changes in life can create a sense of uncertainty and “lost ground”, to respond to change individuals need to reorient themselves to adjust to this change (Lewin, 1948). Identity change is challenging, to reorient themselves individuals will have to start categorizing themselves as member of new groups that they have joined, such as a person with MS. This process of re-categorising social identity is not straightforward or instantaneous. It may take time for a person to begin to adjust his or her own self-concept to begin to claim and accept the new group membership (Iyer et al., 2008). In people with MS, to adjust to the identity change from being a healthy person to a person with MS, individuals will need to first adjust their own self-concept to begin to see themselves and identify as a person with MS.

The Social Identity Model of Identity Change (SIMIC (Jetten & Panchana, 2012), supplements an individual-level approach to adjustment and recognises that social groups (e.g. those centered on family, work, community, sport or religion) provide security, support, purpose and a sense of identity to enable individuals to cope with life transitions. A diagrammatic representation of the SIMIC can be found in Figure 2.1. Belonging to a large number of different groups before a life changing

transition, such as a diagnosis of MS, can protect from the effects of this transition by providing groups to fall back on (Haslam et al., 2008). The SIMIC proposes that previously established social groups can form a secure base for identity reconstruction, in that they provide a basis for social support, whilst providing grounding and connectedness to others, allowing people to build new identities. These new identities are integrated and compatible with previous identities, enhancing a person's identity continuity (Jetten & Panchana, 2012). These newly formed, Integrated and compatible identities can reduce the negative effects of identity loss on psychological wellbeing (Haslam et al., 2008). These previous identities may also ease the cognitive effort required for the integration of an illness identity and pre-existing identities, which could lead to the positive effects of integration in people with chronic illnesses (Whittemore & Dixon, 2008).



Figure 2.1: The Social Identity Model of Identity Change



Whilst it has been established that MS can affect a person’s sense of self, the role of previously established social groups and the process of adjusting to identity change is less well understood. Further research could investigate the process of identity change to identify successful patterns of identity change in response to MS and reduce the effects of depression and anxiety.

## 2.5 – Family

The concept of ‘family identity’ has been defined as “the family’s subjective sense of its own continuity over time, its present situation, and its character. It is

the gestalt of qualities and attributes that make it a particular family and that differentiate it from other families” (Bennett, Wolin, & McAvity, 1988, p. 58). The family identity is co-constructed by its members and includes multiple identities, including the family as a whole, smaller groups (e.g. parents) and the individual member of the family. As the family is co-constructed by its members and can differ between people, for this thesis, a strict definition of the family will not be used, as this may limit whom participants think of as their family. I expect that a broad definition of the family will include blood relatives, spouses, and step-relatives.

The sense of identity a person derives from their family can affect the interaction with the other members (Ownsworth, 2014). Whilst there is a lack of research investigating family identity in people with MS, research into people with traumatic brain injury has shown that illness can cause changes to family roles and responsibilities which affect the entire family system (Degeneffe, 2001; Kosciulek, 1997; Kreutzer, Kolakowsky-Hayner, Demm, & Meade, 2002) and this can have an emotional effect on the family (Ergh, Rapport, Coleman, & Hanks, 2002). Whilst severity of impairment in people with traumatic brain injury appears to be the biggest predictor of family caregiver distress, the family’s internal (mastery, coping and resilience) and external (social support) resources appear to affect this (Ownsworth, 2014). Further research has highlighted the reciprocity of support in people with traumatic brain injury and their family caregivers (Bowen et al., 2009; Kreutzer et al., 2002; Wade et al., 2011), in that the person with the traumatic brain injury’s well-being is associated with the family member’s adjustment. Although, this research has been conducted on

people with traumatic brain injury, it suggests that family may have positive effects on both the person with MS and the family group as a whole if coping strategies and social support are adequate and reciprocal.

Family support has been found to be a salient factor in an individual's adjustment to MS (Wineman, 1990). Furthermore; family support is often cited as being the main source of emotional and physical support for people with MS (Irvine et al., 2009), and indeed, those with other neurological conditions (Jones et al., 2011). In a large-scale study of individuals with traumatic brain injury (Jones et al., 2011), a positive correlation between the severity of the injury and life satisfaction could be explained by the person's increased sense of personal identity, which brought them closer to family and other support networks. Individuals are likely to seek and receive social support from others who they perceive share their social identity (Haslam, Jetten, Postmes, & Haslam, 2009). When people are diagnosed with MS, they may attempt to conceal their diagnosis and do not normally perceive their selves as belonging to that social group (Irvine et al., 2009), and because of this, they may seek support from a social group they feel they do belong to, such as the family. Therefore, a diagnosis of MS may increase an individual's family identity. The social support received from this group could provide a secure base for people to acknowledge their emerging identity as a person with MS and incorporate this into their current identity. As symptoms become more prominent, the person with MS may recognise their illness and family members may take on more of a carer role, which could lead people with MS to recognise and incorporate their changing identity in a supportive environment.

The Social Identity Model of Identity Change (Jetten & Panchana, 2012) hypothesises that using previous social groups to acknowledge and adjust to identity change has a beneficial effect on psychological wellbeing because a person's identity continuity is not disrupted by the identity change. Incorporating their emerging identity as a person with MS into their existing pre-diagnosis identity, may lead people to seek and receive support from other people with MS, as predicted by the SIMIC (Jetten & Panchana, 2012). Family support has been implicated in adjustment to MS (Dennison et al., 2009; Wineman, 1990), however, it is not clear how family identity helps in adjustment to MS. The SIMIC provides a possible explanation for this; further research will allow an examination of the family's ability to provide a secure base for identity reconstruction.

The more people see their family members as available sources of support, the more they use social support focused coping, a form of problem focused coping correlated with lower depression and anxiety scores (Roy-Bellina, Moitrelle, Camu, & Gely-Nargeot, 2009). For social support to be a useful mechanism for adjusting to the psychological effects of MS, the family needs to be available and willing to provide it, and the person with MS has to be willing to use it (Roy-Bellina et al., 2009). The ability of the family to provide a secure base for identity reconstruction needs further investigation. Beliefs and attitudes of family members need to be in line with that of the person with multiple sclerosis to maintain or improve family functioning and prevent disruptive behaviours such as conflict.

The psychosocial problems that a person with MS experiences can cause demoralization, which may be accompanied by deterioration in relationships due to the person with MS and those close to them struggling to adapt to the changed person and circumstances (Mohr et al., 1999). The biographical disruption caused by the chronic illness can affect the family group as well as the person with MS (Green, Todd, & Pevalin, 2007). MS affects the family unit as a whole; due to the wide range of symptoms the individual faces (Antonak & Livneh, 1995) and the thought of increased reliance on the family in the future (Irvine et al., 2009; Wineman, 1990).

Research on the marital unit has found that it is not only the person with MS who suffers from the psychological effects of the disease, but also their significant others (Janssens et al., 2003; Northouse, Dorris, & Charron-Moore, 1995). Care receivers and their partners' level of distress are highly correlated (Northouse et al., 1995). It is common for family members to become carers for people with MS (Buhse, 2008), which can lead to large disruption and change in the family group as members of the family attempt to adapt to the carer identity.

A similar relationship has been found between depression and health-related quality of life of significant others of those with MS, showing that they have low vitality and high depression (Giordano et al., 2012). Multivariate modeling showed that disability had no significant effect on health-related quality of life and depressive symptoms in significant others, however, the level of depressive

symptoms in the person with MS was negatively correlated with most health related quality of life and depression scores.

McAllister (MacAllister, Boyd, Holland, Milazzo, & Krupp, 2007) conducted a review of the psychological consequences of pediatric multiple sclerosis and suggested that the impact of having a family member with MS may affect the overall family functioning. This finding might work both ways, in that having a parent with multiple sclerosis may have a negative effect on their children, further having an effect on the family (Pakenham & Cox, 2012). In an investigation into the effect of parental illness on youth and family functioning, using the family ecology framework, 85 participants with MS and their 127 children/youths completed questionnaires. The family ecology framework is a research framework that draws on general systems, human ecology and stress/coping theories, and describes pathways through which parental illness affects youth and family functioning. Pakenham & Cox (2012) found that parental illness did affect youth and family functioning along the lines of the family ecology framework. Specifically proposed mediators (role redistribution, stress and stigma) were implicated in the processes that link parental disability to youth adjustment. The result also suggested that the additive effects of parental depression were not mediated but directly affected family functioning, which in turn mediated the effect on youth adjustment. Family functioning also mediated the effect between parental depression and youth well-being and behavioural social problems. The effect on having a member of the family with MS can be devastating both directly and indirectly on adjustment and well-being.

Chronic illness can also have a considerable impact on partners, often leading to increased distress and reduced marital satisfaction (Berg & Upchurch, 2007; Bogosian, Moss-Morris, Yardley, & Dennison, 2009). In particular, avoidance of discussing illness-related issues has been associated with worse outcomes for both partners (Manne, 1999; Manne et al., 2006).

The research so far suggests that the family can provide a secure base for identity reconstruction; however, the family is also facing their own problems in response to the MS. Coping styles and resources within the family unit appear to be important in the family's ability to form a secure base for identity reconstruction. In people with MS, the family is often the first to know about the diagnosis, and the first social group to provide social support (Irvine et al., 2009). Following biographical disruption (Bury, 1982), individuals undertake a process of restructuring personal and social resources in an attempt to deal with the uncertain disease progression. Increasing conscious recognition of functional limitations can lead to embarrassment, resulting in social isolation (Bury, 1982). In response, individuals begin to restrict their social environment to local and familiar territory (Barker & Bury, 1978; Goffman, 1968). Due to the reduction of social resources (Bury, 1982) and the disruption to social relationships (Jones et al., 2011) in response to chronic illness, the family is well suited for continued social support throughout the transition process.

## 2.6 Social Support

The SIMIC suggests that social support provided by previously established groups can help with the adjustment process. Social support can be defined as “the provision or exchange of emotional, informational or instrumental resources in response to others needs” (Cohen & Pressman, 2004 p. 780). Social support can be actual support, in the form of received resources, or perceived, the perception that one has assistance available. Social support has been linked to improvements in psychological well-being in important life transitions (Cobb, 1976) and to reduce depression and anxiety in stressful times (Taylor, 2011). In addition, social support has been found to facilitate adjustment to multiple sclerosis (Wineman, 1990).

There are two hypotheses to explain the positive effect of social support. The buffering hypothesis (Cohen & McKay, 1984), states that social support protects individuals in times of stress, whereas in the direct effects hypothesis (Cohen & McKay, 1984), people with high social support are in better health than those with low social support regardless of stress levels. Evidence has been found for both hypotheses (Taylor, 2011).

Support for the theory also comes from a study that investigated women’s adjustment to MS by examining mastery over the condition (Crigger, 1996).

Through interviews and psychometric tests, Crigger (1986) found that relationships among family, friends and a belief in a higher power were considered to be very important when it came to adjusting and achieving mastery



over multiple sclerosis. Life stressors were found to be cumulative, having a detrimental effect on an individual's sense of mastery. Disease disability, based on physical disability measured by the EDSS, had no significant correlation with any other variables (Uncertainty, social support, spiritual well-being, self-esteem and mastery over the condition)

Adjusting to a progressive disease is a continuous process with several phases defined by the individual's personal circumstances; the person needs personal, social and external resources to achieve this. Social support can be important for motivating self-management strategies (Audulv, Asplund, & Norbergh, 2012). Social support can lead to greater recognition of the disease, leading to self-management strategies.

The SIMIC hypothesizes that previous groups provide a source of social support whilst new identities are established. The literature supports the theory, in that reviews have found social support to be an important correlate of adjustment (Dennison et al., 2009). An investigation of the links between family identity and social support will enable further insight into patterns of successful adjustment and identity change.

## **2.7 Coping Strategies**

### **2.7.1 Coping Strategies in the Person with MS**

Despite the physical and psychological problems associated with MS, some people with MS manage to cope well and adapt to living with the illness (Antonak & Livneh, 1995). The impact of symptoms of multiple sclerosis on quality of life appears to be dependent on the coping resources available to the individual (Tromp, 2006). Early psychological analyses of adjustment in people with multiple sclerosis recognized and focused on the roles of individual differences in the onset and exacerbation of MS, however recent perspectives have recognized the role of psychosocial stressors and the adaptive challenges related to this (Devins & Shnek, 2000).

Coping strategies refer to the way in which people respond to stressful situations or demands from the environment. Previous research has suggested that having an adaptive coping strategy, in which an individual acknowledges their situation and responds accordingly, may have positive outcomes in people with MS (Boland, Levack, Hudson, & Bell, 2012; Irvine et al., 2009; Lexell, Lund, & Warsson, 2009). Two patterns of adapting to identity change have been identified in response to chronic illness (Charmaz, 1995): adapting and bracketing. Adapting, involves acknowledging the impairment and the lost identity and reconstructing a new identity based upon the changed sense of self, whereas bracketing involves compartmentalizing the disease to preserve a sense of the pre-diagnosis self, in an attempt to recover the lost identity. Whilst the two responses to adapting to

identity change appear to be separate responses, Bury, (1982), stated that in response to biographical disruption, it is only when symptoms become apparent that people attempt to restructure their personal and social resources to respond to the disruption. Due to the relapsing nature of the disease, people with MS may not always be experiencing symptoms, despite being diagnosed. Participants may respond to the biographical disruption of being diagnosed with MS by bracketing the disease and then begin to use adaptive coping styles as symptoms become more apparent.

In an investigation into the factors predicting life satisfaction in people with progressive neurological conditions, Chen, (2007), found that future time orientation, spiritual well-being, hope, importance of religion, and acceptance explained 42% of variance in life satisfaction. Future time orientation, spiritual well-being, importance of religion and levels of physical functioning also explained 42% of the variance in acceptance of the disability. Life satisfaction was found to be positively correlated with spiritual well-being, hope and self-acceptance of the disability, likewise, hope was positively correlated with spiritual well-being and self-acceptance of the disability. Future time orientation was found to be negatively associated with hope and self-acceptance of the disability. People with MS were found to be more future orientated than those with muscular dystrophy.

There does appear to be some weak evidence to support the positive effect of adaptive coping and the negative effect of avoidance coping in regards to MS, with positive reappraisal coping strategies being negatively correlated with current

and future depressive symptoms, whereas escape avoidance coping strategies were positively correlated with depressive symptoms (Aikens, Fischer, Namey, & Rudick, 1997).

In testing a stress and coping theory to investigate whether the illness-related stressors of MS play a role in adjustment to MS, results supported the hypothesis that threat appraisal and emotion focused coping resulted in poorer adjustment, as measured by depression, global distress, social adjustment and global health status (Pakenham, Stewart, & Rogers, 1997). However, problem focused coping resulted in better adjustment. The research found only weak support for the hypothesis that the relationship between adjustment and both appraisal and coping varied according to the type of illness related stressor. It is possible that problem focused coping is the solution for illness-related stressors in MS patients.

Roy Bellina et al. (2009) found similar results to support the use of adaptive coping strategies. They used a cross sectional sample of 45 people with MS, and measured: locus of control, social support, coping strategies, anxiety, depression and representation of the disease. Problem focused coping was negatively correlated with depression and anxiety scores and emotion focused coping was found to be positively correlated with depression and anxiety scores. Additionally, positive representation of the disease was found to correlate with problem focused coping.

The main-effects hypothesis of stress appraisal and coping, states that stress appraisal, social support and coping strategies have direct effects on adaptation. In

a prospective study testing the main-effects model, Pakenham (1999) assessed a sample of 122 people with MS, over an extended period of time (12 months), and found that, after controlling for time 1 levels of adjustment, time 2 levels of adjustment were related to less disability, greater reliance on problem focused coping and less reliance on emotion-focused coping.

Due to the unpredictable nature of MS, adjustment strategies are constantly changing to meet demands, which can be psychologically taxing (Tromp, 2006). Adaptations to disability and strategies to deal with this remain an important theme in elderly participants with multiple sclerosis, showing that adjusting to the disease is an ongoing process (Molton, Johnson, McMullen, Yorkston, & Jensen, 2010).

In an investigation into coping styles, mood and self-esteem in people with MS who have or have not had an exacerbation of symptoms compared to the general population, McCabe (2005) found that both groups of people with MS experienced poorer mood levels than the general population however the group of participants who suffered an exacerbation showed the highest levels of anxiety and confusion. Coping strategies did not predict mood in either group, however the authors acknowledged that a longer follow up was needed to investigate this.

Optimism has a disease-specific effect on physical adjustment and on the use of emotion orientated and avoidant coping styles. It has been suggested that MS patients may benefit more from optimism than people with other chronic conditions, due to the uncontrollability associated with the disease. As there is no

way to fully medicate and control the symptoms of MS, optimism may be useful (De Ridder, Schreurs, & Bensing, 2000). Although causal inferences cannot be assumed from a cross sectional design, the authors suggested that in people with MS, unlike people with Parkinson's disease, optimism does not necessarily cause avoidant coping styles with the data suggesting that high levels of optimism, result in lower levels of emotion focused coping in people with MS.

However, Fournier, De Ridder & Bensing (2003) found that the effect of optimism on mental health, predicted by a three factor model, has the same effect on mental health regardless of the controllability of the chronic disease. The three factor model did have an effect on physical health, in that when the effect of chronic disease can be controlled by self-care, positive efficacy expectations can have a strong effect on physical health, however, when self-care options for the chronic disease are limited, such as in MS, physical health depends more upon positive unrealistic thinking and relates negatively to positive efficacy expectations. In this way, unrealistic optimism may have a positive effect on people with MS.

From the literature it appears that people with MS use a number of different coping strategies to cope with their MS and that these may be constantly changing as a response to newly emerging symptoms. There appears to be some evidence that positive, adaptive coping strategies appear to have a positive effect in people with MS. Investigating which coping strategies lead to positive outcomes could have implications for helping people with MS cope with their chronic illness.

### **2.7.2 Coping Strategies in MS Caregivers**

The family is often involved in caregiving in people with MS. Partners of people with MS often become caregivers, adding to the demands and challenges of family life (Buhse, 2008). It is important to understand caregivers' coping styles to understand how the family can cope with the diagnosis of MS.

Positive adaptive coping strategies have been found to be effective in regards to MS caregivers (Pakenham, 2002). They evaluated a sample of 213 carers and their care recipients to test the Coping with MS caregiving inventory, and found that coping in caregivers comprises 5 factors: supportive engagement, criticism and coercion, practical assistance, avoidance, and positive reframing. Preliminary construct validation data were found to be consistent with MS caregiving research linking passive avoidant emotion focused coping with poorer adjustment and relationship focused coping and less criticism resulting in better adjustment. A good relationship with the person with MS has been shown to produce better adjustment to MS in line with SIMIC.

Stress appraisal and coping may also affect the carer of the person with MS, similar to the way it does in people with MS (Pakenham, 2001). A model of stress appraisal and coping in carers of people with multiple sclerosis was tested in a sample of people with MS and their carers, who completed a number of self-administered scales at time 1 and time 2, 12 months later. The results showed that nearly a third of carers reported clinically high levels of psychological distress. Regression analysis showed that better time 1 adjustment was related to less

patient disability and distress, higher social support, lower threat appraisals and less reliance on emotion focused coping. Surprisingly, the results showed that less reliance on problem focused coping also improved adjustment. This result appears to be inconsistent with previous research suggesting that adaptive coping strategies are more effective. Having a good relationship with the person with MS and being able to receive and give social support may be beneficial for both the person with MS and their carer.

The literature on the family suggests that coping strategies need to be aligned within the family group for the social group to be effective at easing the identity transition. Investigating the effects of coping strategies within the family unit may be beneficial.

## **2.8 Adjustment over time**

The SIMIC suggests that using previously established social groups, such as the family, could facilitate adjustment through the provision of social support. People with MS are more likely to experience mood problems within the first two years of diagnosis (Janssens et al., 2003), suggesting that people may adjust over time despite individual levels of support received.

In comparing adjustment and self-esteem in a sample of people with MS and a sample of people from the general population over a period of 18 months, it was found that people with MS experienced poorer adjustment and self-esteem, as well as poorer health, lower quality social relationships and lower work capacity



than the general population sample (McCabe & Di Battista, 2004). People with multiple sclerosis were also less likely to adopt a problem focused coping style or a social support seeking coping style; instead they were more likely to adopt a detached style of coping. In both the sample of people with MS and the general population sample it was found that the most important predictor of adjustment and self-esteem at time 2 was the same variable at time 1, however, health, social relationships, work or coping styles explaining little of the variance on time 2 levels of adjustment. This suggests that social relationships, and the social support provided by these, may play a part in adjusting to multiple sclerosis as suggested by the SIMIC.

In one of the few prospective studies in people with MS (Brooks & Matson, 1982), it has been found that most people with MS have positive self-concepts after up to 17 years of illness. Most of the positive adjustment appeared to occur during the first decade of the illness. Improvements in self-concept were found to be positively associated with coping by “accepting it” and negatively associated with reliance upon religion and family, providing some evidence for the importance of previous social groups in adjusting to identity change. This study used a non-standardized coping instrument and a wide variety of coping strategies were used in a small sample, making these results difficult to interpret.

Spiritual well-being, both religious and existential, may play a role in adaptation to MS over time. McNulty et al. (2004) found that spiritual well-being had an significant influence on adaptation to MS and also acted to mitigate the impact of uncertainty on adaptation. Both uncertainty and spiritual well-being

independently predicted psychosocial adjustment, however spiritual wellbeing showed a mediator not a moderator effect.

Whilst, it appears people with MS do adjust to their diagnosis of MS and subsequent change in identity over time, the provision of social support can aid this process, as suggested by the SIMIC.

## **2.9 Psychological Interventions for Mood in People with MS**

Many MS services do not have the financial or human resources to offer individual treatments to every patient with MS who presents with low mood. Therefore group treatments have been introduced (Lincoln et al., 2011).

Psychological interventions can be broadly defined as an intervention, which is underpinned, by psychological theory and methods with the intention of improving biopsychosocial functioning (Smith, 2012). Psychological interventions are a time-limited therapeutic modality that involves a therapist (or team of therapists) working with a client (or a group of clients), with a specific goal of identifying, assessing, and alleviating specific difficulties and improving the psychological well-being of the client, in a clinical or more relaxed setting (e.g. the patients home). These interventions can be manual-based, delivered through a computer-based interface or face-to-face in an individual or group format. Clinical psychologists, MS nurses, psychiatrists, occupational therapists, counsellors or psychotherapists often deliver interventions. Thomas et al. (2006) distinguished between psychological interventions that address mood problems

and those that address cognitive problems in people with MS. The focus for this thesis will be on interventions that address mood problems. There is some support for the effectiveness of psychological interventions in treating anxiety and depression in people with MS (Ameis & Feinstein, 2007; Thomas et al., 2006; Hind et al 2014) from both an individual format (Crawford & McIvor, 1987; Foley, Bedell, LaRocca, Scheinberg, & Reznikoff, 1987; Larcombe & Wilson, 1984; Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001) and group format (Crawford & McIvor, 1987; Mohr et al., 2001). Lincoln et al. (2011) compared a group intervention based on cognitive-behavioural principles with a waiting list control group in a randomized controlled trial. Participants receiving treatment were less distressed and had lower levels of depression and anxiety at 4 & 8 months following randomisation than participants in a waiting list control group. There was also evidence for a significant increase in self-efficacy and a reduction of impact of MS on participant's lives. The efficacy of group-based interventions compared to individual psychological interventions, has not been established.

Psychological interventions work by changing thoughts and behaviours to reduce psychological difficulties or improve the psychological well-being of the client. Thomas et al. (2006) suggested that psychological therapies might improve mood by improving adherence and self-management of the condition, self-esteem, coping skills and general quality of life, whilst reducing stress. Furthermore, interventions may help people develop adaptive coping mechanisms to enable people with MS to deal with difficult thoughts and emotions or challenging external circumstances. Clients may also receive therapy to help them adjust to their diagnosis of MS. Thomas et al. (2006) also highlighted the importance of

group therapy which can decrease feelings of alienation, and provide peer support. People are more likely to receive and accept peer support from individuals they see as sharing this social group identity (Cruwys et al., 2014; Frisch, Hausser, van Dick, & Mojzisch, 2014; Haslam et al., 2008), group-based psychological interventions may have a greater effect than individual based interventions at treating mood, however, this increased efficacy may only occur when people with MS begin to acknowledge their changed identity.

The effect of being in a group might affect the outcome of treatment regardless of the format of treatment. das Nair (2012) found in a randomized controlled trial for memory rehabilitation that regardless of treatment condition; compensation group, restitution group or self help control, all participants' adjustment levels rose over a period of 7 months. The authors stated that the non-specific effects of simply being part of a group couldn't be ruled out, as the control group for this research was a self-help group.

Not everyone invited to take part in an adjustment group takes part. Holmes et al. (2012) found that in examining attendance rates for an adjustment group for people with multiple sclerosis, there were no significant differences in demographic variables, disability, self-efficacy or quality of life between those that did attend and those that did not attend. The only significant factor found was that fewer men attended the adjustment group than women, suggesting that participants may have different views of group or individual interventions. This view of the intervention could affect a participant's willingness to take part in the intervention.

Group interventions may work through a number of different mechanisms. In an investigation into how people with MS experience social interaction with other people with MS, Skar, Smedal, & Torkildsen (2012), conducted focus group interviews with 11 participants who had participated in a rehabilitation stay. The rehabilitation stay consisted of participation in a rehabilitation group with other people with multiple sclerosis, which created a social community where experiences could be shared. Through these communities individuals learned ways to cope with stigma and ways to adjust to the disease, this provided a sense of recognition of self and identity. The recognition of self and identity was found to be important for adjustment and overall well-being. A finding that explains how SIMIC could explain the benefits of a group intervention.

Based on the SIMIC model, the identity changes following a diagnosis of MS may result in group interventions being more effective for the treatment of depression and anxiety due to the peer support that this type of therapy can provide (Thomas et al., 2006). Receiving social support from other people may lead to a greater reduction in mood problems based on the dual effect of the therapy and social support, in line with the literature outlined previously.

People are more willing to accept social support when they identify with the person providing it (Haslam et al., 2009). A diagnosis of MS can be seen as a negative identity change to the person who has been recently diagnosed and may lead them to be unwilling to identify with and accept the support on offer in a group therapy setting. Integration of the chronic illness into the self-concept

through pre-existing social identities could lead to people to recognise their shared identity with people with MS, which could lead to greater improvements in group-based psychological interventions, as they would be more willing to accept the shared social support from a group based intervention.

A comparison of individual and group based interventions will enable insight into whether group interventions can lead to a greater reduction in mood problems. There is a published review examining the two formats of CBT in depressed adults with MS (Hind et al., 2014), However, the previous review did not accept non-English studies, did not contact authors if the data was not in the published review, and only looked at the effect on depression. Investigating both depression and anxiety in a wider literature review may provide insight into differences in efficacy between the two formats of psychological intervention.

## **2.10 Summary and hypothesis**

In summary, there is some literature to suggest that a change of identity occurs following a diagnosis of MS and that this has a negative effect on mood. The SIMIC proposes that previously established social groups may provide a secure base for identity reconstruction and that the family group could ease identity transition whilst the integration of the disease into pre-existing identities, such as the family, occurs. Whilst, the literature suggests that identity loss occurs and that previously established social groups are useful to reestablish this identity, there is a lack of research to confirm this.

The overall aim of this thesis was to investigate the loss of identity following a diagnosis of MS and to investigate how a previously established social identity, the family, can help a person to re-establish their identity.

A number of gaps were identified in the literature. Whilst a lack of social identity could explain the lack of a consistent result for the link between illness severity of MS and mood disorders in people with MS, investigating the loss of social identity and its links to psychological outcomes could help explain this further. Whilst the literature suggests that individuals can experience a loss of self following a diagnosis of MS, the subjective experience of this is not well understood. Therefore, a thorough examination of this, using a qualitative research method, could provide a more detailed explanation of this process and how individuals appear to adjust over time.

The SIMIC helps to explain why social support has been found to be a consistent correlate of adjustment in people with MS. Testing this model in people with MS could explain this further and provide a possible means of intervention in the future. Whilst the family may represent a special type of group, as it is not chosen, it has been found to be a salient factor of adjustment in people with MS (Wineman, 1990) and allows us to explore whether previously established groups can provide support and lead to better adjustment as suggested by the SIMIC. The research literature suggests that using problem focused coping strategies can be beneficial for adjustment in MS; an investigation into this could clarify this.

Whilst psychological interventions for depression and anxiety in people with MS appear to be effective, the efficacy of the format of the intervention has not yet been tested. According to social identity research, people will be more likely to receive and offer support to and from others who share their social identity. In line with this; it leads to the proposal that group interventions may be more effective following an initial adjustment to the disease. A systematic review of psychological interventions for depression and anxiety in people with multiple sclerosis will allow an investigation of this.



### **3 Methodological considerations**

#### **3.1 Chapter Overview**

Following a review of the literature, this chapter provides an overview of how this thesis will make a contribution to our understanding of identity change in response to MS and the impact that this can have on interventions for mood in people with MS. It will present the research questions, epistemological considerations and a rationale for the use of mixed methods.

#### **3.2 Research Questions**

The previous chapter outlined the problem of high incidence in mood disorders in people with MS and suggested this may be partly due to the change in a persons sense of self in response to MS. Focusing on the SIMIC, I posited that changes to a person's sense of self could disrupt identity continuity leading to negative changes to mood. However, the theory states that social groups can protect against this and reduce the negative effects of identity change. The family is a salient group in adjusting to MS (Wineman, 1990) and may reduce the negative effects of identity change, in line with the SIMIC. The family is not a typical social group, and research needs to be done to see whether this group, which the majority of people with MS use as support, is as effective as typical social groups in protecting against the negative effects of identity change. This led to some questions based on the highlighted omissions in the literature:

- Whilst the majority of research has focussed quantitatively on the severity of disability and links to mood, recent research has suggested changes to a persons sense of self following a diagnosis of MS may be associated with changes to mood. These changes to a person's sense of self in people with MS need to be researched and explained further.
- The use of problem focused coping strategies has been found to be beneficial in people with other chronic illnesses, but this has not been investigated in people with MS.
- Whilst social groups have been found to be effective at providing social support for people with MS in line with SIMIC, and the family group is seen as a primary source of support for a large number of people with MS, the efficacy of this social group in reducing the negative effects of identity change needs to be further investigated.
- A systematic review has already been carried out to determine which format of CBT intervention is more effective at treating depression in people with MS (Hind et al., 2014), however, this review only focussed on CBT interventions and on depression and only considered articles written in English.

These omissions in the existing literature highlighted the following questions

- Are problem focused coping strategies beneficial for adjustment in people with MS?
- Do people with MS experience changes to their sense of self following a diagnosis of MS, and if so, what is the subjective experience of this over time?
- Are changes to a person's sense of self associated with changes to mood?
- Does the family act as a secure base for identity reconstruction, in line with the SIMIC?
- What is the efficacy of group interventions for people with MS compared to individual interventions?
- Do group and individual interventions have a different effect on a person's social identity?

### **3.3 Paradigms and Epistemology**

In designing a research study it is important to consider the paradigms and epistemological positions that underpin the research. A paradigm refers to the underlying assumptions and intellectual structure upon which research and

development in a field of inquiry is based (Kuhn, 1962). Each researcher holds their own paradigm and this will affect their theory of knowledge, epistemology and research methods used. This section will explain the epistemological stance of the thesis and the research methods that have been used to answer the research questions.

### **3.3.1 Positivist vs. Interpretivist/Constructivist Epistemology**

Positivism is an epistemological stance that suggests that sensory experience is the source of all knowledge and that this knowledge can be measured objectively. In the social sciences, this involves following the basic premises of scientific inquiry by collecting and interpreting social facts in an objective manner and from these facts produce laws and models of behaviour that are unbiased and neutral (Saks & Allsop, 2007). By producing models of behaviour based on reliable objectively measured social facts, then these models can be generalized to the entire population of research. Quantitative methods are used to measure social facts in an objective manner, the two main aims of quantitative research in psychology is to measure behaviour, quantification, and to predict models of behaviour, determinism.

The use of an objectivist, post-positivist epistemology would enable the researcher to test whether the family identity is associated with positive outcomes in mood, social support and willingness to be part of new social groups in line with the SIMIC. Unlike qualitative methodology, this method uses a representative sample, the size of which depends on the required power for the analysis, of the population

of people with MS. Quantitative methods tend to use larger samples than qualitative studies. This, combined with the use of rigorous testing and strict levels of statistical significance, can allow the researcher to generalize the findings from this research to the population. The process of how these variables are linked, and how change happens, cannot be explained through this methodology, unless a longitudinal study is used. However, the research studies in this thesis are based on existing theory, the SIMIC, which can provide an explanation. A positivist epistemological stance could also answer the question of whether the family can provide a secure base for identity reconstruction through the use of a meta-synthesis of qualitative data. Qualitative data are useful for providing a snapshot of one person's, or a small number of people's, interpretation of an event or phenomenon. By bringing together many different interpretations you are strengthening the evidence for an interpretation by discovering common themes and differences and building new understanding of the topic of interest. In this way this method will allow a new theory to be tested using existing data. Existing data can also be used to answer the question of which format of psychological intervention has a greater effect on mood. A systematic review and meta-analysis can allow us to test the hypothesis that the format of the intervention will have an effect on the results.

There are some criticisms to using a positivist stance to research in the social sciences. By collecting information and generalizing to the population as a whole, this approach fails to take into account the individual experience of the topic under investigation and fails to take into account how this could change over time.

Only qualitative methods can access the individual understanding and subjective experience of participants who are providing information on a research topic.

The interpretive paradigm presents a challenge to the positivist standpoint by asserting that there is no objective reality and that reality is socially constructed based on an individual's meaning of events. An interpretive approach therefore aims to explore what events mean to participants and how they understand them. Instead of testing pre-existing hypotheses an interpretive paradigm allows research to be more flexible, and can lead to the identification of patterns and other factors that do not yet belong to any hypothesis of the event being researched.

It is assumed that everyone has their own social identity, which is defined by the groups a person considers themselves to be a part of (Haslam et al., 2009). To understand and gain further insight into the process of identity change, an interpretive epistemological stance would be taken to collect multiple realities from participants. Using this method it is important to treat each response separately and not collate responses. This methodology enables the researcher to gain insight into the individual, subjective nature of changes to identity and how this might change over time. However, this type of methodology, whilst providing rich data, may not be generalizable to the whole population of people with MS. The hermeneutic, subjective interpretation of qualitative data by the researcher allows the research to be valid; however, it cannot be generalized to the entire research population. Whilst this thesis focuses heavily on social identity, a concept that is socially constructed, the effectiveness of interventions and the

empirical study of factors affecting mood in people with MS also needs to be considered.

A pragmatic approach to the research was therefore used in this thesis. The primary importance of the research question was considered and it was concluded that to answer the research question to its fullest extent, a number of different epistemological stances would need to be combined. The use of multiple epistemological stances and paradigms can result in contradictory ideas and arguments, however, it is the researcher's stance that these should be honored and brought to light in research, even if they are not reconciled. With this mind, mixed methods were used in this thesis

### **3.4 Mixed Methods**

In considering the research question derived from the literature review, it was clear that this required both qualitative and quantitative methodologies. Therefore, this thesis combined both quantitative and qualitative methodology in a mixed methods design.

#### **3.4.1 Definition of Mixed Methods**

Creswell and Plano Clark defined mixed methods research as:

“A research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction

of the collection and analysis of data and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone” (Creswell & Plano Clark, 2007 p. 5)

With this definition in mind, the researcher is required to:

- Base their research on philosophical assumptions to guide their methods of inquiry.
- Collect, analyse, and mix both quantitative and qualitative data, in either single or multiple studies.

### **3.4.2 Triangulation design**

By using mixed methods, the researcher can gain greater insight and understanding into the research topic under investigation. In an attempt to mix data, a triangulation model (Creswell, Plano Clark, Gutmann, & Hanson, 2003) was used. The purpose of this type of design is “to obtain different but complementary data on the same topic” (Morse, 1991 p.122); this will allow a researcher to gain a greater understanding of the research topic, whilst bringing together the different strengths and weaknesses of both quantitative and qualitative methodologies. Using a convergence model (Creswell & Plano Clark,



2007), results from two different studies with different methodologies can be brought together for interpretation. Data on a number of different yet related subjects relating to the research question can be brought together and interpreted together.

### **3.5 Choice of approach**

A number of different research designs were utilised throughout this thesis. A systematic review of the literature allowed the researcher to investigate whether individual or group based psychological therapies have a greater effect on mood scores in people with MS. A meta-synthesis of the qualitative literature allowed insight into whether family identity, a salient factor in adjustment to MS forms a secure base for identity reconstruction following identity change as a result of MS. Semi-structured interviews with people with MS, who had recently taken part in an adjustment group intervention, enabled the researcher to gain insight into the subjective experience of identity change as a result of MS over time. A quantitative study enabled the researcher to empirically test whether the family identity predicts mood, as hypothesised on the basis of the Social Identity Model of Identity Change (SIMIC) (Jetten & Panchana, 2012). Due to the number of different approaches and methods used in this thesis, a more in-depth consideration of methods will be undertaken in each chapter where a different method has been used.

## **4 Group psychological intervention versus individual psychological intervention for mood disorders in people with multiple sclerosis**

### **4.1 Chapter overview**

This chapter presents the systematic review and meta-analysis of the literature around psychological interventions for mood in people with MS.

### **4.2 Rationale and Aims**

A systematic review of the literature was conducted to enable a thorough investigation of the efficacy of individual based interventions compared to group based interventions for low mood in people with MS.

For this review, the effect of psychological interventions was examined based upon their format. Individual interventions are interventions delivered to a single participant per session, whilst group interventions are delivered to more than one participant per session.

### **4.3 Review protocol**

The methods for this review were developed and adapted as a study protocol in 2013. The protocol for this review was not published. The review was undertaken in 2014.

### **4.3.1 Review question and inclusion criteria**

The review sought to answer the following question:

- Which format of psychological intervention has greater efficacy at treating mood in people with multiple sclerosis?

To answer this question, reviews were included if they met the following criteria:

#### **4.3.1.1 Sample**

Studies were included in the review if they involved participants who had received a diagnosis of MS and who had received a psychological intervention for the treatment of mood disorders (including general psychological distress, depression and anxiety). Studies on participants with co-morbid diagnoses were included, as multiple health difficulties are common in people with MS (Marrie et al., 2008). Studies that included participants of mixed aetiologies were also considered, provided that there were separate published data for the participants with MS (or these were obtained from the authors), or more than 90% of the sample had MS. Severity of mood problems were not considered for study selection.

#### **4.3.1.2 Interventions**

All psychological interventions were considered. A psychological intervention can be broadly defined as an intervention, which is underpinned by psychological

theory and methods with the intention of improving biopsychosocial functioning (Smith, 2012). Psychological interventions involved a therapist, or team of therapists, working with a client, or a group of clients, with a specific goal of alleviating difficulties and improving psychological well-being of the client. Only purely psychological interventions were considered. Studies were not included if they involved a psychological therapy being delivered at the same time as a non-psychological intervention to the same group of participants, as this would create difficulties in determining the effect of the psychological intervention.

Psychological interventions included cognitive behavioural therapy, acceptance and commitment therapy, behavioural therapy, psychodynamic therapies and cognitive therapies. The interventions could be provided on a one-to-one basis or in a group format. Studies were included if they compared an individual to group intervention or if they included either an individual intervention or group intervention. Studies were grouped together on the basis of whether they used a group or individual format intervention. No limit was placed on the number of sessions. In line with a previous review (Thomas et al., 2006) psychological assessments were not considered as psychological interventions.

#### **4.3.1.3 Types of studies**

Randomised Controlled Trials (RCTs) and Comparative Controlled Trials (CCTs)/Quasi-randomised Controlled Trials (QRCTs) of psychological interventions were considered for inclusion. Studies using other methodologies were not considered because this could lead to effect estimates that indicate a

more extreme benefit of the intervention and introduce confounders and differences between intervention and control groups.

### **4.3.2 Outcome measures**

Psychological interventions can have a large number of outcomes, which reflect the heterogeneity of the therapeutic modalities and format of delivery; therefore, only outcomes that were most relevant to the research question were considered. Outcomes were considered in the following order and if there was more than one outcome in a domain they were ordered hierarchically on the basis of their psychometric properties.

#### **4.3.2.1 Primary outcomes**

The primary outcome was measures of overall mood. Due to the lack of studies measuring anxiety (Siegert & Abernethy, 2005), and the higher prevalence of depression (Siegert & Abernethy, 2005) in MS than anxiety (Bamer, Amtmann, Ehde, & Johnson, 2008), if both anxiety and depression had been measured, the depression measure was used rather than the anxiety measure. All outcomes were considered using the following hierarchy of measures.

#### Overall Mood

1) The General Health Questionnaire (GHQ; Goldberg, 1978). This scale measures mental well-being by identifying those with general distress who are

likely to have or be at risk of developing psychiatric disorders. This scale is reliable with a Cronbach's alpha of .79-.95, and also has a high level of validity, correlating highly with other measures of mental well-being (Jackson, 2007). The GHQ has been found to be valid and sensitive in a sample of people with MS (Rabins & Brooks, 1981).

2) The Hospital Anxiety and Depression Scale Total score (HADS; Zigmond & Snaith, 1983). Both anxiety and depression sub-scales have been shown to have good internal consistency with .82 & .77 Cronbach's alpha correspondingly with .86 for the total score (Crawford, Henry, Crombie, & Taylor, 2001). The scale is considered good in terms of factor structure; inter-correlation, homogeneity and internal consistency in a large general public sample (Mykletin, Eystein, & Dahl, 2001). The scale has been validated and has a high level of internal reliability in a sample of people with MS with Cronbach's alpha for anxiety, depression and total score being .83, .77 & .87, respectively (Atkins, Newby, & Pimm, 2012).

### Depression

1) The Beck Depression Inventory (BDI; Beck, Rush, Shaw, & Emery, 1979). This scale has excellent psychometric properties, with good internal consistency and acceptable test-retest reliability across clinical and non-clinical samples (Beck, Epstein, Brown, & Steer, 1988). The BDI has been validated in a sample of people with MS (Moran & Mohr, 2005).

2) The Multiple Sclerosis Depression Rating Scale (MSDRS; Quaranta et al., 2012). This scale has been specifically designed for people with MS. It has high internal consistency with a Cronbach's alpha of .739 in a sample of people with MS, and high convergent validity with the BDI ( $r = .763, p = <. 001$ ) in a sample of people with MS (Quaranta et al., 2012).

3) The Patient Health Questionnaire 9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001). This questionnaire has high sensitivity (88) and specificity (88) to major depressive disorder using scores  $>10$  to indicate depression, as well as showing good internal consistencies of .86 & .89 in two samples of people with MS (Kroenke et al., 2001). The PHQ-9 has been validated in a sample of people with MS (Sjonnesen et al., 2012).

4) The Hospital Anxiety and Depression Scale – Depression sub-scale (HADS-D; Zigmond & Snaith, 1983). The depression sub scale of this test has been found to show good internal consistency with Cronbach's alpha .77 in a sample of healthy adults from the UK.

5) Profile of Mood States – Depression-dejection (McNair, Lorr, & Droppelman, 1971). This scale measures six factors of transient, distinct mood states, measuring tension-anxiety, depression-dejection, anger-hostility, fatigue-inertia, vigour-activity, and confusion-bewilderment. The scale has high internal consistency along all six factors, with a Cronbach's Alpha's of .913 along the tension anxiety sub scale. The scale is sensitive to change (Shacham, 1983). The

scale has been used in a sample of people with MS; however, no psychometric properties were reported (McCabe, 2005).

### Anxiety

1) The Hospital Anxiety and Depression Scale – Anxiety sub-scale (HAD-A; Zigmond & Snaith, 1983). The anxiety sub scale of this test has been found to have good internal consistency with Cronbach's alpha .82 in a sample of healthy adults from the UK.

2) The Beck Anxiety Inventory (BAI; Beck et al., 1988). This scale has high internal consistency (Cronbach's Alpha = .94) and acceptable reliability ( $r = .67$ ), in a sample of people with anxiety disorders (Fydrich, Dowdall, & Chambless, 1992). It also has high convergent and discriminant validity against diary self reports (Fydrich et al., 1992). The scale has not been validated in a sample of people with MS.

3) The State Trait Anxiety Inventory (STAI; Spielberger, Gorssuch, Lushenne, Vagg, & Jacobs, 1983). Both sub-scales have good internal consistency (State = .92 Cronbach's Alpha, Trait = .88 Cronbach's Alpha), and the scale also has a psychological meaningful four-factor structure (Spielberger & Vagg, 1984). No details could be found about the psychometric properties of the test in a sample of people with MS.



4) Profile of Mood States - tension-anxiety (McNair et al., 1971). This scale measures six factors of transient, distinct mood states, measuring tension-anxiety, depression-dejection, anger-hostility, fatigue-inertia, vigour-activity, and confusion-bewilderment. The scale has high internal consistency along all six factors, with a Cronbach's Alpha's of .74 along the tension anxiety sub scale. The scale is sensitive to change (Shacham, 1983). The scale has been used in a sample of people with MS; however, no psychometric properties were reported (McCabe, 2005).

#### **4.3.2.2 Secondary outcomes**

As secondary outcomes, psychological functioning, disease specific quality of life, pain and fatigue, were used using the following hierarchy of measures.

##### Psychological functioning

1) The Multiple Sclerosis Self-Efficacy Scale (MSSE; Rigby, Domenech, Thornton, Tedman, & Young, 2003). This scale has high internal consistency (Cronbach's Alpha = .81) and test-retest reliability ( $r=0.81$ ) as well as acceptable validity (Rigby et al., 2003). It was developed for use in people with MS.

2) The General Self Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995). This scale measures a single, universal factor of self-esteem in 25 different countries with high internal consistency (Cronbach's alpha = .81). No studies were found testing the validity of this scale in a sample of people with MS.

3) The Rosenberg Self Esteem Scale (Rosenberg, 1965). This scale has high convergent validity, divergent validity and internal consistency reliability in a number of different samples (Sinclair et al., 2010). No studies were found testing the validity of this scale in a sample of people with MS.

#### Disease-specific quality of life

1) The MS Impact Scale (MSIS; Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001). This scale has shown high reliability in a sample of people with MS with Cronbach's alpha above 0.80, is highly correlated with other tests of quality of life in MS showing high validity, and shows high convergent and divergent validity (McGuigan & Hutchinson, 2004). The scale has been designed for use with people with MS.

2) The Multiple Sclerosis Quality of life Questionnaire (Simeoni, Auquier, & Fernandez, 2008). This test has high levels of internal consistency, reproducibility, test-retest reliability and is highly sensitive to change (Bandari, Vollmer, Khatri, & Tyry, 2010). The scale has been designed for use with people with MS.

3) The Multiple Sclerosis Quality of Life-54 Instrument (MSQOL-54; Vickery, Hays, Harooni, Myers, & Ellison, 1995). This test has a Cronbach's alpha range of .75-.96, with a test-retest reliability of .66-.96 (The National

Multiple Sclerosis Society, 2013b). The scale has been designed for use with people with MS.

4) The Leeds Multiple Sclerosis Quality of Life Questionnaire (LMSQoL; Ford et al., 2001). This test has a Cronbach's alpha of .71, is responsive to change, and results were found to be consistent with the MSQOL-54 (Ford et al., 2001). The scale has been designed for use with people with MS.

5) The RAY Scale (RAYS; Rotstein, Barak, Noy, & Achiron, 2000). This test measure quality of life along 3 sub scales, physical, psychological and social-familial. This test has high internal consistency and significant discriminatory value (Benito-Leon, Morales, Rivero-Navarro, & Mitchell, 2003). The scale has been designed for use with people with MS.

6) Multiple Sclerosis Quality of Life Inventory (MSQLI; Fischer et al., 1999). This test has a Cronbach's alpha range of .67-.97 and a test-retest reliability of .60-.81, however this test needs further testing to see if it is sensitive to change (The National Multiple Sclerosis Society, 2013a). The scale has been designed for use with people with MS.

7) The Multiple Sclerosis Health Related Quality of Life Scale (HRQOL-MS; Pfennings et al., 1999). This questionnaire measures two aspects of health-related quality of life with internal consistencies of over .60 Cronbach's Alpha and concurrent validities of over  $R = .60$  for sub scales when compared to the EDSS. The scale has been designed for use with people with MS.

## Pain

1) The Neuropathic Pain Scale (NPS; Galer & Jensen, 1997). In a sample of people with MS this scale achieved a Cronbach's alpha of .78 showing high internal consistency. This test has a high consistency with other measures of pain and has a test-retest correlation of 0.71 (Rog, Nurmikko, Friede, & Young, 2007). This scale has been validated in a sample of people with MS, showing high internal consistency (Cronbach's Alpha = 0.78) and consistency with other measures (Rog et al., 2007).

2) The McGill Pain Questionnaire (MPQ; Melzack, 1975)). This is a commonly used measure of pain, however, the measure lacks a single measure of perceived pain intensity and suffers from a potential bias of global retrospective reports of pain experience (Kerns, Finn, & Haythornthwaite, 1988). No studies were found testing the validity of this scale in a sample of people with MS.

## Fatigue

1) The Fatigue Severity Scale (FSS, Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). Despite having limited face validity, this has become one of the most popular tests for fatigue in people with MS (Schwid, Covington, Segal, & Goodman, 2002). No studies were found showing the psychometric properties of the test. The scale has been found to show significant differences between people with MS and a healthy control group (Kadriye et al., 2007) as well as other

neurological conditions (Krupp et al., 1989), however, the scale did not fit the Rasch model in a sample of people with MS (Mills, Young, Nicholas, Pallant, & Tennant, 2009).

2) The Fatigue Impact Scale (FAI; Fisk et al., 1994). This test has good internal consistency and validity (Cronbach's Alpha = .93) and is precise at measuring both high and low levels of fatigue based on an Item Response Theory (IRT) analysis (Amtmann et al., 2012), however fatigue is never defined, therefore the test could be measuring other factors (Schwid et al., 2002). The scale has been validated in people with MS showing good test-retest reliability (.68-.85), except for the physical sub-scale. It has high convergent validity with the SF-36, however, it also has unexpected low correlations with the fatigue severity scale (Mathiowetz, 2003)

Visual Analogue measures were considered for all outcomes measures. These are subjective tests of self-reported symptoms.

#### **4.3.3 Data time scales**

Data were recorded regarding the following time scales:

Immediately post-treatment: was defined as within a month post-treatment

Short-term follow-up: was considered to be between 1 and 6 months post-treatment

Medium-term follow-up: between 7 and 12 months post-treatment

Long-term follow-up: over 12 months post-treatment

## **4.4 Literature search**

### **4.4.1 Data sources**

On the 28<sup>th</sup> May 2014, one researcher (AB) searched the Cochrane Multiple Sclerosis and Rare Diseases of the Central Nervous System Group Trials Register which, among other sources, contains CENTRAL, MEDLINE, EMBASE, CINAHL, LILACS, PEDRO and Clinical trials registries (<http://clinicaltrials.gov>) and the WHO International Clinical Trials Registry Platform (ICTRP) search portal (<http://apps.who.int/trialsearch/Default.aspx>) for all prospectively registered and on-going trials. Additionally, PsycINFO (1887 to May 2014), Applied Social Sciences Index and Abstracts (ASSIA) (1987 to May 2014), Web of Science (1950 to May 2014) and Psychbite (2004 to date) were searched. To identify other relevant data, we contacted the authors of published studies if the reported data were incomplete, conducted bibliographical and reference searches to identify further studies and contacted the trial authors to see whether they had any on-going trials at this time. No language restrictions were placed on the search. For studies not published in English, we contacted the author to enquire whether they could provide us with a translation. The search strategy was developed in consultation with a senior librarian.

### **4.4.2 Study selection**

One researcher (AB) independently screened titles and abstracts for inclusion. Trials were identified for inclusion in the review using the four inclusion criteria

(types of trials, participants, interventions, and outcome measures). Articles were excluded if they were reviews, or were duplicate publications of the same study.

#### **4.4.3 Data extraction**

One researcher (AB) used a standardised data extraction form to extract data on the study setting, design, participants, descriptions of the intervention and control groups and outcome data. Baseline characteristics, general mood, depression and anxiety data were extracted. Data were extracted at baseline and follow up as reported in individual studies.

#### **4.4.4 Quality assessment**

One researcher (AB) assessed the quality of the included studies. The overall quality of the evidence was evaluated using the GRADE system, as recommended by The Cochrane Collaboration (Higgins & Green, 2011). Scores on five principal domains were used to assess the quality of the evidence: 1) limitations in design, suggestive of a high likelihood of bias; 2) inconsistency of results; 3) indirectness of the evidence, for instance comparing group interventions to a control group and then individual interventions to a control group, resulting in indirect comparisons; 4) imprecision of results, for instance in studies with a small number of participants where confidence intervals are wide. As the Cochrane Handbook recommends that tests for funnel plot asymmetry should be used only when there are at least 10 studies included in the meta-analysis, we did not evaluate the potential for publication bias (Higgins & Green, 2011).

#### **4.4.5 Synthesis**

As a number of self-reported measures were used in the primary studies, the data of individual studies were pooled together using a fixed effects model if homogeneity was present ( $I^2 < 50$ ) (Hedges & Olkin, 1985; Hedges & Vevea, 1988). If heterogeneity was present ( $I^2 > 50$ ), a random effects model was used to adjust the between-study variance (Hunter & Schmidt, 2004). Forest plots were used to graphically present the summary effect sizes (SES) or summary odds ratio (OR), risk ratio (RR), or relative validity (RV). According to Cohen's classification (Cohen, 1977), effect sizes were classified into small ( $< 0.2$ ), medium (0.2-0.8), and large ( $> 0.8$ ).

### **4.5 Results**

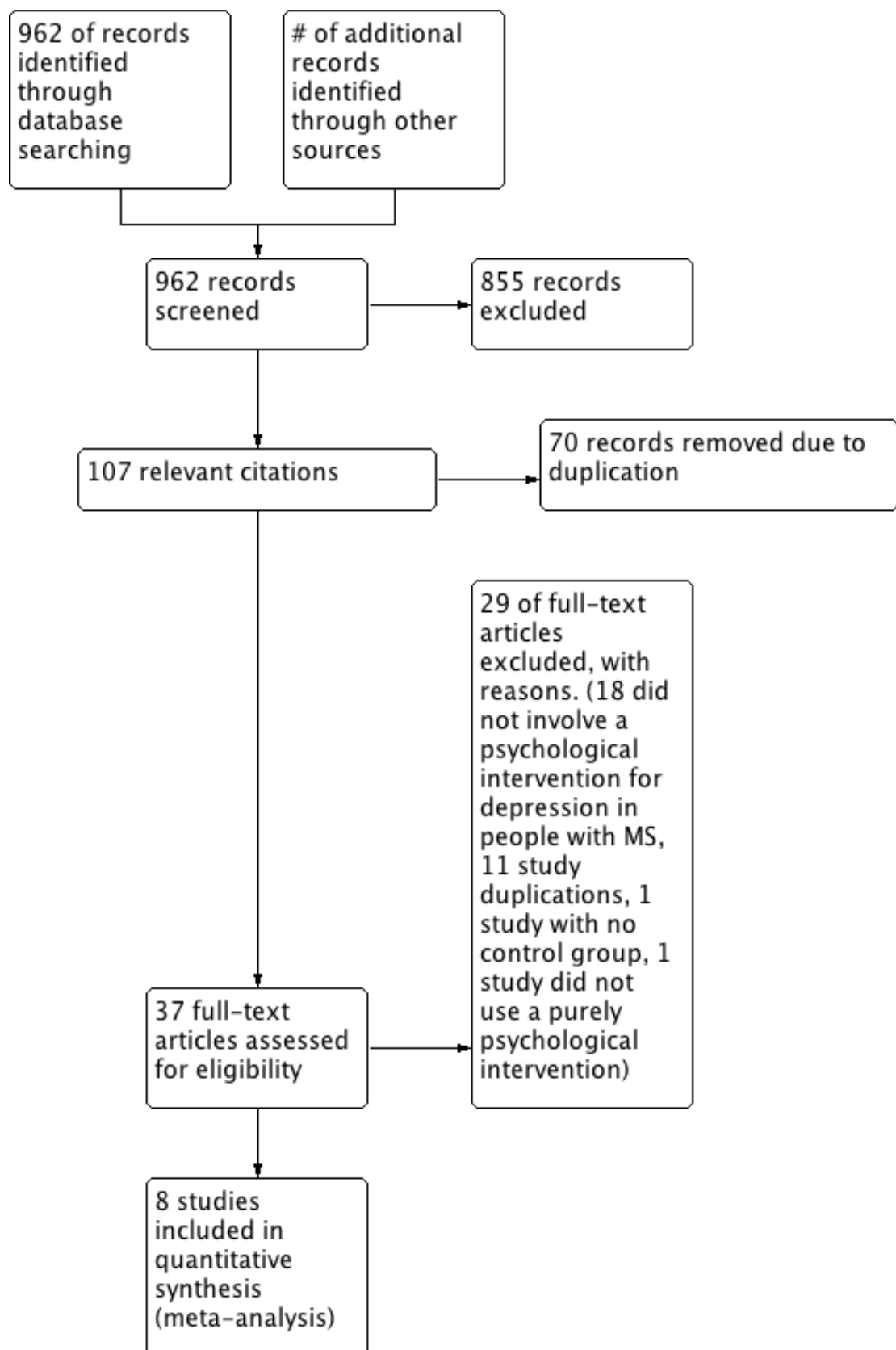
#### **4.5.1 Searches and selection**

Nine hundred and sixty two citations were returned using the search strategy. After eliminating duplicates and trials not meeting inclusion criteria based on their abstracts, 37 unique citations were retrieved from the searches, of which 10 full papers were included. Two studies were removed following full text examination, one study contained no control group and one study did not use a purely psychological intervention. Nine distinct studies, represented by 17 citations due to multiple publications of the same primary studies, met the inclusion criteria (Figure 4.1). The reference lists of identified papers were searched for further relevant trials. In September 2014 we wrote to those who had already undertaken trials in this area to identify other published or unpublished trials. We searched



registers of trials in progress and contacted the primary investigator of any relevant trial.

Figure 4.1: Study flow (PRISMA) diagram



#### **4.5.2 Study characteristics**

The studies were undertaken in the UK (n=3 (Cooper et al., 2011; Forman & Lincoln, 2010; Lincoln et al., 2011)), USA (n=3 (Mohr et al., 2001; Mohr, Hart, et al., 2005; Mohr et al., 2000)), Australia (n=1 (Larcombe & Wilson, 1984)) and Sweden (n=1 (Nordin & Rorsman, 2012)) between 1984 and 2012. Six studies reported the MS diagnostic criteria used, one using the Feighner et al., (1972) criteria (Larcombe & Wilson, 1984), one using the Poser et al., (1983) criteria (Mohr et al., 2001), one using the modified McDonald criteria (Polman et al., 2011); Cooper et al., 2011), three using 'confirmed diagnosis' (Lincoln et al., 2011; Mohr et al., 2005; Mohr et al., 2000). One study (Larcombe & Wilson, 1984) recruited through a multiple sclerosis community centre and through a general hospital which operated a specialised treatment unit for MS and an announcement calling for participants was also placed in a MS society newsletter; one study (Nordin & Rorsman, 2012) recruited participants from a local neurology department; one study (Cooper et al., 2011) recruited participants in the local hospital and nurses visiting patients in the local area. Two studies (Forman & Lincoln, 2010; Lincoln et al., 2011) recruited from MS outpatient clinics at a teaching hospital and by posters at an MS charity office and in their newsletter. Three studies (Mohr et al., 2001; Mohr, Hart, et al., 2005; Mohr et al., 2000) recruited participants using referrals from healthcare providers, advertising with an MS charity and general advertisements.

#### **4.5.3 Sample characteristics**

The average age of participants in each study ranged from 42.5 (Larcombe & Wilson, 1984) to 48.6 (Mohr, Hart, et al., 2005) years. The average number of

years participants had lived with MS varied between studies, from 3 months (Mohr et al., 2001) to 49 years (Forman & Lincoln, 2010). Five studies did not report the type of MS (Larcombe & Wilson, 1984; Mohr et al., 2001; Mohr, Hart, et al., 2005; Mohr et al., 2000; Mokhtari, Neshatdoost, & Molari, 2013).

Relapsing-remitting was the most common type in four studies and ranged from 57.9% (Forman & Lincoln, 2010) to 79% (Cooper et al., 2011). People with secondary progressive MS were only included in one study (Nordin & Rorsman, 2012) and people with primary progressive MS were only included in two studies (Forman & Lincoln, 2010; Lincoln et al., 2011). Two studies did not report the level of MS-related disability (Larcombe & Wilson, 1984; Mokhtari et al., 2013).

Four studies reported the Guy's Neurological Disability Scale (GNDS) with averages ranging from 18 to 23 whilst three studies reported the Expanded Disability Status Scale (EDSS) with averages ranging from 1 to 4. Two studies measured overall mood at baseline using the GHQ-12 (Forman & Lincoln, 2010; Lincoln et al., 2011) with average scores ranging from 2 to 22.4, showing a wide range in overall mood scores at baseline. Six trials measured depression using the BDI (Cooper et al., 2011; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mohr et al., 2001; Mohr et al., 2005) with most median scores at pre-treatment in the moderate range (19-29), however, two trials recruited people with high depression scores (Larcombe & Wilson, 1984; Mohr et al., 2005) and one trial recruited participants with minimal to mild depression (Nordin & Rorsman, 2012). Three trials measured anxiety at baseline (Forman & Lincoln, 2010; Lincoln et al., 2011; Nordin & Rorsman, 2012) with most median scores at the baseline in the mild to moderate range (8 – 10 mild, 11-14 moderate).

Five trials reported the proportion of those approached who met screening criteria (Cooper et al., 2011; Forman & Lincoln, 2010; Lincoln et al., 2011; Mohr, Hart, et al., 2005; Nordin & Rorsman, 2012), which was median of 69% (Range 12% (Cooper et al., 2011) to 95% (Nordin & Rorsman, 2012)). A median of 51% (Range 26% (Forman & Lincoln, 2010), 95% (Nordin & Rorsman, 2012)) of participants screened took part in the trials. The inclusion and exclusion criteria for participants can be found in Table 4.1.

Table 4.1: Study Characteristics

Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Larcombe 1984 (Larcombe & Wilson, 1984)	Diagnosis of MS confirmed by a neurologist. Depression (BDI $\geq$ 20; self reported depression $\geq$ months; met Feighner criteria for “definite” or “probable” depression.	No psychiatric comorbidities; low suicide risk; normal memory function; no concurrent treatment with lithium or tranquilisers	Group CBT (6 weekly sessions lasting 90 minutes)	Waiting list control group	BDI; HRSD; Mood ratings (3 item scale, 10 points); Significant other ratings of depression (6 item scale, 10 points)
Nordin 2012 (Nordin & Rorsman, 2012)	Diagnosis of MS (Macdonald criteria) Symptoms of depression or anxiety ( $\geq 10$ on BDI and/or $\geq 8$ on one or both of the subscales of HADS) No to moderate functional disability (<6 on EDSS)	No history of psychiatric illness or alcohol/substance	Group CBT (Acceptance and commitment therapy, 5 three-weekly sessions)	Relaxation training	BDI; HADS; AAQ-II

Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Lincoln 2011 (Lincoln et al., 2011)	Diagnosis of MS confirmed by neurologist. Diagnosis of MS > 12 months. Disruption to mood (HADS $\geq$ 8 or GHQ-12 $\geq$ 3)	Unable to speak and understand conversational English. Unable to attend group sessions if offered. Currently taking part in other psychological research	Group therapy session based on CBT and psycho-educational framework (6 fortnightly sessions lasting 120 minutes)	Waiting list control group	BDI-II; HADS; GHQ-12; MSIS; MSSE; EQ5D
Forman 2009 (Forman & Lincoln, 2010)	Diagnosis of MS > 3 months. Disruption to mood (HADS $\geq$ 8 or GHQ-12 $\geq$ 3)	None stated	Group therapy session based on Group CBT and psycho-educational framework (6 fortnightly sessions lasting 120 minutes)	Waiting list control group	HADS; GHQ-12; MSIS; MSSE; SF-36

Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Mokhtari 2013 (Mokhtari et al., 2013)	Neurologist referral. Registered with the MS society in Isfahan.	Currently experiencing acute symptoms	Group CBT (6 weekly sessions)	No treatment control group	SCL-90-R (Depression sub- scale)
Cooper 2011 (Cooper et al., 2011)	Confirmed diagnosis of MS (MacDonald criteria) Depression (BDI-II $\geq$ 14 but <29) Low suicide risk	Poor understanding of English language, high functional disability (EDSS < 8.5); poor cognitive function (MMSE < 24; treatment from psychiatrist, psychologist or psychotherapist in the 3 months prior	Individual CBT (Computerised, 8 weekly sessions lasting 50 minutes	Usual Care	BDI-II; MSIS; SF-36; PHQ-9; GAD-7



Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Mohr 2000 (Mohr et al., 2000)	Diagnosis of a relapsing form of MS (confirmed by neurologists) High level of depression (POMS-DD $\geq$ 15) Participants currently in treatment for depression receiving treatment for $\geq$ 3 months	Meeting criteria for dementia. Other neurological condition	Individual CBT (Telephone administered, 8 weekly sessions lasting 50 minutes)	Usual Care	POMS-DS, Post treatment adherence to IFN $\beta$ -1a

Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Mohr 2001 (Mohr et al., 2001)	<p>A confirmed diagnosis of MS (Poser et al., 1983).</p> <p>Relapsing-remitting or secondary-progressive as confirmed by a neurologist.</p> <p>Depression (A diagnosis of MDD (SCID), HRSD <math>\geq</math> 16, BDI <math>\geq</math> 16)</p> <p>Willing to abstain from psychological or pharmacological treatment for depression for the duration of the trial</p>	<p>Comorbid psychological condition for which treatment would be inappropriate.</p> <p>Meeting criteria for dementia.</p> <p>Severe suicidality.</p> <p>Initiation of treatment with interferon treatment within the previous 2 months.</p> <p>Current MS exacerbation.</p> <p>Other disorders of the central nervous system.</p> <p>Current or planned pregnancy.</p> <p>Current psychological or pharmacological treatment for depression.</p>	Individual CBT (16 weekly sessions lasting 50 minutes)	Group supportive-expressive focussed therapy (SEFT) and seteraline	BDI; BDI-18; HRSD, MDD assessed using SCID

Study	Inclusion Criteria	Exclusion Criteria	Intervention	Comparator	Outcomes
Mohr 2005 (Mohr et al., 2005)	<p>Diagnosis of MS confirmed by a neurologist.</p> <p>Functional impairments in activities (Guys neurological scale <math>\geq 3</math>).</p> <p>Depression (BDI <math>\geq 16</math>, HRSD <math>\geq 14</math>).</p> <p>The ability to speak and read English.</p> <p>Age <math>\geq 18</math></p>	<p>Meeting criteria for dementia.</p> <p>Currently undergoing psychotherapy.</p> <p>Showed severe psychopathological features.</p> <p>Currently experiencing MS exacerbation.</p> <p>Physical defects that prevented treatment or assessment.</p> <p>Use medications that affect mood (other than antidepressants)</p>	<p>Individual CBT (Telephone administered, 16 weekly sessions lasting 50 minutes)</p>	<p>Individual supportive expressive focussed therapy (Telephone administered)</p>	<p>BDI; BDI-18; HRSD, MDD assessed using SCID; PANAS-PA</p>

BDI: Beck Depression Inventory; EDSS: Expanded Disability Status Scale; GAD-7: Generalised Anxiety Disorder 7-item; GHQ-12: General Health Questionnaire 12-item; GNDS: Guy's Neurological Disability Scale; HADS: Hospital Anxiety and Depression Scale; HRSD: Hamilton

Rating Scale for Depression; MDD: Major Depressive Disorder; MMSE: Mini Mental State Examination; MSIS: Multiple Sclerosis Impact Scale; MSSE: Multiple Sclerosis Self-Efficacy Scale; PANAS-PA: Positive Affect subscale of the Positive and Negative Affect Scale; PHQ-9: Patient Health Questionnaire 9-item; POMS-DS: Profile of Mood States - Depression-Dejection Scale; SCID: Structured Clinical Interview for DSM-IV; SF-36: Short Form Health Survey; SCL-90-R: Symptom Checklist 90 (Revised)

#### 4.5.4 Intervention Characteristics

The intervention was delivered on an individual basis in four trials. This was face to face (Mohr et al., 2001), by telephone (Mohr, Hart, et al., 2005; Mohr et al., 2000) and via a computer programme (Cooper et al., 2011). All four trials compared CBT to a control group. In six trials, therapy was delivered in a group format consisting of 4-14 individuals. Five of the group trials evaluated CBT (Forman & Lincoln, 2010; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mokhtari et al., 2013; Nordin & Rorsman, 2012) and one study evaluated supportive emotive focused therapy (Mohr et al., 2001).

The duration of the interventions ranged from 4-16 weeks (Median 8 weeks) with follow up periods between 4 and 64 weeks. Most interventions were delivered on a weekly basis. Seven trials reported using a manualised intervention (Forman & Lincoln, 2010; Lincoln et al., 2011; Mohr et al., 2001; Mohr, Hart, et al., 2005; Mohr et al., 2000; Nordin & Rorsman, 2012). In the two trials using telephone based CBT a visual aid workbook was used (Mohr et al., 2001; Mohr et al., 2000). Homework was provided in eight studies (Cooper et al., 2011; Forman & Lincoln, 2010; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mohr et al., 2005; Mohr et al., 2000; Mokhtari et al., 2013; Nordin & Rorsman, 2012). All nine studies reported the duration of the treatment with the number of sessions ranging from 5 to 18, with a median of 6. Seven trials reported the duration of treatment sessions (Forman & Lincoln, 2010; Lincoln et al., 2011; Mohr et al., 2001; Mohr, Hart, et al., 2005; Mohr et al., 2000); sessions lasted for 50-120 minutes with a median duration of 50 minutes.

The aims of the CBT treatments were to restructure cognitive process using both cognitive and behavioural techniques and teaching skills to control thought processes.

Three trials mentioned a specific aim to the sessions, which were to focus on adjustment to illness (Forman & Lincoln, 2010; Lincoln et al., 2011) and increasing social interaction and activities (Larcombe & Wilson, 1984). Two trials mentioned teaching participants MS specific skills (Mohr et al., 2001; Mohr et al., 2000) and one trial used mindfulness and acceptance techniques (Nordin & Rorsman, 2012).

Two studies used doctoral level psychologists with 1 to 8 years of post-doctoral experience of working with people with MS (Mohr et al., 2001; Mohr et al., 2005). One study used an assistant psychologist with experience of running groups (Forman & Lincoln, 2010), one trial used a research psychologist (Lincoln et al., 2011), one study used a graduate student with several years of experience of working with people with MS (Larcombe & Wilson, 1984) and one study used a psychologist who had received training in acceptance and commitment therapy (Nordin & Rorsman, 2012). One study did not require a therapist due to the treatment being delivered through an online programme. In six trials adherence to the treatment was monitored through supervision sessions (Forman & Lincoln, 2010; Lincoln et al., 2011; Mohr et al., 2001; Mohr et al., 2005; Mohr et al., 2000; Nordin & Rorsman, 2012)

#### **4.5.5 Comparator Characteristics**

Four studies used a waiting list control group (Forman & Lincoln, 2010; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mokhtari et al., 2013) whilst two studies used a treatment as usual control group (Cooper et al., 2011; Mohr et al., 2000). Two studies used supportive emotive therapy as a control condition, one in an individual format by telephone (Mohr, Hart, et al., 2005), one in a group format (Mohr et al., 2001). One study used relaxation training as a control (Nordin & Rorsman, 2012). Studies differed in the extent that they restricted continued access to therapy outside that

provided in the trial. Three studies did not report additional treatments than that provided in the trial (Forman & Lincoln, 2010; Lincoln et al., 2011; Nordin & Rorsman, 2012).

#### **4.5.6 Quality assessment**

The quality of studies identified by the systematic review varied. Out of nine trials, only two studies demonstrated concealment of the allocation schedule (Cooper et al., 2011; Lincoln et al., 2011). Five studies stated that participants were randomised, but did not state how (Larcombe & Wilson, 1984; Mohr et al., 2005; Mohr et al., 2000; Mokhtari et al., 2013; Nordin & Rorsman, 2012). Three studies used a block randomisation method (Cooper et al., 2011; Forman & Lincoln, 2010; Mohr et al., 2001), however, the sample size for two of these studies was small and the randomisation of later blocks may have been predictable (Forman & Lincoln, 2010; Mohr et al., 2001), the quasi-randomisation method used by one of these studies is generally thought to be inadequate (Mohr et al., 2001). The median loss to follow up at the primary outcome assessment was 8% (range 4% (Mohr et al., 2005) to 28% (Mohr et al., 2000), with greater attrition being reported in studies that followed up for a longer amount of time. Six studies (Cooper et al., 2011; Lincoln et al., 2011; Mohr et al., 2001; Mohr et al., 2005; Mohr et al., 2000; Nordin & Rorsman, 2012) performed an intent-to-treat analysis with the use of “last observation carried forward”; to impute continuous data missing at follow up. The remaining three studies did not perform an intention-to-treat analysis, one study did not report losing any participants to follow up (Mokhtari et al., 2013), the other trials lost one and two participants respectively (Forman & Lincoln, 2010; Larcombe & Wilson, 1984). Sample sizes for individual CBT studies ranged from 32 to 122 (median 45) and 19 to

151 (median 28) for group CBT studies. Risk of bias assessments for each included study can be found in Figure 4.2.



Figure 4.2: Risk of bias summary: review authors' judgements about each risk of bias item for each included study.

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Cooper 2011	+	+	+	+	+	?	+
Forman 2009	+	+	+	+	+	?	+
Larcombe 1984	?	?	?	?	?	?	+
Lincoln 2011	+	+	+	+	+	?	+
Mohr 2000	?	+	+	+	+	?	+
Mohr 2001	-	?	?	?	+	?	+
Mohr 2005	?	+	+	+	+	?	+
Mokhtari 2009	?	?	?	?	?	?	+
Nordin 2012	?	+	+	+	?	?	+

#### **4.6 Data synthesis**

A direct comparison between group and individual psychological interventions could not be completed, as no studies used both group and individual interventions in the same trial. However, enough studies were similar to allow an indirect comparison between group and individually based CBT. Five studies compared group CBT to waiting list control (Forman & Lincoln, 2010; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mokhtari et al., 2013) or relaxation therapy (Nordin & Rorsman, 2012). One study compared group SEFT to individual CBT and Seteraline (Mohr et al., 2001). Two studies compared individual CBT to usual care/treatment as usual (Cooper et al., 2011; Mohr et al., 2000) and one study compared individual CBT to individual SEFT (Mohr et al., 2005). Only two studies reported scores for overall mood, both studies used the GHQ-12 and used a group intervention, which did not allow a comparison to individual interventions. All trials identified by the review measured depression using a variety of inventories for self reported measures: BDI (Cooper et al., 2011; Larcombe & Wilson, 1984; Lincoln et al., 2011; Mohr et al., 2001; Mohr et al., 2005; Nordin & Rorsman, 2012), HADS-D (Forman & Lincoln, 2010), POMS-DS (Mohr et al., 2000), SCL90-R (Mokhtari et al., 2013). Three studies reported scores for anxiety (Forman & Lincoln, 2010; Lincoln et al., 2011; Nordin & Rorsman, 2012); all three used the HADS anxiety subscale and used a group intervention, which did not allow a comparison to individual interventions. Only two studies looked at psychological functioning, using the MSSS, and both used group interventions, which did not allow for a direct comparison. None of the studies identified in the review investigated pain or fatigue. Only one study included medium and long term follow up data (Mohr, Burke, et al., 2005), to allow a comparison between studies, only short term follow up data was included in the meta-analyses. In

regards to the secondary outcomes, an indirect comparison could only be completed for both physical and psychological disease specific-quality of life.

Due to the lack of available data, a common reference-based indirect comparison was performed using the method suggested by Bucher (Bucher et al., 1997). The indirect comparison of group CBT and individual CBT was adjusted by the results of their direct comparisons with a control group. Using the odds ratio and variance derived from the meta-analysis, a comparison between group and individual CBT was possible. A high level of homogeneity was found in the group intervention studies and because of this a random effects model was adopted.

### 4.6.1. Depression

Figure 4.3: Group Intervention depression post-treatment scores

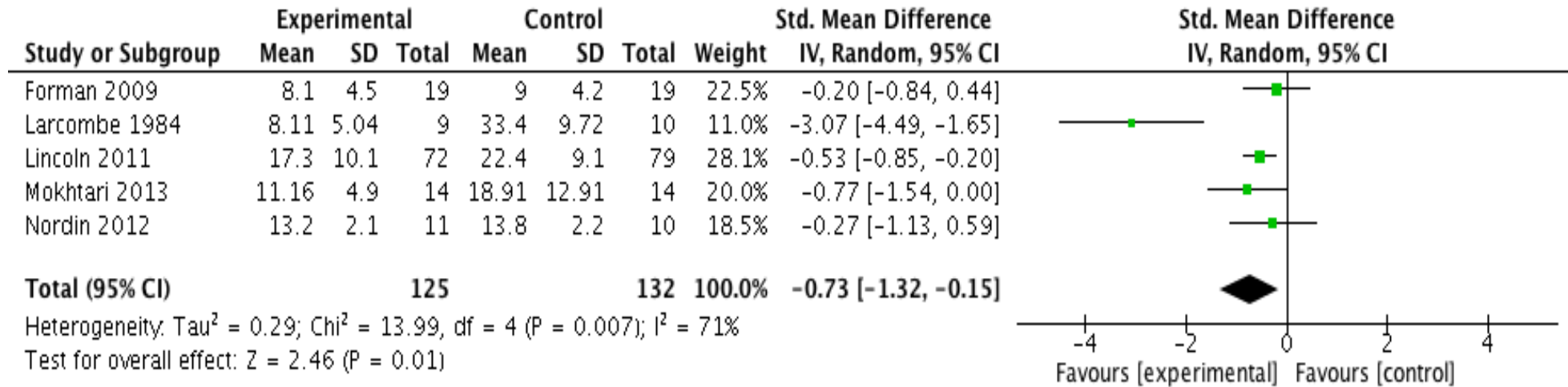
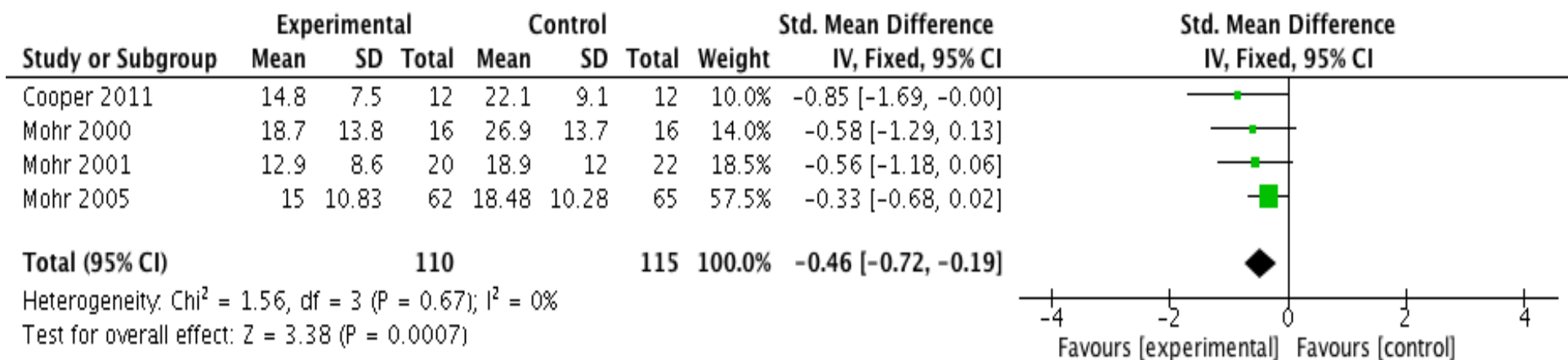


Figure 4.4: Individual intervention depression post-treatment score



Results of the binary meta-analyses can be found in Figures 4.3 and 4.4. The comparison gave a standardised mean difference (SMD) of -0.27 [-1.94, 1.4] showing a medium effect for the increased effectiveness of group CBT compared to individual CBT in treating depression.

#### 4.6.2 Disease-specific quality of life (physical)

Figure 4.5: Group Intervention disease-specific quality of life (physical) post-treatment scores

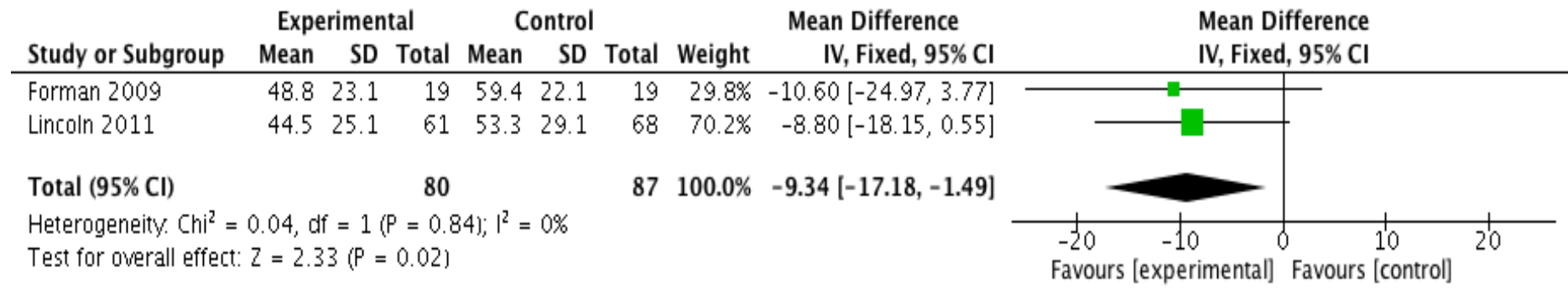
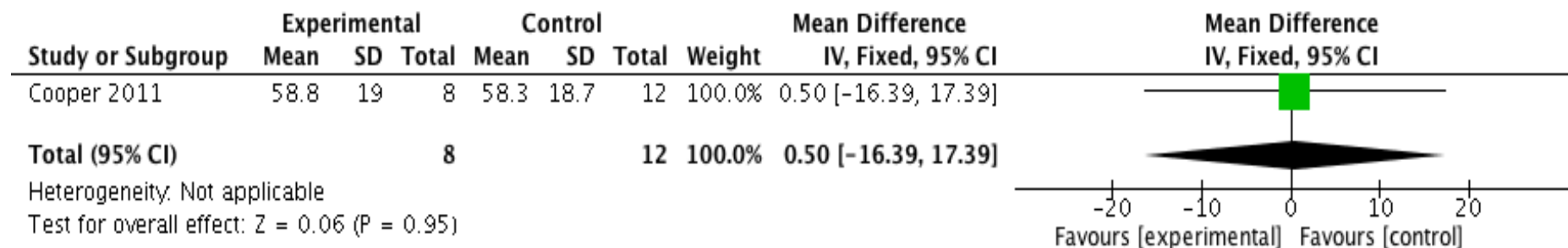


Figure 4.6: Individual Intervention disease-specific quality of life (physical) post-treatment scores



Results of the binary meta-analyses can be found in Figures 4.5 and 4.6. A calculation of the indirect effect was conducted and a SMD of -0.39 [-2.74, 1.96] was found, showing a medium effect for the increased effectiveness of group CBT compared to individual CBT in improving the physical aspects of disease specific quality of life.

### 4.6.3 Disease-specific quality of life (psychological)

Figure 4.7: Group Intervention disease-specific quality of life (psychological) post-treatment scores

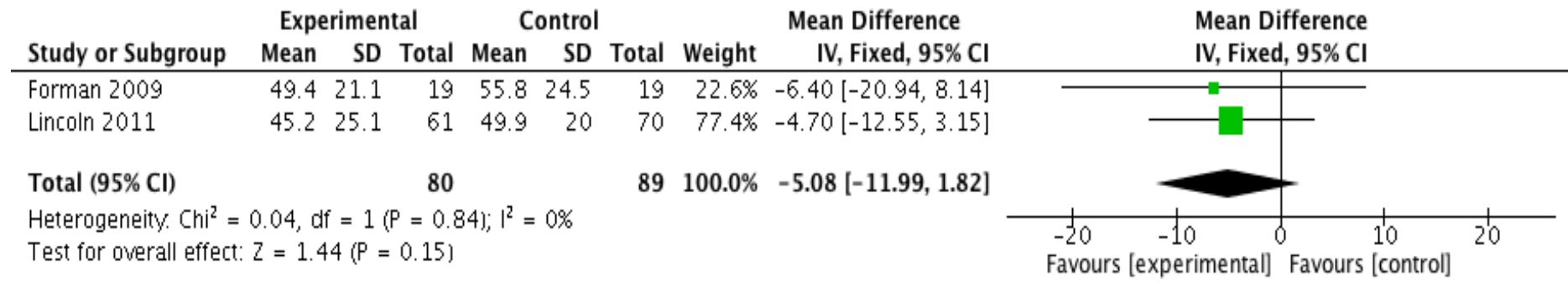
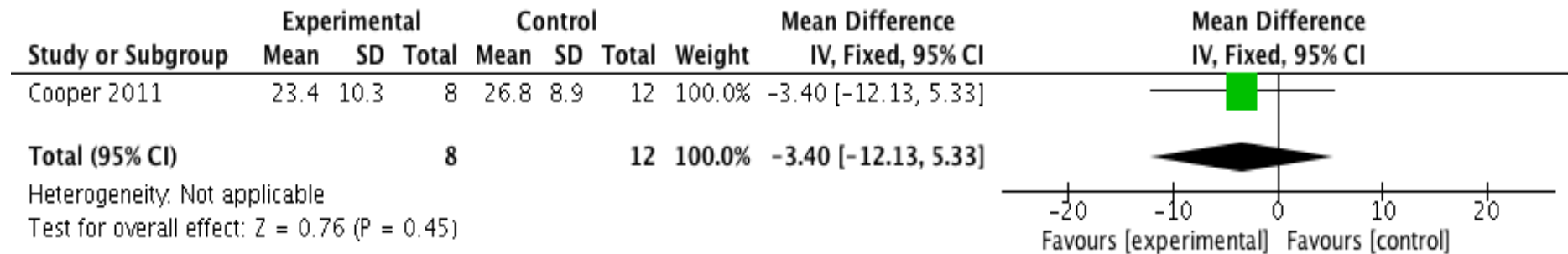




Figure 4.8: Group Intervention disease-specific quality of life (psychological) post-treatment scores



Results of the binary meta-analyses can be found in Figures 4.7 and 4.8. A calculation of the indirect effect was conducted and an OR of 0.12 [1.33, -1.09] was found, showing a medium effect for the increased effectiveness of individual CBT compared to group CBT in improving the psychological aspects of disease specific quality of life.

No studies measured Pain or Fatigue. No comparison could be undertaken. Due to the clinical heterogeneity of programme content, duration and follow-up times, we did not consider it appropriate to undertake a statistical analysis of medium to long term follow up assessments.

## **4.7 Discussion**

### **4.7.1 Principal Findings**

When treating depression in people with MS, group CBT interventions appeared to result in greater decrease in depression scores than individual CBT interventions. In the small number of studies where data was provided, group CBT interventions appeared to improve disease-specific quality of life in comparison to individual CBT interventions.

A previous review into the efficacy of CBT on depression in people with MS (Hind et al., 2014) found that CBT can be an effective method of treatment for depression, however, it noted that further research would need to be conducted to establish optimum conditions and modalities. The current study was conducted to extend the research question to include all psychological interventions, in any language, and to focus on mood in general. By extending the research question we can investigate the effect of the format of the intervention in light of the fact that many services do not have the funds for individual interventions and social identity approach which posits that group interventions may be more beneficial. The current study shows that by investigating all forms of psychological intervention, group interventions appear to have a greater effect on self-reported measures of depression than individual interventions, in line with the social identity approach. The Social identity approach states that a sense of social identity can be beneficial for group members psychologically by providing a sense of belonging and purpose. Maintaining relationships can be beneficial for people with MS (Till et al., 2012). The shared experience and peer support provided

through group interventions may be having a beneficial effect on the person with MS above and beyond that of the intervention alone.

#### **4.7.2 Study Limitations**

The methods for this review, including the research question and inclusion criteria, were developed and established prior to undertaking the review. This review contained moderate to high levels of heterogeneity, a low number of studies and studies with possible risk level of bias and therefore results should be interpreted with caution. The statistical heterogeneity shows that there are underlying differences between the studies included in this review. The majority of heterogeneity can be attributed to a single study, which had a very large effect size. The differences between this study, and the others included the time when it was conducted compared to the other group CBT trials (25 years) and higher baseline BDI scores. A meta-regression to investigate the impact of factors on effect size was not undertaken due to the large number of possible explanations for heterogeneity found between studies, the small number of studies identified and the lack of consistency in the outcome measures.

Whilst this study included studies in any language, it is possible that some studies may have not been included in this review due to the search strategy used, as this consisted of only English search terms. Whilst the search strategy was developed in consultation with the Cochrane Multiple Sclerosis Group, it is possible that the search terms used may have led to some psychological interventions not being included in the review. We did not search other databases, grey literature or dissertation abstracts; further reviews should consider these sources to strength the reliability of the results of the review.

### **4.7.3 Need for further research**

The studies identified in this review suffer from a number of methodological weaknesses, which should be addressed in future research. All studies identified by this review used a form of CBT; research investigating the effect of other forms of psychotherapy will allow an examination of this effect in other therapeutic modalities to see whether it is the effect of the group or the therapy producing the positive effects. The sample size was often small, and whilst a few trials did use multiple therapists, the majority used one, which may have had an impact on the generalisability of the results of trials. The lack of medium and long term follow up in the majority of studies highlights the need for longer follow up to be incorporated into future studies. Whilst one study attempted to compare the difference between the format of intervention (Mohr et al., 2001), two different forms of psychological intervention were used and so a comparison could not take place. Future studies should incorporate both individual and group formats of psychological intervention to investigate the effect of the different types of intervention.

### **4.8 Conclusions**

Whilst previous reviews have shown a moderate effect for CBT on symptoms of depression in people with MS (Hind et al., 2014), this meta-analysis suggests that the format of the CBT intervention may have an effect on outcome. Group CBT interventions appear to have a greater effect on self-reported depression scores and physical aspects of disease-specific quality of life, over the short-term, compared to individual CBT. Further research is needed to investigate whether

these differences appear in a direct comparison of data occur with other forms of psychotherapy, and are maintained over a long period of time.

This study has shown that group based interventions may be more effective for treating depression in people with MS than individual based interventions, showing that the effect of the group may provide added benefit for people with MS over and above content of the intervention per se. However, for a group therapy to be effective a person must see themselves as part of the group (Frisch et al., 2014; Haslam et al., 2008), something that people with MS are unlikely to do in the early stages of the disease (Irvine et al., 2009). Understanding how people come to incorporate the MS as part of their identity could help to improve the efficacy of group based interventions.

## **5. The role of the family in identity reconstruction following a diagnosis of MS: a meta-synthesis of qualitative research**

### **5.1. Chapter Overview**

This chapter presents a meta-synthesis of the qualitative literature. The literature has shown that family support is a salient factor in adjustment to MS (Wineman, 1990). This is in line with the SIMIC in that the social groups a person belongs to can help with identity reconstruction following identity change. This chapter aims to examine the role of the family in identity change in the pre-existing literature.

### **5.2 Rationale and Aims**

An integrative review of qualitative studies, meta-synthesis, was conducted to evaluate identity reconstruction following a diagnosis of MS by drawing together studies to gain an overall impression of the role of the family in identity reconstruction. The aim of this meta-synthesis was to investigate identity reconstruction following a diagnosis of MS, by reviewing qualitative studies of the changes to a person's family identity in people with multiple sclerosis.

### **5.3 Methods**

The meta-ethnographic analytic approach (Noblit & Hare, 1988) was used for this meta-synthesis. This approach involves identifying themes across different studies, so that the results of a synthesis are grounded in the data, whilst, allowing a re-conceptualization across studies (Doyle, 2003). The aim was to determine how the

studies were related to each other, by identifying common themes, taking into account refutational data, and forming a line of argument to represent the results. A line of argument approach is a form of grounded theorizing, which involves creating a picture of the whole from studies of its parts.

The criteria for inclusion were defined before searching for data. For the purpose of this study, the family was defined as a group of people related by blood, marriage, civil partnership or cohabitation. Studies were considered if they included participants with MS or involved a family member with MS, which explored their experience of living with MS; and discussed their sense of identity. Studies were considered if they used qualitative methods of data collection and analysis. Mixed methods studies were also considered if there was a distinct qualitative component from which data could be extracted. Studies were not excluded on the basis of their quality. Any quality issues were considered in the synthesis of the studies to reduce the distortion or the impact of the interpretation of the study.

A constructivist standpoint was used for this meta-synthesis in that, all studies, despite their flaws do contribute to an area of knowledge. Because of this, no studies were excluded due to the quality of the study. Studies were excluded from the analysis if they did not investigate the family in people with MS, or did not contain a qualitative element.

To ensure a broad and consistent search of the literature across databases a table was created to ensure that all search terms appropriate to the research question were searched in selected databases.

Table 5.1: Summary of Search Terms

Research Question: What are the changes to a person's family identity following a diagnosis of multiple sclerosis?				
Concept	Multiple sclerosis	Identity	Family	Time since diagnosis
Synonyms	MS	Self Social Identity	Significant Other Next of Kin	Duration Onset, Advanced
Broader	Inflammatory Neurological	Self Concept Identity	Family Group	Psychosocial Adjustment
Narrower	Relapsing Remitting Secondary Progressive, Primary Progressive Benign	Self	Husband Wife Partner Parent Mum Dad Mother Father Child Sibling Spouse	
Related Terms	Chronic Conditions,	Self Categorisation		
Alternative Spelling				Mom

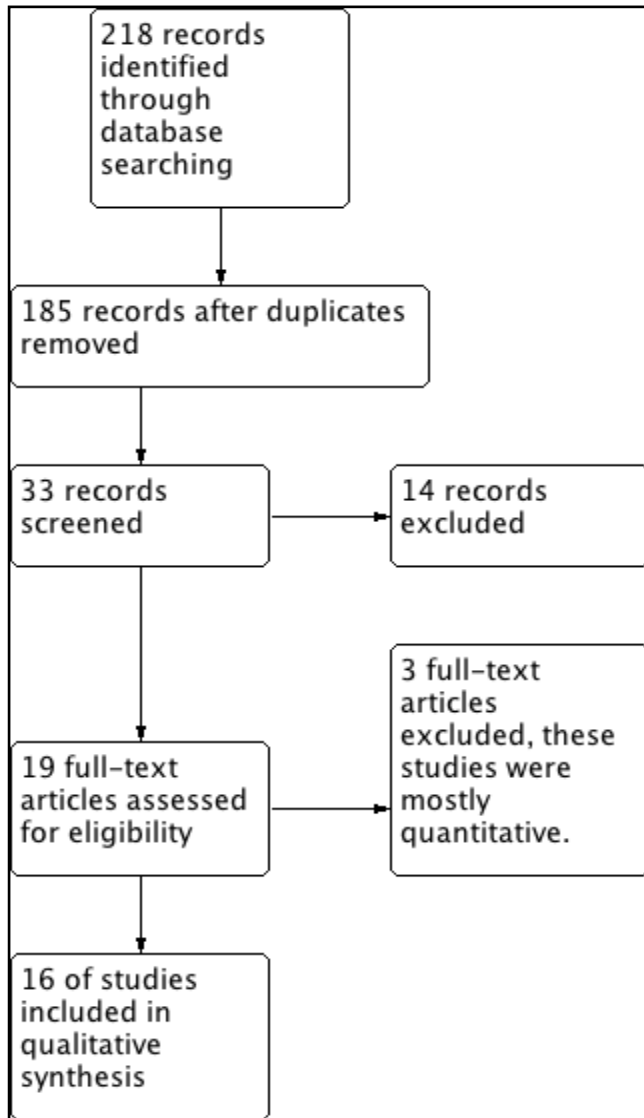


The following databases were searched EMBASE (1980 to 2015 Week 38), Medline (1996 to September Week 3 2015), PsychINFO (1806 to September week 3 2015, Web of Knowledge (All years), and Science Direct (All Years). The search was completed by the first author (ABB) and checked by the secondary supervisor (RdN).

An original search was conducted in 2013. For this thesis, the search was undertaken again to bring the review up to date. No new studies were identified.

## 5.4 Results

Figure 5.1: Flow Diagram Representing Literature Search



Two hundred and eighteen records were retrieved from the databases (see Figure 6.1), the relevance of the citations was assessed by the first author (ABB) and checked by the secondary supervisor (RdN).. Duplicates were removed using a reference management programme (Endnote), leaving 33 records that were then screened, using their abstracts, to assess suitability for inclusion. 14 records were excluded due to the participants of the study not having MS. Full texts of the

remaining 19 were then assessed for inclusion. A further three studies were excluded as they used a mixed methods approach but only provided quantitative results. Solari et al., (2010) used interviews to generate items for a psychometric test, but the results refer to medical communication of MS, not the family relationship. Paliokosta et al., (2009) used interviews to gather demographic information about participants and to assess psychological wellbeing. The interviews did not examine changes in family identity. Lawson, Robinson, & Bakes, (1985) used diaries and interviews to record how people spend their daily lives and analysed these quantitatively.

Sixteen studies met the criteria and were included in the meta-synthesis. Each paper was read multiple times before themes and concepts were extracted from the data. Once these themes were identified, they were compared and contrasted across studies. Themes and concepts were grouped together based on their similarities, at which point all of the studies in each group were re-read before forming broad themes based on the understanding of the literature. A line of argument synthesis was then constructed based on how these themes related to each other. The themes, concepts, metaphors and phrases from each study were extracted and organized into a grid. These were then reciprocally grouped together based on the meaning of the theme, concept, metaphor or phrase found in the original text resulting in a list of themes that occurred across studies.

The synthesis yielded three overarching themes: “the family as a secure base for identity reconstruction”, “the problems encountered with living with MS”, and

“coping strategies”. The most common themes and the studies that endorsed these themes are shown in Table 5.2.

Table 5.2: Common themes found in studies

Studies/Themes	Shared domestic duties	Support from partners and the family	Bringing families closer together	Regret at losing employment	Dependency between the person with MS and family members	Unpredictability of the disease and future plans	Coping strategies	Accepting and adjusting	Benefit finding	Concealing symptoms
Boeije et al. (2002)	-	+	+	+	-	+	+	+	-	-
Irvine et al. (2009)	-	+	-	+	+	+	+	+	+	+
Boland et al. (2012)	+	+	-	-	-	+	+	+	+	-

Studies/Themes	Shared domestic duties	Support from partners and the family	Bringing families closer together	Regret at losing employment	Dependency between the person with MS and family members	Unpredictability of the disease and future plans	Coping strategies	Accepting and adjusting	Benefit finding	Concealing symptoms
Liedstrom et al. (2010)	-	+	+	+	+	+	+	+	-	-
Bowen et al. (2011)	-	+	+	-	-	+	+	+	-	-
Dyck (1995)	+	-	-	+	+	+	+	-	-	-
Lexell et al. (2009)	-	-	+	+	-	-	+	+	+	-

Studies/Themes	Shared domestic duties	Support from partners and the family	Bringing families closer together	Regret at losing employment	Dependency between the person with MS and family members	Unpredictability of the disease and future plans	Coping strategies	Accepting and adjusting	Benefit finding	Concealing symptoms
Lexell et al. (2011)	+	+	-	-	+	-	+	-	-	+
Stuart & Sullivan (1982)	-	+	-	-	-	+	-	-	-	-
Robinson (1980)	-	-	-	-	-	-	+	-	+	+
McLaughlin &	+	+	-	-	-	-	+	-	-	-

Studies/Themes	Shared domestic duties	Support from partners and the family	Bringing families closer together	Regret at losing employment	Dependency between the person with MS and family members	Unpredictability of the disease and future plans	Coping strategies	Accepting and adjusting	Benefit finding	Concealing symptoms
Zeeberg (1983)										
Johnson et al. (2010)	+	+	-	+	-	-	+	-	-	+
Boyd & McMillan (1995)	-	+	+	-	-	-	+	-	-	+
Douglas et al.	-	-	-	-	-	-	+	+	-	+



Studies/Themes	Shared domestic duties	Support from partners and the family	Bringing families closer together	Regret at losing employment	Dependency between the person with MS and family members	Unpredictability of the disease and future plans	Coping strategies	Accepting and adjusting	Benefit finding	Concealing symptoms
(2008)										
Mutch (2010)	-	+	+	-	+	+	+	+	-	-
Riazi et al. (2012)	-	-	+	-	-	+	+	-	+	-

#### **5.4.1 The family as a secure base for identity reconstruction**

This theme was reflected in the primary themes, concepts and phrases of 13 out of the 16 studies. The family unit was often the first to know about the diagnosis (Irvine et al., 2009; Stuart & Sullivan, 1982) and the first to provide social support. In the three studies examining couples, the spouse was described as the main source of support (Boland et al., 2012; Douglas, Windsor, & Wollin, 2008; Johnson, Starks, Morris, Yorkston, & Gray, 2010). This relationship appeared to be reciprocal (Boland et al., 2012), so that both the person with MS and their partner received support whilst they came to terms with the diagnosis, representing the shared difficulties associated with MS. Mutual support was a common theme identified in three studies (Boland et al., 2012; Johnson et al., 2010; Liedstrom, Isaksson, & Ahlstrom, 2010). In studies where the person with MS was single or divorced, other family members, such as parents or children, appeared to be the main source of social support (Boland et al., 2012; Liedstrom et al., 2010).

Using the family as a source of support appeared to be useful for increasing the sense of family identity, this provided grounding for the person with MS. In one study (Boland et al., 2012), sharing domestic duties was seen to be a way in which the family acted as a secure base for identity reconstruction, this was seen as a way of normalizing couples situation and gave them both something to focus on. One study (Douglas et al., 2008) found that the shared experience of coming to terms with the diagnosis strengthened the relationship in a marriage. People with

MS recognized that the family was helping them to come to terms with and accept their MS (Liedstrom et al., 2010), the supportive relationships within the family had deepened since diagnosis and this helped with adjusting to the loss of identity caused by the MS. Four studies found that people with MS experienced benefits from their diagnosis (Boland et al., 2012; Irvine et al., 2009; Lexell et al., 2009; Robinson, 1990) for example by: spending more time with the children (Lexell et al., 2009), couples coming closer together and learning to appreciate each other more (Douglas et al., 2008; Liedstrom et al., 2010) and positive changes in perception and outlook (Irvine et al., 2009).

Using the family as a source of support following a diagnosis of MS appears to build a secure base to establish new identities. Seven studies found that the family identity was strengthened following a diagnosis of MS (Boeije et al., 2002; Bowen, MacLehose, & Beaumont, 2011; Boyd & MacMillan, 2005; Douglas et al., 2008; Lexell et al., 2009; Liedstrom et al., 2010; Riazi, Bradshaw, & Playford, 2012), and two studies (Boeije et al., 2002; Irvine et al., 2009) found that after a period of adjustment and receiving support from the family, people with MS were found to enjoy support groups, an activity which some participants with MS admitted they were reluctant to go to after first being diagnosed (Irvine et al., 2009). This shows that using the family as a source of support following a diagnosis of MS allowed participants to incorporate the MS into their identity and seek support from this group.

#### **5.4.2 Problems encountered with living with MS**

The difficulties in coming to terms and living with MS included social withdrawal, (Boeije et al., 2002; Irvine et al., 2009) the effects of losing or reducing work (Boeije et al., 2002; Dyck, 1995; Irvine et al., 2009; Johnson et al., 2010; Lexell et al., 2009; Liedstrom et al., 2010), and dependency tensions (Boeije et al., 2002; Dyck, 1995; Irvine et al., 2009; Lexell, Iwarsson, & Lund, 2011; Liedstrom et al., 2010). Social support from the family appeared to affect the impact of these problems, as well as the coping strategies used by both the person with MS and the family members (Irvine et al., 2009).

The main source of problems identified in the studies appeared to originate from an inability to accept and adapt to the changed identity of the person with MS, by both the individual and the family. The person with MS struggled to adapt to their new identity and did everything they could to retain their previous identities (Lexell et al., 2011), resulting in a stressful situation when change was unavoidable. Stress was often caused from regret at leaving employment (Boeije et al., 2002; Dyck, 1995; Irvine et al., 2009; Lexell et al., 2009; Liedstrom et al., 2010), but despite this, people with MS often found meaning and enjoyment through engaging with domestic work (Dyck, 1995; Irvine et al., 2009; Lexell et al., 2011). However, this caused further problems, in the form of dependency tension, wherein family members did not know whether they should assist the person with MS or not (Douglas et al., 2008; Dyck, 1995; Irvine et al., 2009; Liedstrom et al., 2010; McLaughlin & Zeeberg, 1993; Stuart & Sullivan, 1982) and the person with MS did not always want help due to the enjoyment and

meaning they found in being able to do the task. Some participants with MS found that they lacked support and help from family members (Liedstrom et al., 2010; Stuart & Sullivan, 1982), this was sometimes due to shame and feelings of hindrance that the person with MS experienced (Boeije et al., 2002; Irvine et al., 2009; Lexell et al., 2011; Lexell et al., 2009; McLaughlin & Zeeberg, 1993). Feelings of shame and hindrance were also associated with wanting to keep the diagnosis private by bracketing it off from the rest of their lives, with participants only telling people when they felt they had to tell (Boeije et al., 2002; Boyd & MacMillan, 2005; Douglas et al., 2008; Robinson, 1990).

People with MS may feel powerless and helpless towards their diagnosis and the progression of the disease (Boeije et al., 2002; Douglas et al., 2008; Liedstrom et al., 2010), this was often associated with tragic illness narratives (Boeije et al., 2002; Robinson, 1990) in which the person with MS bracketed MS from their lives and restricted social contact, especially concerning social support with regard to the illness (Boeije et al., 2002). In four studies (Boeije et al., 2002; Boland et al., 2012; Douglas et al., 2008; Lexell et al., 2011), participants with MS concealed their symptoms to retain a sense of family life, and minimize disruption. People with MS concealed their symptoms because a new symptom resulted in a change to the coping strategies adapted by the family unit (Boland et al., 2012), and the anger that members of the family experienced when a new symptom arose (Douglas et al., 2008). The uncertain progression of MS also caused problems in the family unit by creating a sense of unpredictability, causing the family unit, as a whole, to rethink their plans and future (Boeije et al., 2002; Boland et al., 2012; Douglas et al., 2008; Dyck, 1995; Irvine et al., 2009; Johnson et al., 2010).

Family support appears to influence the extent to which the difficulties in coming to terms and living with MS affect a person. Using the family as a secure base for identity reconstruction can reduce the impact that problems have allowing a person to incorporate the MS into their identity.

### **5.4.3 Coping**

Participants often used an adapting coping style to cope with problems they encountered; this involved adjusting, accepting and managing problems as they occurred. (Boeije et al., 2002; Boland et al., 2012; Douglas et al., 2008; Dyck, 1995; Irvine et al., 2009; Lexell et al., 2009; Liedstrom et al., 2010). Working together to overcome the difficulties encountered in daily life created a sense of “togetherness” in the person with MS with regards to their partner (Boland et al., 2012). This form of coping appears to be positive for psychological well-being, as the person with MS is receiving social support from previous groups and identities. However, these groups and identities acknowledge the changed identity of the person with MS, so that they and the support they provide are compatible with the new identity of a person with MS.

In some cases, the family wanted to get more involved in helping the person with MS adjust to their illness, however the person with MS did not want their support (Boeije et al., 2002; Boyd & MacMillan, 2005; Johnson et al., 2010). The person with MS was attempting to retain a pre-diagnosis identity that was not compatible with the individuals changed sense of self. These participants used a bracketing

coping style, removing the illness from the general flow of life to minimize the effects of identity change, which was often associated with negative outcomes, such as social withdrawal (Boeije et al., 2002) and the person with MS being “out of sync” with their spouse (Johnson et al., 2010).

Whilst completing domestic duties to replace paid employment has been identified as a source of tension in other members of the family (Boland et al., 2012), if the family respects the person with MS’s need to feel valued and do household chores, this can be seen as a positive way of coping (Boland et al., 2012; Dyck, 1995; Lexell et al., 2011). Establishing a routine to share domestic duties helped to overcome the problem of dependency tension (Boland et al., 2012; Dyck, 1995; Johnson et al., 2010; Lexell et al., 2011; McLaughlin & Zeeberg, 1993).

The varying nature and severity of the symptoms of MS make it an unpredictable disease. The psychological impact of unpredictability alters through diagnosis, remission and relapse (Wilkinson & Das Nair, 2013). One way to overcome the unpredictability of MS was to constantly plan daily life (Boland et al., 2012; Johnson et al., 2010; Lexell et al., 2011; Lexell et al., 2009). This prevented plans being made for the future, but it prepared the family group to deal more effectively with any problems they did encounter (Boeije et al., 2002; Boland et al., 2012; Douglas et al., 2008; Johnson et al., 2010). In other studies this was seen as a hindrance (Boland et al., 2012; Douglas et al., 2008; Dyck, 1995; Stuart & Sullivan, 1982).

Another way of coping with the problems encountered through living with MS was to attempt to preserve a sense of normal family life. This was achieved, for instance, by downplaying pervasive symptoms of the illness (Boeije et al., 2002; Boland et al., 2012; Douglas et al., 2008; Lexell et al., 2009). Whilst this was often related to negative outcomes, such as social withdrawal (Boeije et al., 2002), some studies found that attempting to bracket the illness whilst making small changes to adapt led to positive outcomes, such as bringing the family closer together (Lexell et al., 2009).

Over time, through using the family as a secure base to adjust to their current circumstances, a number of studies found that participants with MS managed to find benefits from their current situation (Boland et al., 2012; Douglas et al., 2008; Irvine et al., 2009; Lexell et al., 2009; Robinson, 1990). This included an acknowledgement that the person with MS felt that they were a better person than they were before diagnosis (Irvine et al., 2009), having a richer family life (Lexell et al., 2009), and increased strength as a couple (Boland et al., 2012; Douglas et al., 2008).

Due to the progression of MS, new symptoms can appear which lead to new problems emerging in the relationship between the person with MS and their family (Boland et al., 2012). The emergence of a new symptom can lead to a re-evaluation of coping strategies (Johnson et al., 2010). This makes adjusting to MS a constant process.



The use of adaptive coping strategies by both the person with MS and their family can reduce the impact of problems caused by living with MS and reduce the impact of future problems. This aligned coping can bring the family group together, strengthening a person's family identity and allowing a person to incorporate their MS into this identity. However, due to the nature of MS and the presentation of symptoms, people may be at different stages of responding to the biographical disruption and identity change. People may be more inclined to bracket the disease in an attempt to maintain normality, however as symptoms become more prominent, adaptive coping strategies may lead to more positive outcomes. An alignment of coping strategies from both the person with MS and their family group appears to be important.

#### **5.4.4 Line of argument**

The line of argument that appeared out of these themes is that people with MS reported a loss of identity and appeared to use a combination of coping strategies to deal with it. Having a large number of adaptive coping strategies appeared to be associated with positive outcomes such as, family engagement with MS (Boland et al., 2012; Lexell et al., 2011), and increased social activity following an initial withdrawal stage after diagnosis (Irvine et al., 2009). In contrast, having many bracketing coping strategies, compartmentalizing the disease in an attempt to preserve a sense of pre-diagnosis self, was associated with negative outcomes, such as loss of roles, identity and self-worth (Johnson et al., 2010), and social withdrawal (Boeije et al., 2002). The family was recognized as helping the person with MS to come to terms with and accept their MS (Liedstrom et al., 2010).

Adjusting to a changed identity appeared to reduce the negative effects of identity loss, as predicted by the SIMIC (Haslam et al., 2008; Jetten & Panchana, 2012). As predicted by the SIMIC (Jetten & Panchana, 2012), the family, a previously established social group, appears to be a useful base for receiving social support and establishing a new identity. Following a period of support and identity reconstruction, people with MS acknowledged that other people with MS shared their identity and they were now willing to receive support from this group. In this way people with MS were reconstructing their identity using the family group as a secure base, as predicted by the SIMIC (Jetten & Panchana, 2012).

Using adaptive coping styles to overcome the problems encountered in everyday life appeared to be positive for the family group. This could be due to the emergence of a shared sense of social identity (Haslam et al., 2009). As predicted by the SIMIC (Jetten & Panchana, 2012), bracketing appeared to have a detrimental effect on psychological wellbeing. The identity that the person was trying to retain was not compatible with their emerging identity as a person with MS; however, this could be due to the process of adapting to the chronic illness and the biographical disruption this can cause.

The family can provide a secure base for identity reconstruction by providing support and helping people with MS adjust to their emerging identity as a person with MS. This secure base was further strengthened if problems encountered through everyday life with MS were adapted into the individual and family identity using positive coping styles. Support from the family group, an in-group, may enable the person with MS to accept their new personal identity and seek

support from other people with MS, a previous out-group (Jetten & Panchana, 2012). This separation of the self from their peers has been reported in the literature (Irvine et al., 2009) and appears to be due to the reluctance to be associated with a stigmatized group.

## **5.5 Discussion**

The review was limited by the paucity of research investigating the role of the family on identity reconstruction in people with MS. The participants were all from Europe or North America; therefore, caution should be applied when generalizing to other settings. The meta-synthesis examined studies that were methodologically different, and without knowledge of the epistemological stances of the studies, it is likely that some content from the primary studies may have been lost.

A constructivist approach was used, in that all studies, despite their flaws, were considered to contribute to the area of investigation. No quality appraisal was used, some authors consider it inappropriate for qualitative reviews to use appraisal tools due to discrepancies in how these tools appraise the quality of studies and the many different research designs, and theoretical approaches used in qualitative research (Dixon-Woods, Shaw, Agarwal, & Smith, 2004; Sherwood, 1997). However, it is generally accepted that the quality of studies included in a meta-synthesis will influence the results (Salter, 2008).

Whilst the use of checklist measures in assessing the quality of qualitative studies remains controversial (Murphy et al., 1998), and the fact that rigid exclusion criteria on the basis of quality risks the loss of valuable findings, Sandelowski {Sandelowski et al., 1998) suggests using general quality appraisal that can be applied to any qualitative study, regardless of analysis method. Based upon this Murphy et al., suggests assessing qualitative studies on the basis of credibility and relevance. In future studies, it would be useful to assess the quality of included studies on the basis of credibility and relevance (Murphy et al., 1998; Salter, 2008)

The lack of a grey literature search and the decision to exclude studies of mixed-aetiology samples, may have affected the results. It would have been difficult to tease out MS-specific information from mixed-aetiology studies, and including such non-specific data would increase the heterogeneity of the findings. Only studies published in peer reviewed journals were included, because these could be systematically searched.

## **5.6 Conclusions and implications**

This meta-synthesis suggests that there are benefits from using the family to establish a new identity after the changes to identity that can occur due to a diagnosis of MS. ‘Adapting’ or ‘bracketing’ can be used as ways of coping with the difficulties arising out of living with MS. Adapting to the daily challenges and problems faced with living with MS appeared to be associated with positive outcomes, allowing the family to remain a secure base to establish a new identity. Bracketing appeared to be a way of attempting to preserve a pre-diagnosis identity,

rather than establishing a new identity, which may have a detrimental effect on psychological wellbeing (Haslam et al., 2008; Jetten & Panchana, 2012). However, the two forms of coping could be due to different stages of adapting to the chronic illness.

The family was not always successful in providing a secure base for identity reconstruction. In these cases support groups might be beneficial. Some people with MS were able to establish new identities after a period of adjustment (Boeije et al., 2002; Irvine et al., 2009), and normalizing a diagnosis of MS by attending support groups may allow a person rebuild their social identity. This has its benefits: the shared social identity of members of stigmatised groups provides a basis for shared social support that can provide individuals with the emotional, intellectual, and material resources to cope with and resist the injustice of discrimination, prejudice, and stigma (Levine, Cassidy, Brazier, & Reicher, 2002).

The study indicates the role of the family in forming a new identity following a diagnosis of MS. By providing information on effective coping styles in response to living with MS, to both the person with MS and their family members, new identities may be formed which reduce the negative effects of the loss of identity. Whilst previous research has shown that the family can be a salient factor in coming to terms with a diagnosis of MS, this meta-synthesis provides a link to the SIMIC to explain how and why this relationship could help in this situation and shows some support that these relationships can enable a person to establish new identities.



## **6. Changes to identity following a diagnosis of multiple sclerosis: A qualitative enquiry**

### **6.1 Chapter Overview**

This chapter presents a qualitative inquiry into the changes to identity following a diagnosis of MS. The previous chapters have described how changes to a person's social identity following a diagnosis of MS have an impact on mood. Whilst people with MS experience changes to their sense of self following a diagnosis of MS, the subjective experience of identity change over time is less well understood. This chapter presents an exploration into changes to identity over time from the participants' perspective to help us understand the process of identity change. The implications for psychological treatments for mood in people with MS are then discussed.

### **6.2 Rationale and Aims**

People with MS experience changes to their social identity and sense of self. The subjective experiences of changes to identity following a diagnosis of MS are not well understood. Therefore, an exploration into the subjective experience of identity change over time was undertaken. A qualitative investigation, involving narrative and thematic analyses, into the subjective experience of identity loss and how this changes over time was designed to provide insight into this process and to reveal some of the factors that prevent the negative effects of identity loss. This could have implications for the delivery of psychological interventions aimed at

reducing distress associated with MS. The aim of the study was to explore perceptions of people with MS regarding changes to their sense of self over time..

### **6.2.1 Narrative Approach**

A narrative approach emphasizes the 'lived experience' and assumes that people enjoy telling 'stories' and that this storytelling is a way of making sense of events that have happened in their and others' lives. An important concept in narrative analysis is that people make sense of difficult or threatening experiences by creating coherent stories (Janoff-Bulman, 1992; Joseph & Linley, 2005). Narratives are not about truth and reality; elements may have been consciously or unconsciously fabricated so that an event makes sense to the individual. The creation of these stories allow them to grow from these events and reconcile the event into their greater life stories (Pannebaker & Seagal, 1999). Stories reflect the individual experience of the storyteller as they see it and how they wish to present it (Becker, 1997). The construction of the narrative reflects a person's attempt to revise, select and order biographical meaning to their life experience (White, 1987). In this way, a person can define who they are through presenting a story of an event, and their sense of identity can be reflected in the narrative that they tell. The inclusion and acknowledgement of MS in a person's narrative will reflect successful adaptation and meaning making of their diagnosis. We see ourselves as 'storied' in that "our life narrative is the story we tell ourselves that knits together our recollected past and our wished for future thereby influencing our sense of self in the present" (Brock, 1995 p.152).



Events in a narrative have an order; they do not happen in isolation but are part of the wider narrative. Events are linked together by the plot (Ricoeur, 1991).

However, stories usually do not emerge all at once in a linear chronological order but meander, backtrack, jump ahead, or digress, with multiple stories or narratives. Because of this and the time it might take for a person to tell their narrative as a whole, an in-depth semi-structured interview method was used to obtain aspects of narratives relating to the research question.

## **6.3 Methods**

### **6.3.1 Participants**

Participants were identified from a feasibility randomised controlled trial (RCT) of an adjustment intervention for people with MS. Participants either received the adjustment programme (Lincoln et al., 2011) on a one-to-one basis or in a group format. The content of both interventions were the same, only their format of delivery differed. Briefly, the intervention consisted of six sessions over six weeks and focused on adjustment to illness, covering topics such as information about MS, problem-solving and realistic target setting, worry (anxiety), gloom (depression), relationships and the future.

The intervention was delivered by a clinical psychologist or a research psychologist (under the supervision of a clinical psychologist). This interview study formed part of the RCT, ethical approval for which was granted by the East Midlands, Nottingham 1 Research Ethics Committee (12/EM/0380) and the University of

Nottingham Institute of Work, Health and Organisations Research Committee.

Participants who consented to be interviewed were contacted four months after randomisation in the trial.

The inclusion criteria for the RCT were that participants who;

1. Had a clinical diagnosis of MS
2. Gave consent to take part
3. Reported low mood (score of more than 3 on the GHQ-12)
4. Reported feeling depressed (score of more than 8 on the HADS-D scale)
5. Reported feeling anxious (score of more than 8 on the HADS-A scale)

The exclusion criteria were participants who;

1. Had received their diagnosis of MS within the last 12 months
2. Did not speak English
3. Engaged in other research about psychological interventions
4. Had visual or auditory impairments that would preclude them from participating in the therapy sessions.

The inclusion criteria to take part in the interviews were that participants gave consent to take part.

## **6.4 Data Analysis**

### **6.4.1 Interviews**

Two PhD students conducted the interviews: AB is a 25-year-old White male, and KS is a 31-year-old White female. The researchers split the participants used in this study to increase access to participants (AB = 9, KS = 7). Both sets of interviews used the same interview schedule, however both researchers were interested in

different research aspects depending on their research question. AB and KS conducted semi-structured individual interviews using an interview schedule that was established following a review of the literature. A copy of the interview schedule can be found in Appendix 1 (Page 209). Interviews were conducted both at the University of Nottingham or in participants' own homes based upon the personal preference of the participant. When interviews were conducted on campus, they were conducted in a private room without distractions. When participants requested that interviews take place in their own home, the researcher requested that the interview take place in a quiet place, without distractions, where the participant would feel relaxed. Open-ended questions were asked about the participants' experience of the intervention, thoughts and feelings on the content and format and their social relationships before and after diagnosis. This analysis focuses on changes to social relationships over time. Interviews were audio recorded.

A thematic analysis was conducted (Braun & Clarke, 2006) based on the SIMIC. The interview data were examined to identify categories most pertinent to the research question. Once this had been achieved, the process of sense making was used to find connections and relationships in the data. This was achieved by successive reading of the texts, critical reflection and persistent immersion in the text.

### **6.4.2 Transcription and Coding**

All interviews were transcribed verbatim. An example transcript can be found in Appendix 2 (Page 210). Alongside coding for coherence, interview transcripts were also coded using the thematic analysis method (Braun & Clarke, 2006).

### **6.4.3 Eco-Mapping**

Eco-maps allow a graphical representation of the relationships that people have and their connection to larger social networks (Wright & Leahey, 2000), this can provide a researcher with valuable information about a person's social network, including the structure, size and function of the network and individual connections (Tracy, Whittaker, Pugh, Kapp, & Overstreet, 1994). Eco-maps are a useful tool for mapping and tracking changes to people and their social relations and contacts over a period of time, capturing the participants own perceptions (McCarty, 2002), in a visual, standardized manner (Hartman, 1995). Eco-maps have been successfully used as a clinical tool (Early, Smith, Todd, & Beem, 2000). Modified eco-mapping techniques have been used as a way of identifying and advertising the support available to people who were dying and to identify associations between different support providers. However, it was only fairly recently that eco-mapping was first used as a research tool, (Ray & Street, 2005) used eco-mapping techniques to gather information about the social networks of carers living with motor neuron disease (MND) and found that this technique can be useful for facilitating discussion around the structure and strength of social networks.

The use of eco-maps allowed the researcher to gain insight into participant's social lives both before and after the diagnosis of MS. In this way, the interview can be guided towards changes to social identity following a diagnosis of MS.

## 6.5 Results

### 6.5.1 Data Analysis

All participants who had taken part in and completed the preceding intervention were eligible to take part. 16 participants completed the intervention and were asked to take part in an interview. 5 participants dropped out of the intervention before completion and were not asked to be interviewed.

Of those interviewed, nine participants had attended individual sessions and seven had attended the group-based adjustment programme. Demographic information of the participants can be found in Table 6.2.

Table 6.1: Participant Demographics

	Mean	Range
Age	47.25 years	28-66 years
Time Since Diagnosis	7.62 years	1-22 years

<u>Gender</u>	<u>Number</u>
Men	11
Women	5
<u>Type of MS</u>	
Relapsing Remitting	9
Secondary Progressive	2
Neuromyelitis Optica	1
Missing	4
<u>Employment</u>	
Full Time	5
Part Time	1
Unemployed	4
Retired	3
Student	2
<u>Relationship Status</u>	
Married	9
Single	6
Divorced	1
<u>Living Arrangements</u>	
Living alone	5 (31.25)
Living with family or partners	11 (68.75)
<u>Ethnicity</u>	
White British	14 (87.5)
White Malaysian	1 (6.25)
Indian	1 (6.25)

Interviews lasted between 20 and 44 minutes.

### **6.5.2 Eco-maps**

Eco-maps were used on a sub-sample of eight participants. Three attended a group-based intervention, five attended individual-based intervention. In line with the research on biographical disruption it appears as though people with MS do restructure their social resources following a diagnosis of MS. All participants in the eco-mapping sub-sample reported strong relationships with family members both before and after diagnosis. Participants reported stronger relationships with friends before the diagnosis of MS. Participants reported more social contacts in the present than before the diagnosis of MS, these included medical professionals and friends made through MS related activities, such as the Expert Patient Programme. This suggests that the peer support provided in group-based MS activities can extend beyond the activity itself.

### **6.5.3 Thematic Analysis**

#### **6.5.3.1 Overview**

Themes identified in the data were; denial of MS, presenting a more positive identity, effects of increasing symptoms/changing relationships with others, social support, family as a secure base, self reflected appraisal and coping with MS.

A thematic content analysis revealed three patterns of adjusting to MS over time, with different factors affecting identity changes at different stages. The three patterns of adjustment all began with participants denying their diagnosis and compartmentalising the MS whilst presenting a more positive identity. Due to increasing symptoms and changed relationships with others, participants began to

experience the negative effects of identity change and sought social support, which led to a self-reflected appraisal and an acknowledgement of MS as an identity that they hold. Following this realisation, participants either incorporated their MS into their self-concept, or did not accept MS as part of their self-concept and kept this identity compartmentalised. An example of quotes within a theme can be found in Appendix 3 (Page 211).

### **6.5.3.2 Keeping MS private**

Diagnosis was often seen as an identity marker, and signaled the start of the adjustment process. However the difference between first acknowledging symptoms and receiving a diagnosis might have made it difficult for some participants to come to terms with their MS.

Charlotte 16-22 "...I struggled with MS when I was first diagnosed with it, and I struggled with the idea of having it and the fact that I'd had it an awful long time but wasn't diagnosed."

Despite receiving a diagnosis being a significant marker of the MS identity, some participants felt that they should attempt to preserve their pre-diagnosis identity, and to hold on to their established sense of self and identity; participants felt that they should keep their diagnosis private.

Kim 370-371 "I've not gone around announcing that I have MS."

Participants may have felt that they needed to preserve their previous identity due to the perceived stigma they attached to the MS identity; they saw MS as a stigmatised



identity. Furthermore, participants may have been unwilling to accept their MS identity due to the implications this has on their idea of their future self:

Anna 9-18 “it is a bit early days. But as I mentioned before I have avoided certain situations where there are MS meetings, because, you know, it is hard to think that, you know, personally that I might be in that, in a wheelchair so many years down the line. Having said that I quite understand I could be in a wheelchair for other reasons, beside MS. You know, it’s... But it hits home more, if you are with people that are... (AB: Yeah)...I mean I can... I mix with people that are in wheelchairs with other problems and that doesn't bother me. But erm... it does, it brings it home more, and it becomes more personal.”

Some social relationships reinforced the pre-diagnosis identity, which may have led to participants seeing their identity as unchanging.

Kim 167-168 “There’s erm, one or two [friends], that treat the MS as though its never happened.”

Being treated in a way in which the MS has never happened is seen as a reminder of her previous identity appeared to be good for the participant’s mood and is a reflection of Self Complexity Theory (Linville, 1987). To maintain high self-esteem, the participant appears to be acknowledging positive aspects of their self as important and unchanging whilst attaching low importance to aspects of identity related to negative self-beliefs such as the MS. This coping strategy appears to be effective for incorporating changes to an identity over a period of time, taking a

positive view of the self will allow individuals to accept reflected appraisals that they consider to be less important (McNulty & Swann, 1994).

In a similar way, participants attempted to regain aspects of their previous identity that may have been lost due to the effects of MS, specifically lost or changed relationships with others.

Stewart 269-270 “I used to be able to socialise before and I’m trying to make it so that I can still socialise so it’s the same.”

This externalisation of MS is a way of coping for the participant and provides a source to vent their frustrations. Another example of the externalisation of MS can be seen in the initial denial and relative secrecy regarding a diagnosis of MS. This pattern of compartmentalising thoughts about the self can provide greater resilience in times of stress (Alloy & Abramson, 1999), and may reflect early stages of adjustment (Linville, 1987). As time goes on, these opposing thoughts about the self can become integrated:

Sarah 246-247 “Everybody just treats me the same but with problems.”

### **6.5.3.3 Presenting a more positive identity**

In line with Social Identity Theory (Hogg, Terry, & White, 1995), participants articulated numerous identities. One participant found the identity of being a parent to be a more highly valued identity than being a person with MS, and therefore built social relationships around their parent identity. Acknowledging and talking about the diagnosis of MS was often difficult for participants. Exchanging a stigmatised

negative identity for something that the participant saw as valued was one technique for coming to terms with the diagnosis. This exchange of identities can be quite a stressful process that requires considerable psychological resources (Showers & Kling, 1996), however, social support was seen as a way to normalise this process to minimise the negative effects of identity change, and the use of social support had a positive effect on the participant.

Whilst participants presented an identity they saw more positively than the MS identity, the MS was compartmentalised to reduce the negative effect an identity seen in a negative light can have.

Anna 54-58 “You tend to try and forget that you have got MS, you just get on with the impracticalities that it has brought about, like having to use a catheter and things like that. You just do it automatically and you don't think, you know, it is part of your way of life. You don't think I have got an incurable degenerative disease.”

Another example of the re-evaluation of sense of self, can be seen in the narrative of one participant who attempted to preserve a prominent marker of her pre-diagnosis identity, work, despite increasing symptoms having an effect on this.

Allison 166-170 “One year when I got ill I was going in, going in, going in and I was pushing through, pushing through, pushing through, and I got told off by HR because I shouldn't have been in in the first place.”

Because of the highly valued nature of this (work) identity, Allison attempted to hold on to this identity despite the increasing symptoms. Allison downplayed markers of an identity that she saw as unimportant and stigmatised (MS) whilst acting in accordance to an identity that she saw as highly valued (work) in an attempt to keep her self-esteem (Hogg & Abrams, 1990). Presenting an identity that allows participants to present a positive view of the self, so that they see themselves as part of the in-group that they were previously a member of, might also allow them to accept reflected appraisals that may not be that positive (McNulty & Swann, 1994).

#### **6.5.3.4 Effects of increasing symptoms/changing relationships with others**

The physical symptoms of MS are markers of the illness progression and changing sense of self, as these become more prominent participants find that their sense of self is not consistent with markers of their own identity, or how others see them, and that these inconsistent views lead to a re-evaluation of what the participant views as their self. This re-evaluation triggers a subjective shift in self-perception.

Sarah 234-235 “I had to put on an act of being OK, even when I wasn’t”

The physical symptoms of MS often led to changes to a person’s social relationships. Increasingly, intrusive symptoms of MS often led to perceived changes in their relationships with other people. This led participants to re-evaluate their sense of self and they began to see the MS as part of who they are.

Stewart 272-276 “And they [friends], they probably don’t realise there’s a difference but, cause, there is a difference, because I’m not,

I'm not the same person. On the outside I am, but not on the inside.

I can't always do the same things that I used to be able to do."

### **6.5.3.5 Social support**

Participants saw social relationships as a way of dealing with the problems associated with MS. Social support was seen as a way of normalising the situation for the participant, because of this, participants often chose the type of support that they felt they required at the time. In this way, participants were actively choosing which identity and reflected appraisal they wanted at that moment in time. Social support gained from other people with MS normalised the situation for participants and was seen as having a positive effect on mood.

A common way of coping was to pick and choose friends for different situations to receive the support the person believes they require at that point:

Erin 46-349 "[Friends] haven't really changed, it's been more about me finding out, which friend can offer me the right support at the right time."

This is linked to the idea of adjustment being a journey, some of these friends use negative coping, for example, acting as though the MS never happened. It may be necessary to receive this form of support whilst people with MS adjust to the change in identity. Social support in general appeared to be closely linked to mood in the participants and could be recognised as helping people come to terms with their diagnosis. One participant explained that she became withdrawn after a diagnosis, however, noted that social support helped her to become who she is again:

Charlotte 320-321 “She [friend] almost brought me back in to the fold, so to speak.”

Social relationships also caused negative emotions due to the conflict they caused between a person’s previous identity and their newly emerging one:

Kim 195 “ I find it really hard to say to somebody I’d like to do that but I can’t because I’m just too tired.”

This sort of dilemma makes the participant feel as though she is a burden to her friends and that they don’t understand. Kim has not accepted her changes in activity levels as part of her emerging identity and therefore does not wish to discuss this matter with markers of her previous active social identity, her friends.

Whilst receiving social support appeared to have a positive effect on participants’ psychological well-being, a number of relationships were lost or disrupted following the changes to identity due to MS. The loss of social relationships due to identity change did appear to be linked to mood in the participants:

Chris 368-369 “That upsets me. It makes me feel very lonely.”

One participant found that relationships with friends had stayed relatively similar despite them having to adapt and accommodate to the MS. Being treated the same by friends whilst having to perform a stigmatised MS act, e.g., ordering a disabled hotel room, allowed him to retain his previous identity whilst accepting markers of his MS identity:

Charlie 301 “...and it was taken in fun and its funny.”

In a similar way, both the participant and his close personal friends chose to talk negatively about markers of the emerging MS identity, using the phrase “Spaz chair” to refer to a wheelchair. However, the participant views this as a positive thing.

Receiving social support from other people with MS appeared to normalise the emerging MS identity. The shared experiences of people in a similar situation allowed the participant to identify with other people in a similar situation:

Allison 222-224 “There’s actually people out there that have, are doing, have done, have experienced what I’ve gone through, have been through.”

Receiving social support from others who she perceived to share her social identity appeared to be beneficial for her mood. However, due to the reluctance to accept MS as part of their identity during the early stages of the adjustment process, people may be more inclined to seek social support from those who they see as sharing their pre-diagnosis identity.

#### **6.5.3.6 Family as a secure base**

Participants acknowledged that the family relationship stayed the same despite changes in other relationships.

Rob 260-261 “My family, they are pretty much the same as they’ve always been.”

The family provided a source of identity continuity for participants in line with the Social Identity Model of Identity Change (Jetten & Panchana, 2012). In line with the

theory, the family provided a source of social support for the participants during the identity change.

Charlotte 193-194 “They’re [family] being great at the moment in helping me deal with it.”

Charlotte has realised that acknowledging the diagnosis is an internal process that she needs to ‘deal’ with and the family is a supportive environment for this. Charlotte’s earlier experiences, ‘just burying it’, is in stark contrast to how the family can facilitate adjustment to a changing identity.

The family was often the first people to know about the diagnosis of MS. One participant stated that when he could not tell work about the diagnosis in fear of the repercussions this would have, he turned to his family and friends.

Family was also seen as useful for fixing some of the problems that can occur during identity change. One participant, Charlotte, stated how their partner realised she was acting odd around their friends and so convinced her to disclose her diagnosis to them, which had a positive effect on her by increasing her social contact with friends. Recovering a damaged relationship gave Charlotte additional social support and resources to recover her current sense of self.

The family can be quite a large social group. One participant who before diagnosis had expressed strong ties with his wider family group found that this diminished following diagnosis so that he only remained close to immediate family members. This change was due to the emerging symptoms of MS changing the outlook of the participant. The participant found that with the symptoms of MS having a greater effect on his life, it was easier to reduce his social and family commitments.



Participants saw the family as having an expectation to support them, and a number of participants willingly accepted this support, in a similar way participants recognised that the family wanted to be involved with their lives.

Allison 97-101 “Immediate family have to spend time with me no matter what...what mood im in, and what’s going on yeah, that’s the best support there is...”

However, due to participants wanting to maintain their previous sense of identity, some potential sources of social support were not informed about issues relating to the MS.

Stewart 198-199 “They [parents] do help me a bit, they do, they do try but I shelter them away from most of it.”

Stewart explained that this is due to the reaction that he expects these sources of support to take, such as increased worrying. He explains that he also shelters his brother from the MS, however his brother is more inquisitive and asks more questions about it; this is perceived as a helpful form of support. The changed way in which the family is responding to the person with MS may help them to acknowledge their changed sense of identity. The family allows a person to present their pre-diagnosis identity and through communication and everyday activities, a person can come to accept their changed identity in a secure supportive environment.

However, some participants found that not all aspects of their family initially provided a secure base for identity reconstruction:

Sarah 227-228 “My ex-partner began to resent me as soon as my disability became really apparent.”

For the family to be an effective secure base for identity reconstruction, all members of the family need to work together to accept and adjust to the diagnosis. This narrative of the family not acting as a secure base suggests how important it is for coping strategies and understanding to be aligned in this sort of situation.

It appears that for the family to be a useful source of support during the adjustment process, open communication from family members and the alignment of positive goals appears to be essential.

#### **6.5.3.7 Self reflected appraisal**

Due to the stigmatised personal features of the symptoms of MS, the person with MS maybe more perceptive of other people's responses to them allowing for reflected appraisal, perceiving the way in which others see and evaluate the person with MS, and coming to see themselves in a similar way (Cioffi, 2000; Khanna, 2010; Santuzzi & Ruscher, 2002). In this way, reflected appraisals may have become more apparent as stigmatised symptoms become more prominent, leading to a shift in perception of self-identity. Existing self views can restrict a person's ability to interpret and respond to a reflected appraisal (Wallace & Tice, 2012). The emergence of symptoms in people with MS may cause a person to re-examine their identity and sense of self and be more open to self-reflected appraisals.

Allison was attempting to act in a way that corresponded with a previous marker of her previous identity, however, other people, Human Resources, responded to this in a way that made her acknowledge her changed identity. Following on from this, she acknowledged her changed identity and sought support from others who shared this.

Allison 222-224 “There’s actually people out there that have, are doing, have done, have experienced what I’ve gone through, have been through.”

Over time, participants often began to acknowledge the changed sense of self in how others respond to them.

Charlie 673 “If people see the stick, they’ve got a completely different attitude towards you.”

#### **6.5.3.8 Coping with MS**

Despite a person’s individual identification with the MS identity, a number of participants expressed how, over time, they had worked out their own way to deal with aspects of their MS:

Rob 12-13 “I’ve already worked out my right own way of doing things.”

Participants saw the adjustment process as a journey, in that over time they will be able to cope with their MS more effectively. Participants revealed that some aspects of the MS they had figured out and found a way to cope with whereas others they had not.

Other coping strategies such as planning and maintaining a positive outlook were found to be seen as important when coping with problems encountered with living with MS across the narratives.

#### **6.5.4 Integration of the MS identity into changing sense of self**

The process of integrating markers of the MS identity into a pre-existing identity appears to depend upon the effort, attention and cognitive ease of integration (Showers & Kling, 1996). Over time the MS, which is externalised due to the negative identity connotations, can become integrated into a pre-existing self-concept based upon self-reflected appraisals. Participants come to view themselves based on how others react to the way in which they act. As participants' symptoms become more prominent they begin to display their symptoms more, which lead to changes in the way in which people see them, which leads participants to re-evaluate their sense of self.

Charlie 560-563 "I knew for 3 years before I actually let it affect my life...And then it got to the point where it does, so you cant hide it anymore"

The ability to retain a sense of identity continuity appeared to be associated with positive psychological wellbeing and this can be seen in the literature surrounding identity change (Haslam et al., 2008; Jetten & Panchana, 2012). Compartmentalising the disease to present a more positive self-image is often seen in the literature as an early coping mechanism (Linville, 1987). Participants in this study used this as an early coping mechanism until the disease becomes more prominent, at which point participants felt a need to incorporate this identity into their sense of self and engage in activities that are more representative of the MS identity, such as attending MS groups. In our study three participants continued to compartmentalise the disease following the recognition of the MS identity. This

could reflect differences in willingness to incorporate the MS identity into overall sense of self.

#### **6.5.4.1 Compartmentalising the MS identity**

The MS identity is one that is forced onto a participant and not something they have developed through motivations or goals. The stigmatised nature of the identity often results in a lack of personal value being placed on the MS identity. Personally valuing an identity is the basis for sustained identification and behaviour consistent with this identity, as people do not originally value this identity, they do not wish to identify with it or behave in a way that is consistent to the MS identity. As such, one pattern of adjusting to the MS identity was to continue to compartmentalise the identity and choose not to incorporate this into the overall self-concept.

Lauren 167-168 “My way of coping is... if I don't think it is happening, then it is not. If I ignore it, it is not there. (AB:...yeah...) It is like a tree falling in the forest, does anybody hear it, you pretend its not there.”

One participant stated how they have changed their locus of control over time to see his MS as a separate entity to himself, so that he can distance this from his current identity:

Chris 409-410 “I’ve almost named the MS, so I can have something to shout, swear and be offensive to.”

Externalising and compartmentalising the MS identity presents a relative absence of internalisation of the MS into the self concept. A lack of motivation towards the MS identity will result in a lack of willingness to engage with this identity, such as not wanting to socialise with other people with MS:

Lauren 162-165 “Mmm I went to the MS Society’s Yoga Group once, never again, (KS: ...right...) because it was just phenomenally depressing for me.”

Instead, participants present identities that they consider to be more highly valued. However, in line with Self Complexity Theory (Linville, 1987), this could reflect early coping strategies and it appears that individuals can assimilate the MS identity into their self-concept at a later time.

Erin 124-127 “Because my MS has got worse recently so that’s why I’ve probably got a bit more proactive than I was, because I just didn’t do anything for years because I have been diagnosed, what, 12 years, and I haven’t done...I’ve just got on with it.”

#### **6.5.4.2 Assimilating the MS identity into self-concept**

Upon recognition of the MS identity, a number of participants began to assimilate this identity into their sense of self.

Chris 8-9 “I think we as MS’ers.”

Following a diagnosis of MS, the illness is seen as an external entity, however, over time the MS is internalised into the participant's self-concept before being understood and accepted.

Charlotte 370-378 "Because it was mine and I wanted to control it. I didn't understand it, so how can I tell people what I've got if I don't understand it? I didn't understand it. I did lots of research and reading up, and that, and I still didn't understand it. I knew all the words, but they just didn't work for me then. It wasn't until two years after I was diagnosed, I suppose, that I actually got to grips with it and thought, 'This is ridiculous, make friends with it and stop worrying about it', which is what I did."

The level of identification with the MS identity appeared to differ between participants with some participants strongly identifying with the MS identity, whereas others saw the MS identity of one of many identities that they have.

One way in which participants acknowledged their identity change was by accepting that they have MS and that they can accept help for their condition:

Sarah 200-201 "My life has changed since I employed the carers privately, completely changed."

This implies that the participant's life had been difficult before she was able to acknowledge her condition and seek help, suggesting a link between acceptance of an emerging identity by the individual and accepting help. A common theme in the sample was that after an initial adjustment to the diagnosis of MS, participants expressed an acknowledgement that they were more willing to talk about their

disease. After learning to talk about the disease in their new job, one participant explained that they were more willing to talk about their MS, and in doing so present this as part of their identity. Another participant worded this differently. When asked about their ability to open up in an intervention session she explained:

Kim 35-37 – “...but I think its also an element that I’m only just starting to come to terms with the MS so for a long time its been bury it and then you don’t have to deal with it.”

This is important because this statement implies that participants may be unwilling to talk about their diagnosis without first adjusting to their diagnosis and incorporating the MS identity into their self-concept. In line with Self-Determination theory (Ryan & Deci, 2000), acting in accordance to an identity that individuals identify with, can result in autonomous behaviour in line with this identity. This has implications for the delivery of interventions for depression and anxiety in participants with MS, in that they may be more beneficial once a person has started to come to terms with the diagnosis and incorporate the MS identity into their self-concept. Similarly, whilst social support can help a person adjust to their changing identity, acceptance of a changed identity can have implications for the social support a person seeks and receives in the future. Participants did not wish to be associated with the MS identity when they were first diagnosed, however, once a person comes to accept the MS as part of their identity, they may be more willing to seek, receive and accept support from other people who have MS, as they now share a social identity.

Lisa 111-117 “No, I probably wasn’t ready. The first year I couldn’t get about anyway. I was quite ill for the very first year and



then I... sort of started just getting used to having problems and I probably... No. I think, you know, people say, 'Oh, there's this you can phone' and I had always thought, oh I don't want to speak to other people, it's all the same thing and... You know, I would always have that, sort of, attitude. I think I was just about ready now to have some contact."

Participants may have now begun to see the MS as an aspect of their identity allowing them to see themselves as having specialist knowledge that can be provided to others. Once a participant acknowledged the MS as part of who he/she is, they find their own way of overcoming problems and feel that they are at a stage where they can share their advice.

## **6.6 Methodological Considerations**

Whilst interesting themes have emerged, it is important to be mindful of some limitations of the methods used in this study. Firstly, causality cannot be assumed by comparing the coherent narrative to social support themes. Each researcher coded all of the interviews independently; because of this, each researcher would have a number of interviews that they conducted and coded (AB: 8, KS: 7) as well as a number of interviews that they did not conduct but they did code (AB: 7, KS: 8). In the interviews that the researcher conducted and coded, prior knowledge and understanding may have guided the coding process. On reflection, the use of multiple researchers in conducting the interviews may have influenced the outcomes of this research. Each researcher was exploring different research topics, because of this, important themes or topics may not have been expanded upon in interviews. In future studies, the researcher should be fully immersed in all interviews to gain a

thorough insight into the participants experiences of identity change. The researcher attempted to maintain reflexivity throughout the study, in an attempt to keep the analysis as close to the data as possible.

There is controversy in assessing the quality and maintaining rigour in qualitative research (Murphy et al., 1998). Given the diverse nature of qualitative research there is currently no consensus on assessing the quality of a piece of qualitative research (Leung, 2015). To ensure quality in the research study, data was rigourously analysed. Following the recognition of themes, with the support of quotes, these were discussed and compared and contrasted with more experienced qualitative researchers, my supervisors, Roshan das Nair and Nigel Hunt. The participants in this research study were a unique group of people at a certain time speaking in a certain context with a particular researcher. By describing the participants in this study and how they were accessed, the context in which data creation occurred and the role of the researcher in in creating the data in detail, rigour can be established. Describing the research study and process in detail can increase the credibility and transferability of the qualitative study.

This study used a narrative approach with a small number of participants. To strengthen the results of this study further research may be required. Triangulation, receiving similar results through using different methods, will strengthen the results of this study whilst removing the methodological considerations. A longitudinal study investigating identification with the MS identity, social support, and wellbeing from early in diagnosis to a number of years later could strengthen the results of this study. Another concern with the use of a small sample is that this sample could be biased in that only people who are successfully adjusting to their changed identity may wish to take part in research. The narrative method is based upon examining

and comparing narratives across a small sample, this could mean that the results of this study could be based on the understanding of these narratives or could be a coincidence based upon the small sample of participants interviewed.

All participants who took part in this study were recruited from a feasibility trial and may not be representative of the entire population of people with MS. The inclusion criteria for the trial, included participants with low mood who were feeling depressed or anxious, these participants may not be representative of the population of people with MS. The exclusion criteria for the trial excluded participants if they had been diagnosed within the last twelve months of the trial commencement date, because of this, the results of this interview study may not represent participants in the early stages of the disease. It should also be noted that the intervention used cognitive behavioural techniques that could have affected a participants responses to questions or lead to increased articulation around the topics under investigation.

The five participants who did not complete the intervention were not asked to take part in an interview. All participants in this sample were positive about the effect of the intervention, this may have been different if participants who had dropped out were also interviewed. The thematic content from those interviewed suggests that a person needs to have come to terms with the MS identity for group-based interventions to be effective. In future studies it would be useful to interview participants who have dropped out to see if this had anything to do with the format of the intervention.

As stated in the methods section, interviews were conducted either at the University of Nottingham or at the participants own home, based upon their personal preference.

Whilst efforts were taken to create a quiet calm environment for participants in either setting, the researcher did notice that it took a bit more time and effort to gain rapport and open conversation with participants at the University. This may reflect differences in perceived “power” in the interview setting and context. In future research, conducting the interview in the participant’s own home may provide a more relaxed environment to allow participants to openly converse in the interview.

## **6.7 Discussion**

Participants presented narratives that told the story of how MS is incorporated into their existing identity over time. In the early stages of the disease progression following diagnosis, participants wished to compartmentalise the disease and continue with their pre-diagnosis identity, however, over time they came to accept and acknowledge their MS and learned to cope with the everyday problems associated with living with MS. Previous research suggests that MS can result in biographical disruption (Green et al., 2007), evidence for this was also apparent in our study. In line with previous research into biographical disruption (Bury, 1982), participants restructured their social resources in an attempt to adapt to the MS. By adapting their social resources to close family members and friends, participants were able to acknowledge their emerging identity in a supportive environment in line with the Social Identity Model of Identity Change (Jetten & Panchana, 2012). This suggests that there are stages to adjustment; however, these do not appear to be universal across the sample.

A number of themes were similar across narratives, suggesting that the process of coming to accept MS as part of their identity appeared to be similar across the sample. Participants initially did not acknowledge the MS as part of their identity and instead saw this as a stigmatised identity which led to an initial denial of the diagnosis and a period of withdrawal. Presenting a more positive self-image and compartmentalising the disease allowed participants to cope with the early stages of adjustment. However, as symptoms become more prevalent, people around the participant may begin to treat them differently causing a reflected self-appraisal and a changing self-concept. The use of social support during this time appeared to be beneficial for coming to terms with this change in identity. The increasing prevalence of MS identity markers combined with social support and interaction with others appeared to be beneficial for helping people recognise the MS as an identity that they hold. In line with Self-Determination Theory (Ryan & Deci, 2000), a person's identification with the MS identity, and therefore assimilation of this identity into their self-concept, appears to be linked to the coping strategies they use. Compartmentalising the disease allows people to continue to present an identity that they see as more highly valued to maintain self-esteem (Hogg & Abrams, 1990), whereas assimilating the identity into a person's self-concept appears to be linked to giving and receiving social support with others who share the MS identity. This has implications for the delivery of group-based psychological interventions.

Using the family group for social support may be useful for accepting the change of identity caused by a diagnosis of MS. Participants used a compartmentalising coping strategy to present a pre-diagnosis, more positive self-image. The family is involved

with and supportive of the person with MS both before and after diagnosis, providing a base for support whilst a person comes to terms with their MS.

The study has provided insight into how people with MS can come to acknowledge and incorporate their MS into their self-concept over time. Interestingly, it appears that people with MS do incorporate their illness into their identity over time based on their narratives, and this appeared to have a positive effect on mood. A thematic analysis has revealed that other variables, such as the amount of social support a person has and the coping strategies used may affect the time it takes for a person to come to terms with this change of identity. MS is more readily accepted as part of a person's identity if it is not stigmatised and is only *a part* of a person's identity. If the diagnosis is stigmatised people may not readily acknowledge this is a significant part of their identity, which may restrict their willingness to receive social support, which could impact on their mood. Using a previous social identity such as the family, can allow a person to acknowledge their changed identity and accept social support, which can have a positive effect on their mood.

## **7. Social Identity in people with MS: An examination of social support and connectedness to others in mediating the effects of family identity and mood.**

### **7.1 Chapter Overview**

This chapter will describe a study to empirically test whether family identity predicts mood, as hypothesised on the basis of the Social Identity Model of Identity Change (SIMIC) (Jetten & Panchana, 2012). The previous chapters have highlighted that the family is implicated in identity reconstruction. Social support and relationships with others appear to be beneficial for the person with MS to establish a new sense of self. An investigation into family identity and mood, and the possible mediators of this relationship, could provide greater understanding of the effects of identity change. This examination could highlight possible mechanisms for improving mood in people with MS. The literature on identity change suggests that maintaining identity to groups, such as the family, after a life changing transition can provide people with social support and connectedness to others. This chapter describes a study to investigate whether family identity predicts mood in people with MS and whether this effect is mediated by social support and connectedness to others.

### **7.2 Rationale and Aims**

There were two objectives to this quantitative study. Firstly, to test whether family identity predicted mood in people with MS and secondly, to test whether social

support and connectedness to others mediated the relationship between family identity and mood in line with the SIMIC (Jetten & Panchana, 2012).

### **7.3 Methodology**

The design of the research was a cross-sectional survey. Questionnaires were used to collect data.

Ethical approval for the study was granted by London - Bromley National Research Ethics Service (NRES) committee (14/LO/0703) and R&D approval by University Hospitals of Leicester NHS Trust.

#### **7.3.1 Sampling**

Participants were identified from two sources. People with MS who had attended the University Hospitals of Leicester Neurology Service and people who were recruited via the MS Societies research webpage. A list of 400 past and current patients with MS over the age of 18 was compiled from the patient database at University Hospital of Leicester Neurology Service. Those on the database had visited the clinic in the 6 months before the list was compiled in August 2014. Invitations to take part and questionnaire packs were sent to a randomised, every 4<sup>th</sup> name on an alphabetical list, sample of 400 people. Invitations to take part consisted of a letter written from the Neurology service at Leicester General hospital detailing the rationale for the study and why the participant had been selected. The invitation letter also explained what was in the questionnaire pack



and explained that if they wanted to take part they needed to fill in the questionnaire and return it in the pre-paid envelope. The packs contained a participant's information sheet that outlined the purpose of the study, why the participant had been chosen to take part, what the study would entail, any risks to the participant in taking part, whom had provided ethical approval for the study as well as contact details for further information.

The other source of participants was through the MS society website. An online version of the questionnaire pack was hosted on the research section of the MS society website between August 2014 to March 2015. The information on the website consisted of the title of the study and why it was being conducted, a brief description of how the survey will help people with MS, what participants had to do if they chose to take part, who can take part, how long the study was open for and the names and contact details of the researchers undertaking the study. The website also contained a link to an online version of the survey if participants chose to take part.

### **7.3.2 Procedure**

Invitations to take part and questionnaire packs were compiled, a copy of the invitation to take part can be found in Appendix 4 (Page 216). It was also explained to participants that completing and returning the questionnaire packs would imply consent. A copy of the Participant Information Sheet can be found in Appendix 5 (Page 218). Participants were asked to complete demographic questions on age, gender, nationality, as well as categorical questions relating to

type of MS, time since diagnosis, living arrangements and ethnicity. A copy of the demographic information sheet can be found in Appendix 6 (Page 222).

Participants' were asked to complete the following questionnaires on family identity, perceived social support, willingness to engage in social groups following diagnosis and mood. A copy of the questionnaire booklet can be found in Appendix 7 (Page 225). The paper copy of the questionnaire was piloted on a local MS support group (The Ilkeston MS Social Group), feedback was positive in that they felt they could understand and answer the questionnaire. Concerns were raised for those who could not answer due to physical impairments, however, this was recognised as a limitation of the sampling and methods used in this study. The online version of the questionnaire was piloted on 3 people to ensure that the questionnaire could be filled in, and answers recorded before allowing participants to take part. To ensure a large enough sample for the study, the study was advertised on the following Facebook groups and pages (Multiple Sclerosis – UnPlugged, World Multiple Sclerosis (MS) Day Multiple Sclerosis Association of America, Overcoming Multiple Sclerosis MSWorld) as well as twitter (@abbarkerpsych).

### **7.3.2.1 Family Identity**

The Social Identification Scale (Doosjie, Ellemers, & Spears, 1995) is a four-item measure of a person's identification with a social group. The scale was designed so that questions can be adapted to focus on the social group under investigation by substituting the section in brackets with the social group under investigation;

for example, I identify with [social group]. The scale was adapted in this study to focus on the family group,. Participants were asked to rate items such as, “I see myself as a member of the family group” on a 7 point likert scale, from 1 = *Do not agree at all* to 7 = *Agree Completely*. Family identity was scored as the sum of all four items with higher scores indicating greater family identity.

### **7.3.2.2 Perceived Social Support.**

The Multi-dimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988) is a 12-item measure of three aspects of a person’s perceived social support; family, friends and significant other. There are four questions on each. Participants rated items on a 7 point likert scale from 1 = *Very strongly disagree* to 7 = *Very strongly agree*. All 12 items were scored and calculated to provide an overall score of perceived social support. As the study was concerned with social support from the family group, the scores on the family and significant other subscales were combined to provide an overall score for the family group, in line with the definition of the family provided in chapter two.

### **7.3.2.3 Willingness to engage in new social groups**

The Exeter Identity Transition Scales (Haslam et al., 2008) are a collection of three subscales that measure multiple group memberships, continued group memberships and new group memberships. As the aim was to investigate the family identity, only the new groups sub-scale was used. The scales can be altered to reflect the life-changing event under investigation, the questions were designed

to investigate various life changing transitions such as “after [life changing transition], I have joined one or more new groups”. The new groups subscale is a four-item measure and was used to investigate new groups that participants had engaged with following their diagnosis of MS, whether they have any friends in these groups and whether they identify with these groups. Participants rated items on a 7-point likert scale ranging from 1 = *Do not agree at all* to 7 = *Agree completely*. Willingness to engage in new social groups was scored as the sum of all four items.

#### **7.3.2.4 Mood.**

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) is a 14-item scale of two aspects of mood, depression and anxiety, with 7 items each. The total score of the anxiety and depression subscale was combined to provide an overall measure of mood. Participants rated items such as, “I get sudden feelings of panic” on a 4-point likert scale to reflect the level of depression or anxiety.

An error was made by researchers on the responses to two of the HADS questions (Question five, response four, was written as “not at all” instead of “only occasionally” and question fourteen, response four, was written as “seldom”, instead of “very seldom”). To test that the reliability of the test were not affected, a reliability analysis was carried out. The multi-dimensional scale of perceived social support, the social identification scale and the Exeter identity transition scale, had never been used in MS samples before, because of this it is important to record the internal consistency of these scales.

### **7.3.3 Inclusion Criteria**

Participants were invited to take part if they had a diagnosis of MS (including benign, relapsing, remitting, secondary progressive and primary progressive) and were aged 18 or over. Participants were considered to have given informed consent by returning and completing their questionnaires. Participants attending the MS Clinic at Leicester General Hospital had a confirmed diagnosis of MS and questionnaires were only sent to those over 18. For the online version of the questionnaire, it was clear before taking part that we were interested in people with MS over the age of 18. Due to this sampling technique, there was no way to check this.

### **7.3.4 Power Analysis**

An a priori power calculation based on 3 potential predictor variables and a medium effect size of 0.15, indicated a total of 119 participants would be required to provide 0.95 power.

### **7.3.5 Analysis**

The data provided by participants was entered into and analysed using SPSS version 21. A non-normal distribution of scores was found on all predictor questionnaires Family Identity new groups (Shapiro-Wilk =  $<0.05$ ) Family social support (Shapiro-Wilk, =  $<0.5$ ); new groups (Shapiro-Wilk =  $<0.05$ ). A normal

distribution of scores was found on dependent variable, HADS total score (Shapiro-Wilk =  $>0.05$ ) because of this a bootstrapping mediation analysis was conducted. Descriptive statistics were examined and a mediation analysis was conducted. The mean, standard deviations and correlations of the variables included in the analysis can be found in table 7.4.

Mediation analysis is a technique used to test how a causal variable has an effect on a dependent variable. The literature review and the results of chapter five suggested that people with MS experienced increased social support and willingness to join new social groups as a result maintaining social group identity following their diagnosis of MS. A parallel mediator model was used to test whether family identity had a positive effect on mood through these mediators.

By conducted a regression analysis on the independent variables associated with the dependent variables, the standardised regression co-efficients were examined to see whether the effect of family identity on mood scores was greater than its indirect effects on social support or willingness to join new social groups.

## **7.4 Results**

### **7.4.1 Participants**

In total 123 participants out of 400 invited returned the postal copy of the questionnaire, a response rate of 30.75%. A further 80 participants completed an online version of the questionnaire through the MS Society website, providing a sample of 203 participants.

## 7.4.2 Data Preparation

Following data inputting, data checking took place on 10% of the data. As a number of errors were found in this 10%, the decision was made to check the entirety of the dataset for errors. Correction of the errors found in the dataset led to a second 10% error check, which produced no errors.

Due to the nature of questionnaire design some participants had failed to fill in questions before returning the questionnaire. As the questionnaire was completely anonymised, participants could not be contacted to provide the missing information. The decision was made that for participants missing a single question from any scale; mean substitution, based on the participant's scores on every other item on the questionnaire, was used to fill in the missing data. Any participants who had missed out more than one question on a questionnaire were excluded from the analysis. Eight participants were removed from the analysis due to missing data, bringing the total sample to 195. The demographics of the final sample used can be found in Table 7.1.

Table 7.1: Demographic characteristics of the sample.

	Mean (Standard Deviation)	Range
Age in years	48.19 (11.02)	23 - 85 years

.	Frequency	Percentage
<u>Time Since Diagnosis</u>		
Less than 1 year	10	5.1
1 – 3 Years	37	19.1
3 – 5 Years	24	12.3
5 – 10 Years	39	20
10 – 15 Years	45	23.1
More than 15 Years	37	19
Missing	3	1.5
<u>Gender</u>		
Men	50	25.6
Women	141	72.3
Missing	4	2.1
<u>Type of MS</u>		
Relapsing Remitting	102	52.3
Primary Progressive	34	17.4
Secondary Progressive	42	21.5
Benign	10	5.1
Missing	7	3.6
<u>Relationship Status</u>		
Married / Partner	142	72.8
Divorced / Separated /	26	13.3
Widowed		
Single	23	11.8
Missing	4	2.1



<u>Living Arrangements</u>		
Living with Partner	118	60.5
Living Alone	24	12.3
Living with Family	35	17.9
Living with Friends	2	1
Other	12	6.2
Missing	4	2.1
<u>Ethnicity</u>		
White	169	86.6
Black	5	2.5
Asian	10	5.1
Mixed	3	1.5
Any Other	4	2.1
Missing	4	2.1

A regression analysis was conducted on both the original data file and the changed data file, mean substitution of scores did not change the direction of the results. Details regarding number of completed responses included in the analysis, mean questionnaire scores, standard deviations and range of results can be found in Table 7.2.

Table 7.2: Descriptive statistics for questionnaires used.

	n	Minimum	Maximum	Mean	Standard Deviation
Family Identity	195	4	28	22.22	7.19
Family Social Support	195	4	28	19.81	6.30
Willingness to join new groups	195	4	28	13.57	8.92
HADS (Total Score)	195	0	38	17.84	8.04
Valid number of cases	195				

### 7.4.3 Reliability

The results of the reliability analysis can be found in table 7.3.

Table 7.3: Internal consistency of scales used.

Scale	Reliability (Cronbach's $\alpha$ )
Multi-dimensional Scale of Perceived Social Support (Family and significant other)	.91
Social Identification Scale (Family)	.96
Exeter Identity Transition Scale (New groups sub-scale)	.95
HADS Total Score	.88

Table 7.4: Descriptive statistics and correlations of variables included in the mediation analysis

Variable	Mean	Standard Deviation	Family Identity	Family group social support	Willingness to join new groups	Mood
1) Family Identity	22.35	7.13		.508**	.166*	-.320**
2) Family group social support	42.96	10.46	.508**		.129	-.375**
3) Willingness to join new groups	13.72	8.99	.166	.129		-.214**
4) Mood	17.91	7.97	-.320**	-.375**	-.214**	

\*\* p = <0.01

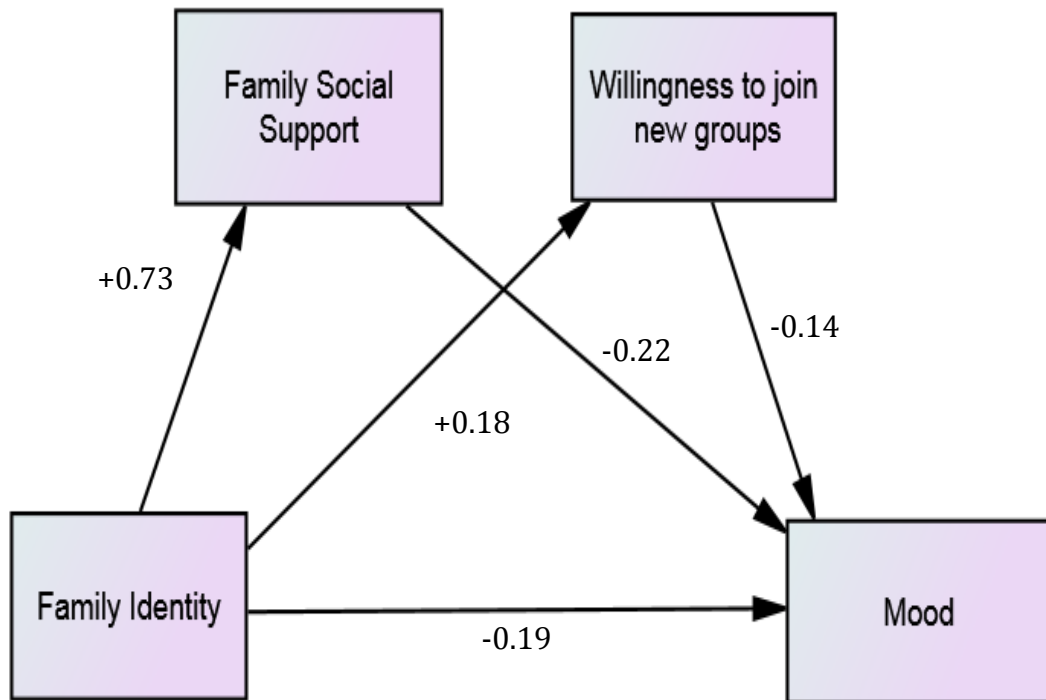
\* p = <0.05

Family identity was found to be significantly positively correlated with family group social support (p <0.01) willingness to join new groups (p <0.05) and negatively correlated with mood (p <0.01). Family group social support was found to be negatively correlated with mood (p <0.01). Willingness to join new groups was found to be negatively correlated with mood (p <0.01).

#### 7.4.4 Mediation Analysis

From a simple multiple mediator mediation analysis constructed using ordinary least squares regression, family identity influenced mood indirectly through its effect on social support and willingness to join new groups. As can be seen in Figure 7.1 and Table 7.5, participant's family identity positively predicted levels of social support ( $\beta = 0.73, p < .01$ ). Social support levels were also found to predict mood levels ( $\beta = -0.22, p < .01$ ). Family identity was found to predict willingness to join new groups ( $\beta = -0.18, p < 0.05$ ). Willingness to join new groups were found to predict mood levels ( $\beta = -0.14, p < 0.05$ ). A bias-corrected confidence interval for the indirect effect ( $\beta = -0.16$ ) of family identity of mood through social support (based on 5,000 bootstrap samples) was entirely below zero (95% CI's = -0.27 to -0.08). A bias corrected confidence interval for the indirect effect ( $\beta = -0.03$ ) of family identity of mood through willingness to join new groups (based on 5,000 bootstrap samples) was entirely below zero (95% CI's = -0.07 to -0.001). There was also evidence that family identity influenced mood independent of the mediating effect of social support and willingness to join new groups ( $\beta = 0.19, p < .05$ ).

Figure 7.1: Model with regression coefficients



All p values were significant at  $p < 0.05$ .

Table 7.5: Model Coefficients

	Consequent											
Antecedent	M <sup>1</sup> Family Social Support				M <sup>2</sup> Willingness to join new groups				Y Mood			
	Path	Co-efficient.	SE	p	Path	Co-efficient.	SE	p	Path	Co-efficient	SE	p
X Family Identity	A <sup>1</sup>	0.7253	0.1064	<0.01	B <sup>1</sup>	0.1805	0.0845	<0.05	C	-0.1890	0.0928	<0.01
M <sup>1</sup> Family Social Support	-	-	-	-	-	-	-	-	A <sup>2</sup>	-0.2211	0.0579	<0.05
M <sup>2</sup> Willingness to join new groups	-	-	-	-	-	-	-	-	B <sup>2</sup>	-0.1433	0.0617	<0.01
CONSTANT	I <sup>1</sup>	26.5274	2.6161	<0.01	I <sup>2</sup>	9.5138	5.0342	<0.01	I <sup>3</sup>	33.4285	2.4319	<0.01
	R <sup>2</sup> = 0.2447				R <sup>2</sup> = 0.0211				R <sup>2</sup> = 0.2019			
	F (1, 191) = 46.4673, p = <0.01				F (1, 191) = 4.5591, p = <0.05				F (3, 189) = 16.5620, p = <0.05			

The results of the mediation analysis showed that family identity predicted mood through the parallel mediators of family social support and willingness to join new groups.

The SIMIC (Jetten & Panchana, 2012), proposes that identifying with previously established groups will enable a person to receive social support and gain a sense of connectedness to others. Chapter six suggests that people need to adjust to their MS identity before they are willing to accept support from others, a process which could take some time. An analysis of new group membership, grouped by years diagnosed, suggests that based on mean score, people with MS seem to be more willing to take part in new groups after a period of time. New groups membership over time can be found in Table 7.6.

Table 7.6: New group membership grouped by years

Years diagnosed	Number	Mean	Standard Deviation
Less than 1 year	10	9	6.2
1 – 3 years	37	14.81	8.56
3 -5 years	24	10.46	9.19
5 – 10 years	39	11.62	8.46
10 – 15 years	45	13.89	9.13
More than 15 years	37	16.7	9.05



## 7.5 Discussion

This study found that family identity was negatively associated with mood. Increases in family identity were associated in lower scores on the HADS, which can be interpreted as better overall mood. A mediation analysis further showed that family identity predicted mood through the parallel mediators of family social support and willingness to join new groups.

A number of theoretical implications can be derived from the results. One of the more important implications can be seen in the direct effect of family identity on mood. In line with the SIMIC, identifying with the family group had a positive effect by reducing mood scores. This finding can help explain why the family is often a salient factor in adjustment to MS, as identifying with the family group appears to be protecting people with MS from the harmful effects of identity change following the life changing transition of being diagnosed with the disease. The results of this study have shown that those with higher levels of family identity have less distress, i.e. better mood.

The mediating effects on the relationship included social support from the family group and willingness to join new groups. Previously established identities provide a basis for drawing social support and a good platform for people to establish new identities that are compatible and integrated with old identities to enhance identity continuity (Jetten & Panchana, 2012). The mediating effects in this model have shown that family identity has an effect on mood through the

mediators of increased family social support and increased willingness to join new groups, in line with the SIMIC (Jetten & Panchana, 2012).

The main strengths of this investigation were the size of the sample used. Using both an NHS MS database and an online questionnaire resulted in a large number of people taking part in the study. Another strength is the testing of the family identity in a quantitative study. Whilst this has been implicated in adjustment to MS, it has only so far been investigated in qualitative studies (Irvine et al., 2009).

A limitation of this study is the use of the Exeter Identity Transition Scales to measure willingness to join new groups. The SIMIC (Jetten & Panchana, 2012), proposes that identifying with previously established groups will enable a person to receive social support and gain a sense of connectedness to others. There are no established questionnaires to measure connectedness to others and because of this the decision was made to measure attempts to join newly established groups, using the new groups sub-scale of the Exeter Transition Scales. However, this measure only assesses new groups that a person has joined since being diagnosed with MS and not thinking about joining new groups. As the results of chapter six show, people with MS are more willing to join new groups after they have assimilated the MS identity into their overall sense of self, a process which can take a long time. Forty eight participants in the sample were within 3 years of being diagnosed and may not have felt they were yet at a stage to join new social groups as they had not assimilated the MS identity into their overall sense of self.

The sampling procedure used in this study enabled the researchers anonymous access to a large number of NHS patients, however, this meant that a majority of people who took part were from a single geographic area, which limits the generalizability of the study. However, it was a large urban area and probably representative of many parts of the UK.

Using an NHS register of current and previous users of an MS clinic may have included more people in the early stages of the disease, which further complicates the validity of the sample. Problems also arise with the use of questionnaires. The return rate of completed questionnaires was 37.75%. In an attempt to increase the size of the sample, an online version of the questionnaire was created. The online version of the questionnaire was hosted on the research section of the MS society website but the response rate to this version is unknown.

A limitation of this study is the low response rate to the postal version and unknown response rate to online version. However, the sample is large and the characteristics of the sample are similar to what you would expect i.e. average age late forties and three quarters are women.

An examination of the mean scores for the HADS depression and anxiety subscales revealed that the sample had moderate levels of depression [Mean = 10.10 (4.72 SD)] and anxiety [Mean = 7.85 (4.17 SD)] (Zigmond & Snaith, 1983). Considering that people with MS in general have high prevalence of depression and anxiety, this is consistent with what might be expected.

Another limitation to the study could be that not everyone who took part completed all questionnaires. This resulted in participants being excluded from the study, which reduced the overall sample size. It would have been useful to include a measure of disability in the questionnaire booklet to provide a more complete description of the sample characteristics and to include this in analyses. However this was not included to keep the questionnaire short and improve the response rate. It is unknown whether participants filled in their own questionnaires or whether they received help in filling out the questionnaires due to functional limitations. Having help in filling out the questionnaire may have influenced answers.

There are several implications of this study. Firstly, family support in response to MS diagnosis may be more beneficial than is currently understood. A number of UK MS charities provide bibliotherapy on the use of the family in support following diagnosis (Multiple Sclerosis Society, 2007; The MS Trust, 2014). Involving the family in the early stages of diagnosis and treatment of MS could increase support for the individual and reduce the high prevalence of mood disorders. Secondly, family identity and family social support are highly correlated constructs. Whilst the direction of the association cannot be established by simply examining a correlation, teaching family members on how to successfully provide social support to the family member with MS could lead to greater identification with the family group and a reduction in low mood. However, this would need to be examined in further research. Thirdly, after increasing support from the family group and after a period of adjustment, families could be taught how to encourage participation in other social groups. By

taking part in new groups, the person with MS may be further incorporating their identity continuity by establishing new identities that are compatible and integrated with the family identity.

The findings of this study could be extended by longitudinal quantitative research into the role of the family on reduction of low mood in people with MS. By gathering data on family identity, support and mood in the early stages after diagnosis and following participants over a period of time, may allow the identification of periods where support, or wanting to join new groups might be most beneficial. For a longitudinal study, I would recommend using an NHS sample with a confirmed diagnosis of MS to maintain a homogenous sample where the demographics of this sample is confirmed. I would include a measure of disability such as the EDSS (Kurtzke, 1983) to provide a more complete description of the sample characteristics. I would also include qualitative interviews with the same participants as well as quantitative measures to assess changing support needs over time.

Testing the SIMIC in other social groups might be another way to extend the results of this study. A number of participants in the qualitative study expressed that friendship groups were also important for support. Friendship groups can vary in their degree of support and identification with the group over time. A study, similar to the one presented here, could test this model in other social groups. Measuring the family at the same time, we could investigate the effect of a second social group when the effects of one social group are controlled for.

## 8 Conclusions

The original research questions will be considered. The overall research topic that was to be addressed was:

Understanding social identity change in people with MS: a social identity approach to the role of the family in identity reconstruction.

To answer this question, the following sub-questions were addressed:

- What is the efficacy of group psychological interventions for people with MS compared to individual psychological interventions?
- Do people with MS experience changes to their sense of self-following a diagnosis of MS, and if so, what is the subjective experience of this over time?
- Are changes to a person's sense of self associated with changes to mood?
- Are problem focused coping strategies beneficial for adjustment in people with MS?
- Can the family act as a secure base for identity reconstruction in line with the SIMIC?

- Is high family identity related to a reduction in mood scores?
- Does family identity lead to changes in mood through social support and willingness to join new groups, as predicted by the SIMIC?

## **8.1 Sub Question Conclusions**

Here I will outline the various sub-question and provide a conclusion for each based on previous chapters.

### **8.1.1 The efficacy of group psychological interventions for treating mood in people with MS compared to individual psychological interventions**

The first question was addressed in a systematic literature review on the effectiveness of group versus individual psychological interventions treating mood disorders. Whilst there is a lack of randomised controlled trials surrounding this topic and no trials that report a direct comparison between the two, the findings of an indirect comparison were as follows:

- Group CBT interventions have a greater effect on self-reported depression scores and the physical aspects of disease specific quality of life in short-term follow-ups.
- More studies need to be conducted to allow a direct comparison between the two and long-term data needs to be reported.

- Group based interventions may be more effective for treating depression in people with MS than individual based interventions, showing that the effect of the group may be more beneficial for people with MS than the content of the intervention.

Taking into account the lack of a direct comparison, group interventions may result in a greater reduction of depression and anxiety than individual based interventions. This has positive implications for the delivery of psychological interventions for depression and anxiety in people with MS as group based interventions are relatively cheaper and can be delivered to a number of participants at the same time. However, as discussed in the literature review, attendance at group based psychological interventions can be low. For a group therapy to be effective a person must see themselves as part of the group (Cruwys et al., 2014; Frisch et al., 2014; Haslam et al., 2008), something that people with MS are unlikely to do in the early stages of the disease (Irvine et al., 2009). Because of this, the remainder of the thesis chose to examine how people with MS come to incorporate the MS identity into their sense of self.

### **8.1.2 The family groups ability to act as a secure base for identity reconstruction and the importance of aligned coping strategies**

The literature review and the qualitative study suggested that social support was important for adjusting to identity change in people with MS. Due to the restructuring of social resources following a change in identity and the availability



of the family to provide support, it appeared as though the family could be a source of support for people with MS and form a secure base for identity reconstruction. However, the family unit is often affected by the MS diagnosis and may not be able to provide the support that the person with MS may require. To answer the question of whether the family could provide a secure base for identity reconstruction, a meta-synthesis of the qualitative literature on identity change was conducted. To be effective the literature states that coping strategies need to be aligned between the person with MS and their family, this meta-synthesis provided an opportunity to answer this question. The meta-synthesis found that:

- There are benefits from using the family to establish a new identity after the changes to identity that can occur due to a diagnosis of MS.
- Coping strategies used by the person with MS and the family needed to be aligned to have a positive effect. Positive adaptive coping strategies resulted in positive effects such as bringing the family closer together and strengthening the sharing of social support. Negative coping strategies such as “bracketing”, appeared to have negative effects on psychological well-being, however, it was acknowledged that this could represent different stages of adjusting to identity change due to the wide sample found in the qualitative literature.

- Some people with MS were able to establish new identities after a period of adjustment and normalised their change in identity by attending support groups for people with MS.
- The family did not provide a secure base for identity change in all studies.

Using the family as a secure base for identity reconstruction can have positive effects such as increased social support and a willingness to join new groups such as support groups after a period of time, as predicted by the SIMIC. The coping strategies used by both the person with MS and the family were crucial in the success of the family to form a secure base for identity reconstruction. Coping strategies need to be aligned to have a positive effect; a conflict of coping strategies could result in a negative effect. However, the use of adaptive coping by both the family group and the person with MS resulted in positive outcomes, such as increased social support, a factor that appears to be implicated in identity reconstruction as found in the qualitative study. Importantly, whilst the family provided a secure base for identity reconstruction in a large number of studies, the family did not always provide a secure base for adjustment. In these cases, seeking support from other sources may be beneficial for the person with MS, however this requires further study.

### **8.1.3 The changes to a person's sense of self following a diagnosis of MS**

People with MS undergo changes to their sense of self and that these changes may have an impact on a person's mood. The subjective experience of identity change

in people with MS is not currently understood in the literature and so a qualitative interview study with people with MS was used to address the second and third sub-questions. While considering the limitations of the sampling technique used for this study, the findings were as follows:

- Participants initially did not acknowledge the MS as part of their identity and instead saw this as a stigmatised identity which led to an initial denial of the diagnosis and a period of withdrawal. Presenting a more positive self-image and compartmentalising the disease allowed participants to cope with the early stages of adjustment.
- Social support was important for helping people with MS acknowledge and respond to their changing identity. As symptoms become more prevalent, people around the person with MS may begin to treat them differently causing a reflected self-appraisal and a changing self-concept.
- Whilst participants acknowledged their MS identity over time, there were individual differences in the incorporation of this identity into their overall sense of self. This appeared to be dependent on the coping strategies and support that the person with MS utilised.

From these interviews, it was apparent that people with MS do undergo changes to identity following a diagnosis of MS. Participants coped with the change of identity in different ways. Social support and increasing symptoms created a situation where the person with MS was able to recognise their changed identity.

The value of the MS identity led people to cope with this identification differently, some participants incorporated this into their sense of self, whereas others did not. This appeared to reflect the early and latter stages of coping with identity change, as participants who had been diagnosed a relatively small amount of time, tended to compartmentalise their diagnosis and present a less stigmatised identity. Whilst there were common themes to the adjustment process, all individuals coped with their change of identity differently and the time it takes to acknowledge a change in identity may differ.

#### **8.1.4 The effect of family identity on mood**

After finding that the family can provide a secure base for identity reconstruction, an empirical test of the family identity based on the SIMIC was needed to triangulate the data. The SIMIC states that previously established social groups can protect against the negative effects of identity change and provide a source of social support and connectedness to others. A survey study was used to answer the sub questions of whether family identity is related to changes in mood scores, and whether this change occurs through family social support and/or willingness to take part in new social groups. A survey study found that:

- Family identity had a direct effect on mood. As identification with the family increased, participants had less mood problems.
- Family identity had an effect on mood through the parallel mediators of family social support and willingness to join new groups

In line with the SIMIC, a previously established identity, the family, not only has a positive effect on mood scores, but also has a direct effect on mood through family social support and willingness to join new groups.

## **8.2 Overall Conclusions**

Despite the individual studies included in this thesis having individual strengths and weaknesses, which can be found in each individual chapter, this was the first study to investigate the role of the family in identity reconstruction in people with MS. The following tentative conclusions can be drawn from the research included in this thesis:

- Group psychological interventions have a greater effect on depression and anxiety in people with MS compared to individual interventions. However, based on the literature, people will be more willing to attend a group based intervention if they see MS as part of their sense of self.
- People with MS do experience changes to identity as a result of MS, however, coherent narratives show that MS is incorporated into a person's narrative, showing acceptance of the condition. Early coping may involve compartmentalising the disease. Increasing symptoms and receiving social support may enable people with MS to acknowledge their changing identity. Over time and depending on a person's willingness to integrate the MS identity into their sense of self, people with MS may choose to continue to compartmentalise the MS identity, or incorporate the MS

identity into their sense of self. Continued compartmentalisation of the disease may represent early coping strategies and further research will be needed to examine this. Increased social support throughout this early period of adjustment could help people with MS to acknowledge the identity change and incorporate the MS identity into their sense of self earlier. Offering group support from others with MS after this period of adjustment may produce better results in the person with MS, through increased willingness to accept support and increased attendance with the group.

- The family can provide a secure base for identity reconstruction; however, coping strategies need to be aligned between the person with MS and the family. Positive adaptive coping strategies can result in increased social support and increased family identity through bringing the family closer together. Teaching the family and the person with MS adaptive coping strategies could reduce the prevalence of depression and anxiety in people with MS. Using the family for identity reconstruction can result in the person with MS seeking support from others with MS by attending MS support groups, which could have positive implications for group psychological therapy attendance. The family did not always provide a secure base for identity reconstruction; further research will be needed to see if other social groups can have the same positive effects as the family.
- Identifying with the family group can have a direct positive effect on a person's mood, in line with the SIMIC. Family identity can also have an

indirect effect on a person's mood through the parallel mediators of family social support and willingness to join new social groups.

The research presented in this thesis highlights the positive effect that using the family as a secure base for identity reconstruction can have, in particular the effect that this identity change can have. Whilst it has previously been suggested that a diagnosis of MS can cause disruptions to a person's sense of self (Boeije, Duijnste, Gryndonck, & Pool, 2002), this thesis shows how this change of identity can have a disruption on mood and suggests that people attempt to reconstruct their identity as part of their adjustment to the chronic condition. A previous review of CBT interventions for mood in people with MS found little difference between the two forms of intervention (Hind et al., 2014). Another review for psychological treatments for mood in people with MS suggested that group interventions may have a positive effect over and above the intervention due to the social support provided in a group format (Thomas, Thomas, Hillier, Galvin, & Baker, 2006). The updated review found in this thesis features a wider search strategy and suggests that there may indeed be a difference between the two forms of intervention. The qualitative investigation found in chapter 6, suggests that this positive effect may only occur following an initial adjustment to the MS. This chapter builds upon previous research by providing an insight into the adjustment process. This thesis builds upon previous research by investigating and showing that the social identity approach and the SIMIC can have positive effects in people with MS. The family has been found to be a salient factor in adjustment to MS in the literature (Wineman, 1990), this thesis presents evidence that the family may play a part in the adjustment process by providing a source of

identity continuity throughout the adjustment change and social support throughout the adjustment process. Following the emergence of new symptoms, the family may help a person come to terms with their change of identity through self-reflected appraisals. In line with the SIMIC, maintaining a family identity following the identity change can have positive effects on mood. The change of identity brought about by maintaining a family identity can lead to increased willingness to take part in new social groups, which can have positive effects for group-based interventions for mood. People are more likely to receive and accept peer support from individuals they see as sharing this social group identity (Cruwys et al., 2014; Frisch et al., 2014; Haslam et al., 2008). Using the family as a source of support during identity reconstruction can enable people to assimilate the MS identity into their sense of self and be more willing to accept social support from other people with MS. This may explain the mixed results in the comparison between group and individual interventions in the literature.

This thesis has implications for clinical practice. The family appears to play a part in adjusting to the diagnosis of MS, including the family in the diagnosis process, teaching the family group how to provide support and increasing communication between the person with MS and the family group could lead to less disruption during the adjustment process. Whilst group interventions have been introduced due to lack of funds, these may not always be effective. A person needs to initially adjust to the change in identity to identify with the group of people with MS for the peer support to be effective. Before this time, people with MS may see the MS identity as stigmatised and may not wish to take part in the group. People with MS should be given the choice between the form of intervention so that they can



choose the format of intervention more suited to them, depending on where they are in the adjustment process.

This thesis does have some limitations. Whilst mixed methods have been used to gain a number of perspectives on the topic under investigation, the lack of a longitudinal study makes it difficult to make conclusions about the adjustment process over time. As the majority of research into MS has taken part in western countries, the basis of this thesis, that the family plays a part in adjustment to MS, may reflect traditionally western family types. Further research will be needed to investigate whether the beneficial effect of using the family for adjustment is universal. All people and families are different, whilst it can be concluded that family social support is beneficial to the adjustment process, social support may differ between family types and this may be difficult to increase in individual families. Some people with MS no longer have a family group; research into other social groups will be needed to see if other social groups can have a beneficial effect. This thesis suggests that group interventions are more beneficial to people with MS after they have incorporated the MS identity into their sense of self.

Without a trial investigating the effects of group and individual based psychological interventions on people at different stages of the adjustment process, this can only be suggested from this thesis. The adjustment process may not be universal and it might be problematic to identify the level of adjustment in people with MS.

Following the findings of this thesis, the next step in this area of research is to further establish the relationship between previously established groups and mood

in people with MS. The family did not provide a secure base for identity reconstruction in everyone, it will be important to acknowledge if other social groups could have the same effect as the family. This thesis has shown that people have multiple identities, maintaining previously established identities after a diagnosis of MS appears to have a positive effect on adjustment in people with MS. It is also important to establish the effect of social identity change in other conditions and whether the family can have similar positive effects in different populations. In this way, the finding of this study, that the family can help people with MS to adjust to their change in identity, can be further strengthened.

## References

- Aikens, J. E., Fischer, J. S., Namey, M., & Rudick, R. A. (1997). A replicated prospective investigation of life stress, coping, and depressive symptoms in multiple sclerosis. *Journal of Behavioural Medicine, 20*(5), 433-445.
- Alloy, L., & Abramson, L. (1999). The Temple-Wisconsin Cognitive Vulnerability to Depression Project: Conceptual Background, Design, and Methods. *Journal of Cognitive Psychotherapy, 13*, 227-262.
- Amato, M. P., Zipoli, V., Goretti, B., Portaccio, E., De Caro, M. F., Ricchiuti, L., . . . Trojani, M. (2006). Benign multiple sclerosis: Cognitive, psychological and social aspects in a clinical cohort *Journal of Neurology, 253*(8), 1054-1059.
- Ameis, S., & Feinstein, A. (2007). Treating depressed multiple sclerosis patients. *Therapy, 4*(3), 339-347.
- Amtmann, D., Bamer, A. M., Noonan, V. K., Lang, N., Kim, J., & Cook, K. F. (2012). Comparison of the psychometric properties of two fatigue scales in multiple sclerosis. *Rehabilitation Psychology, 57*(2), 159-166.
- Antonak, R. F., & Livneh, H. (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science & Medicine, 40*(8), 1099-1108.
- Arnett, P. A., Barwick, F. H., & Beeney, J. A. (2008). Depression in multiple sclerosis: review and theoretical proposal. *Journal of The International Neuropsychological Society, 14*(5), 691-724.
- Atkins, L., Newby, G., & Pimm, J. (2012). Normative data for the Hospital Anxiety and Depression Scales (HADS) in multiple sclerosis. *Social Care and Neurodisability, 3*(4), 172-178.
- Audulv, A., Asplund, K., & Norbergh, K.-G. (2012). The Integration of Chronic Illness Self-Management. *Qualitative Health Research, 22*(3), 332-345.
- Bamer, A. M., Amtmann, D., Ehde, D., & Johnson, K. L. (2008). Anxiety in multiple sclerosis: prevalence and associated factors in a large community sample. *Multiple Sclerosis, 14*(1), 155.
- Bandari, D. S., Vollmer, T. L., Khatri, B. O., & Tyry, T. (2010). Assessing quality of life in patients with multiple sclerosis. *International Journal of MS Care, 12*(1), 34-41.
- Barak, Y., Achiron, A., Elizur, A., Gabbay, U., Noy, S., & Sarova Pinhas, I. (1996). Sexual dysfunction in relapsing remitting multiple sclerosis: magnetic resonance imaging, clinical, and psychological correlates. *Journal of Psychiatry and Neuroscience, 21*(4), 255-258.
- Barker, J., & Bury, M. R. (1978). 'Mobility and the elderly: a community challenge' In V. Carver & P. Liddiard (Eds.), *An Ageing Population*. Sevenoaks: Hodder and Stoughton.
- Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: psychometric properties. *Journal of Consulting and Clinical Psychology, 56*(6), 893-897.
- Beck, A. T., Rush, A. J., Shaw, B. F., & Emery, G. (1979). *Cognitive therapy of depression*. New York: Guilford Press.
- Becker, G. (1997). *Disrupted lives* Berkeley: University of California Press.

- Benedict, R. H. B., Fishman, I., & McClellan, M. M. (2003). Validity of the Beck Depression Inventory-Fast Screen in multiple sclerosis. *Multiple Sclerosis*, 9(1), 393-396.
- Benito-Leon, J., Morales, J. M., Rivero-Navarro, J., & Mitchell, A. (2003). A review about the impact of multiple sclerosis on health related quality of life. *Disability and Rehabilitation*, 25(23), 1291-1303.
- Bennett, L. A., Wolin, S. J., & McAvity, K. J. (1988). Family identity, ritual and myth: A cultural perspective on life cycle transitions. In C. J. Falicov (Ed.), *Family Transitions* (pp. 211-234). New York: Guildford Press.
- Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133(6), 920-954.
- Boeije, H. R., Duijnste, M. S. H., Grypdonck, M. H. F., & Pool, A. (2002). Encountering the downward phase: biographical work in people with multiple sclerosis living at home. *Social Science & Medicine*, 55(6), 881-893.
- Boland, P., Levack, W. M. M., Hudson, S., & Bell, E. M. (2012). Coping with multiple sclerosis as a couple: 'peaks and troughs' - an interpretative phenomenological exploration. *Disability and Rehabilitation*, 34(16), 1367-1375.
- Borgosian, A., Moss-Morris, R., Yardley, L., & Dennison, L. (2009). Experiences of partners of people in the early stages of multiple sclerosis. *Multiple Sclerosis*, 15(7), 876-884.
- Bowen, C., Hall, T., Newby, G., Walsh, B., Weatherhead, S., & Yeates, G. (2009). The impact of brain injury on relationships across the lifespan and after school, family and work contexts. *Human Systems: The Journal of Therapy, Consultation & Training*, 20, 62-77.
- Bowen, C., MacLehose, A., & Beaumont, J. G. (2011). Advanced multiple sclerosis and the psychosocial impact on families. *Psychology & Health*, 26(1), 113-127.
- Boyd, J. R., & MacMillan, L. J. (2005). Experiences of children and adolescents living with multiple sclerosis. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*, 37(6), 334-342.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Psychology*, 3(2), 77-101.
- Brinthaup, T. M., & Lipka, R. P. (1992). *The self: Definitional and methodological issues*. Albany: State University of New York.
- Brock, C. S. (1995). Narrative and Medical Genetics: On Ethics and Therapeutics. *Qualitative Health Research*, 5(2), 150-168.
- Brooks, N. A., & Matson, R. R. (1982). Social-psychological adjustment to multiple sclerosis. A longitudinal study. *Social Science and Medicine*, 16(24), 2129-2135.
- Buhse, M. (2008). Assessment of Caregiver Burden in Families of Persons With Multiple Sclerosis. *Journal of Neuroscience and Nursing*, 40(1), 25-31.
- Burnell, K. J., Hunt, N., & Coleman, P. G. (2009). Developing a model of narrative analysis to investigate the role of social support in coping with traumatic war memories. *19*, 1(91-105).

- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.
- Carver, C. S. (2012). Self-Awareness. In M. R. Leary & J. P. Tangney (Eds.), *Handbok of Self and Identity* (Second Edition ed., pp. 50-69). New York: Guildford Press.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36(4), 657-680.
- Chen, R. K.-Y. (2007). Life satisfaction among people with progressive disabilities. *Dissertation Abstracts International Section A: Humanities and Social Sciences. Vol.*, 68(1-A), 90.
- Chiaravalloti, N. D., & DeLuca, J. (2008). Cognitive impairment in multiple sclerosis. *The Lancet: Neurology*, 7(12), 1139-1151.
- Cioffi, D. (2000). The looking-glass self revisited: Behaviour chose and self reflection in the social token. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 184-219). New York: Guilford Press.
- Clark, C. M., James, G., Li, D., Oger, J., Paty, D., & Klonoff, H. (1992). Ventricular size, cognitive function and depression in patients with multiple sclerosis. *Canadian Journal of Neurological Sciences*, 19, 352-356.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, 38(5), 300-314.
- Cohen, J. (1977). *Statistical Power Analysis for the Behavioural Sciences* (2nd ed.). New York: Academic Press.
- Cohen, S., & McKay, G. (1984). Social support, stress and the buffering hypothesis: A theoretical analysis. In J. E. Baum, Singer., & S. E. Taylor (Eds.), *Handbook of psychology and health* (Vol. 4, pp. 253-267). Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.
- Cohen, S., & Pressman, S. (2004). Stress-Buffering Hypothesis. In N. B. Anderson (Ed.), *Encyclopedia of Health and Behaviour* (Vol. 2, pp. 780-782). Thousand Oaks: Sage.
- Compston, A., & Coles, A. (2008). Multiple sclerosis. *Lancet*, 372(9648), 1502-1517.
- Cooper, C. L., Hind, D., Parry, G. D., Isaac, C. L., Dimairo, M., O'Cathain, A., . . . Sharrack, B. (2011). Computerised cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: external pilot trial. *Trials*, 12(259), 1-14.
- Cottrell, D. A., Kremenutzky, M., Rice, G. P. A., Koopman, W. J., Hader, W., Baskerville, J., & Ebers, G. C. (1999). The natural history of multiple sclerosis:a geographically based study5. The clinical features and natural history of primary progressive multiple sclerosis. *Brain*, 122(4), 625-639.
- Crawford, J. D., & McIvor, G. P. (1987). Stress management for multiple sclerosis patients. *Psychological Reports*, 61(2), 423-429.
- Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40(1), 429-434
- Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, California: Sage Publications.

- Creswell, J. W., Plano Clark, V. L., Gutmann, M., & Hanson, W. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioural research* (pp. 209-240). Thousand Oaks, California: Sage Publishing.
- Crigger, N. J. (1996). Testing an uncertainty model for women with multiple sclerosis. *Advances in Nursing Science*, *Vol.*, *18*(3), 37-47.
- Cruwys, T. S., Haslam, A., Dingle, D. A., Jetten, J., Hornsey, M. J., Chong, D., & Tian, O. P. S. (2014). Feeling connected again: Interventions that increase social identification reduce depression symptoms in community and clinical settings. *Journal of Affective Disorders*, *159*(1).
- das Nair, R., Lincoln, N. B., Kratz, A. L., Hirsh, A. T., Ehde, D. M., Jensen, M. P., . . . Pavlou, M. (2012). Evaluation of Rehabilitation of Memory in Neurological Disabilities (ReMiND): A randomized controlled trial. *Clinical Rehabilitation*, *26*(1), 894-903.
- De Ridder, D., Schreurs, K., & Bensing, J. (2000). The relative benefits of being optimistic: Optimism as a coping resource in multiple sclerosis and Parkinson's disease. *British Journal of Health Psychology*, *5*(2), 141-155.
- Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health and Social Work*, *26*, 257-268.
- Dennison, L., Moss-Morris, R., & Chalder, T. (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review*, *29*(2), 141-153.
- Dennison, L., Moss-Morris, R., Silber, E., Galea, I., & Chalder, T. (2010). Cognitive and behavioural correlates of different domains of psychological adjustment in early-stage multiple sclerosis. *Journal of Psychosomatic Research*, *69*(4), 353-361.
- Devins, G. M., & Shnek, Z. M. (2000). Multiple Sclerosis. *Frank, Robert G [Ed]*.
- Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Qual Saf Health Care*, *13*(3), 223-225.
- Doosjie, B., Ellemers, N., & Spears, R. (1995). Percieved intergroup variability as a function of group status and identification. *Journal of Experimental Social Psychology*, *31*(5), 410-436.
- Douglas, C., Windsor, C., & Wollin, J. (2008). Understanding chronic pain complicating disability: Finding meaning through focus group methodology. *Journal of Neuroscience Nursing*, *40*(3), 158-168.
- Doyle, L. H. (2003). Synthesis through meta-ethnography: paradoxes, enhancements, and possibilities. *Qualitative Research*, *3*(3), 321-344.
- Dumont, C. (2013). Identity. In J. H. Stone & M. Blouin (Eds.), *International Encyclopaedia of Rehabilitation*. Available online: <http://www.cirrie.buffalo.edu/encyclopedia/en/article/156/>.
- Dungan, J. M. (1997). Dungan model of dynamic integration. *Nursing Diagnosis*, *8*, 17-28.
- Dyck, I. (1995). Hidden geographies – The changing lifeworlds of women with multiple sclerosis. *Social Science & Medicine*, *40*(3), 307-320.
- Early, B. P., Smith, E. D., Todd, L., & Beem, T. (2000). The needs and supportive networks of the dying: an assessment instrument and

- mapping procedure for hospice patients. *American Journal of Hospice and Palliative Care*, 17, 87-96.
- Eisenstadt, D., & Leippe, M. R. (1994). The self-comparison process and self-discrepant feedback: Consequences of learning you are what you thought you were not. *Journal of Personality & Social Psychology*, 67, 611-626.
- Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation*, 17, 155-174.
- Filley, C. M., Franklin, G. M., Heaton, R. K., & Rosenberg, N. L. (1989). White matter dementia. *Neuropsychiatry, Neuropsychology, and Behavioural Neurology*, 5(5), 239-254.
- Fischer, J. S., LaRocca, N. G., Miller, D. M., Ritvo, P. G., Andrews, H., & Paty, D. (1999). Recent Developments in the assessment of quality of life in multiple sclerosis (MS). *Multiple Sclerosis*, 5(4), 251-259.
- Fisk, J. D., Ritvo, P. G., Ross, L., Haase, D. A., Marrie, T. J., & Schlech, W. F. (1994). Measuring the functional impact of fatigue: initial validation of the fatigue impact scale. *Clin Infect Dis*, 18(1), 79-83.
- Fleury, J. D. (1991). Empowering potential: a theory of wellness motivation. *Nursing Research*, 40, 286-291.
- Foley, F. W., Bedell, J. R., LaRocca, N. G., Scheinberg, L. C., & Reznikoff, M. (1987). Efficacy of stress-inoculation training in coping with multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 55(6), 919-922.
- Ford, H. L., Gerry, E., Tennant, A., Whally, D., Haigh, R., & Johnson, M. H. (2001). Developing a disease-specific quality of life measure for people with multiple sclerosis. *Clinical Rehabilitation*, 15(3), 247-252.
- Ford, D. V., Jones, K. H., Middleton, R. M., Lockhart-Jones, H., Maramba, I. D. C., Noble, G. J., . . . Lyons, R. A. (2012). The feasibility of collecting information from people with Multiple Sclerosis for the UK MS Register via a web portal: characterising a cohort of people with MS. *BMC Medical Informatics and Decision Making*, 12(73), 1-8.
- Ford, H. L., Gerry, E., Tennant, A., Whally, D., Haigh, R., & Johnson, M. H. (2001). Developing a disease-specific quality of life measure for people with multiple sclerosis. *Clinical Rehabilitation*, 15(3), 247-252.
- Forman, A. C., & Lincoln, N. B. (2010). Evaluation of an adjustment group for people with multiple sclerosis: a pilot randomized controlled trial. *Clinical Rehabilitation*, 24(3), 211-221.
- Freeman, M. (1992). Self as narrative: The place of life history in studying the life span. In T. M. Brinthaupt & R. P. Lipka (Eds.), *The self: Definitional and methodological issues* (pp. pp. 15-43). Albany: State of New York University.
- Frisch, J. U., Hausser, J. A., van Dick, R., & Mojzisch, A. (2014). Making support work: The interplay between social support and social identity. *Journal of Experimental Social Psychology*, 55(1), 154-161.
- Fruehwald, S., Loeffler-Stastka, H., Eher, R., Saletu, B., & Baumhackl, U. (2001). Depression and quality of life in multiple sclerosis. *Acta Neurologica Scandinavica*, 104(5), 257-261.

- Fydrich, T., Dowdall, D., & Chambless, D. L. (1992). Reliability and validity of the beck anxiety inventory. *Journal of Anxiety Disorders*, 6(1), 55-61.
- Galer, B. S., & Jensen, M. P. (1997). Development and preliminary validation of a pain measure specific to neuropathic pain - The Neuropathic Pain Scale. *Neurology*, 48(2), 332-338.
- George, M. S., Kellner, C. H., Berstein, H., & Goust, J. M. (1994). A magnetic resonance imagining investigation into mood disorders in multiple sclerosis: a pilot study. *The Journal of Nervous and Mental Disease*, 182(7), 410-412
- Gilchrist, A. C., & Creed, F. H. (1994). Depression, cognitive impairment and social stress in multiple sclerosis. *Journal of Psychosomatic Research*, 38(3), 193-201.
- Giordano, A., Ferrari, G., Radice, D., Randi, G., Bisanti, L., & Solari, A. (2012). Health-related quality of life and depressive symptoms in significant others of people with multiple sclerosis: A community study. *European Journal of Neurology*, 19(6), 847-854.
- Goffman, E. (1968). *Stigma: Notes on the Management of Spoiled Identity* Harmondsworth: Penguin.
- Goldberg, D. P. (1978). *Manual of the General Health Questionnaire*. Windsor, England: NFER Publishing.
- Goodin, D. S. (2010). The genetic basis of multiple sclerosis: a model for MS susceptibility. *BMC Neurology*, 10(101), 1-28.
- Green, G., Todd, J., & Pevalin, D. (2007). Biographical disruption associated with multiple sclerosis: using propensity scoring to assess the impact. *Soc. Sci. Med.*, 65(3), 524-535.
- Gustavsson, A., Svensson, M., Jacobi, F., Allgulander, C., Alonso, J., Beghi, E., . . . Oleson, J. (2011). Cost of disorders of the brain in Europe 2010. *European Neuropsychopharmacology*, 21, 718-779.
- Hakim, E. A., Bakheit, A. M. O., Bryant, T. N., Roberts, M. W. H., McIntosh-Michaelis, S. A., Spackman, A. J., . . . McLellan, D. L. (2000). The social impact of multiple sclerosis - a study of 305 patients and their relatives. *Disability and Rehabilitation*, 22(6), 288-293.
- Hartman, A. (1995). Diagrammatic assessment of family relationships *Families in Society* 76, 111.
- Haslam, C., Holme, A., Haslam, S. A., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation*, 18(5-6), 671-691.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology. *Applied Psychology-an International Review*, 58(1), 1-23.
- Hedges, L. V., & Olkin, I. (1985). *Statistical Methods for meta-analysis*. Orlando, Florida: University Press.
- Hedges, L. V., & Vevea, J. L. (1988). Fixed and random effects models in meta-analysis. *Psychological Methods*, 3, 486-504.
- Hermann, B. P., Vickrey, B., Hays, R. D., Cramer, J., Devinsky, O., Meader, K., . . . Ellison, G. W. (1996). A comparison of health-related quality of life in patients with epilepsy, diabetes and multiple sclerosis. *Epilepsy Research*, 25(2), 113-118.



- Hernandez, C. A. (1995). The development and testing of an instrument to measure integration in adults with diabetes mellitus. *Canadian Journal of Diabetes Care, 19*, 18-26.
- Hernandez, C. A. (1996). Integration: the experience of living with insulin (type 1) diabetes mellitus. *Canadian Journal of Nursing, 28*, 37-56.
- Higgins, E. T. (1987). Self-Discrepancy: A theory relating self and affect. *Psychological Review, 94*, 319-340.
- Higgins, J. P. T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]*
- Hind, D., Cotter, J., Thake, A., Bradburn, M., Cooper, C., Isaac, C., & House, A. (2014). Cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: a systematic review and meta-analysis. *BMC Psychiatry, 14*(5), 1-13.
- Hobart, J., Lamping, D., Fitzpatrick, R., Riazi, A., & Thompson, A. (2001). The Multiple Sclerosis Impact Scale (MSIS-29): A new patient-based outcome measure. *Brain, 124*(5), 962-973.
- Hogg, M. A., & Abrams, D. (1990). Social motivation, self-esteem and social identity. In D. Abrams & M. A. Hogg (Eds.), *Social Identity Theory: Constructive and critical advances* (pp. 28-47). New York: Harvester Wheatsheaf.
- Hogg, M. A., Terry, D. J., & White, K. M. (1995). A tale of two theories: A critical comparison of identity theory with social identity theory. *Social Psychology Quarterly, 58*(4), 255-269.
- Holmes, J. M., Ford, E., Yuill, F., Drummond, A. E., & Lincoln, N. B. (2012). Attendance at a psychological support group for people with multiple sclerosis and low mood. *Disability and rehabilitation, 34*(15), 1323-1327.
- Honarmand, K., & Feinstein, A. (2009). Validation of the Hospital Anxiety and Depression Scale for use with multiple sclerosis patients. *Multiple Sclerosis, 15*(1), 1518-1524.
- Honer, W. G., Hurwitz, Y., & Li, D. K. B. (1987). Temporal lobe involvement in multiple sclerosis patients with psychiatric disorders. *Archives of Neurology, 44*(187-190).
- Hunter, J. E., & Schmidt, F. L. (2004). *Methods of meta-analysis: Correcting error and bias in research findings* (2nd Edition ed.). Newbury Park, CA: Sage.
- Irvine, H., Davidson, C., Hoy, K., & Lowe-Strong, A. (2009). Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition. *Disability and Rehabilitation, 31*(8), 599-606.
- Iyer, A., Jetten, J., & Tsivrikos, D. (2008). Torn between identities: Predictors of adjustment to identity change. In F. Sani (Ed.), *Self-continuity: Individual and collective perspectives* (pp. 187-197). New York: Psychology Press.
- Jackson, C. (2007). The General Health Questionnaire. *Occupational Medicine, 57*(1), 79-80.
- Janardhan, V., & Bakshi, R. (2002). Quality of life in patients with multiple sclerosis: the impact of fatigue and depression. *Journal of Neurological Sciences, 205*(1), 51-58.

- Janoff-Bulman, R. (1992). *Shattered Assumptions – Towards a New Psychology of Trauma* Free Press.
- Janssens, A. C., van Doorn, P. A., de Boer, J. B., van der Meche, F. G., Passchier, J., & Hintzen, R. Q. (2003). Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurol Scand*, *108*(6), 389-395.
- Jetten, J., & Panchana, N. (2012). Not wanting to grow old; a social identity model of identity change (SIMIC) analysis of driving cessation among older adults. In Jetten J, Haslam AS, & Haslam C (Eds.), *The Social Cure: Identity, Health and Well-Being*. Hove & New York.: Psychology Press.
- Joffe, R. T., Lippert, G. P., Gray, T. A., Sawa, G., & Horvath, Z. (1987). Mood disorder and multiple sclerosis. *Archives of Neurology*, *44*(4), 376-378.
- Johnson, K., Starks, H., Morris, M., Yorkston, K., & Gray, R. (2010). Being in- or out-of-sync: A qualitative study of couples' adaptation to change in multiple sclerosis. *Disability and Health Journal*, *32*(3), 196-206.
- Jones, J. M., Haslam, A., Jetten, J., Williams, W. H., Morris, R., & Saroyan, S. (2011). That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychology and Health*, *26*(3), 353-369.
- Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*, *9*, 262-280.
- Kadriye, A., Korkmaz, C., Nilufer, K., Ilke, S., Vildan, I., & Irem Akbiyik, D. (2007). The validity and reliability of the Fatigue Severity Scale in Turkish multiple sclerosis patients. *International Journal of Rehabilitation Research*, *30*(1), 81-85.
- Kerns, R. D., Finn, P., & Haythornthwaite, J. (1988). Self monitored pain intensity: Psychometric properties and clinical utility. *Journal of Behavioural Medicine*, *11*(1), 71-82.
- Khanna, N. (2010). "If you're half black, you're just black": Reflected appraisals and the persistence of the one-drop rule. *Sociological Quarterly*, *51*, 96-121.
- Kikuchi, H., Mifune, N., Niino, M., Ohbu, S., Kira, J.-i., Kohriyama, T., . . . Kikuchi, S. (2011). Impact and characteristics of quality of life in Japanese patients with multiple sclerosis. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation.*, *20*(1), 119-131.
- Kosciulek, J. F. (1997). Relationship of Family schema to family adaptation. *Brain Injury*, *11*, 821-830.
- Kratz, A. L., Hirsh, A. T., Ehde, D. M., & Jensen, M. P. (2013). Acceptance of pain in neurological disorders: Associations with functioning and psychosocial well-being. *Rehabilitation Psychology. Vol.*, *58*(1), 1-9.
- Kreutzer, J., Kolakowsky-Hayner, S., Demm, S., & Meade, M. (2002). A structured approach to family intervention after brain injury. *Journal of Head Trauma Rehabilitation*, *17*, 349-367.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606-613.

- Krupp, L. B., LaRocca, N. G., Muir-Nash, J., & Steinberg, A. (1989). The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology*, *46*(10), 1121-1123.
- Kuhn, T. S. (1962). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Kurtzke, J. F., Beebe, G. W., Nagler, B., Kurland, L. T., & Auth, T. L. (1977). Studies on the natural history of multiple sclerosis—8. Early prognostic features of the later course of the illness. *Journal of Chronic Disease*, *30*(1), 819–830.
- Larcombe, N. A., & Wilson, P. H. (1984). An evaluation of cognitive-behaviour therapy for depression in patients with multiple sclerosis. *British Journal of Psychiatry*, *145*(OCT.), 366-371.
- Lawson, A., Robinson, I., & Bakes, C. (1985). Problems in evaluating the consequences of disabling illness: The case of multiple sclerosis. *Psychological Medicine*, *15*(3), 555-579.
- Levine, M., Cassidy, C., Brazier, G., & Reicher, S. (2002). Self-categorisation and bystander non-intervention: Two experimental studies. *Journal of Applied Social Psychology*, *7*, 1452–1463.
- Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Research and Audit* *4*(3), 324-327.
- Lewin, K. (1948). *Field theory in social science*. New York: Harper and Row.
- Lexell, E. M., Iwarsson, S., & Lund, M. L. (2011). Occupational Adaptation in People With Multiple Sclerosis. *Otjr-Occupation Participation and Health*, *31*(3), 127-134.
- Lexell, E. M., Lund, M. L., & Warsson, S. (2009). Constantly Changing Lives: Experiences of People With Multiple Sclerosis. *American Journal of Occupational Therapy*, *63*(6), 772-781.
- Liedstrom, E., Isaksson, A. K., & Ahlstrom, G. (2010). Quality of Life in Spite of an Unpredictable Future: The Next of Kin of Patients With Multiple Sclerosis. *Journal of Neuroscience Nursing*, *42*(6), 331-341.
- Lincoln, N. B., Yuill, F., Holmes, J., Drummond, A. E., Constantinescu, C. S., Armstrong, S., & Phillips, C. (2011). Evaluation of an adjustment group for people with multiple sclerosis and low mood: a randomized controlled trial. *Multiple Sclerosis*, *17*(10), 1250-1257.
- Linville, P. W. (1987). Self-complexity as a cognitive buffer against stress-related illness and depression. *Journal of Personality and Social Psychology*, *54*(2), 663-676.
- MacAllister, W. S., Boyd, J. R., Holland, N. J., Milazzo, M. C., & Krupp, L. B. (2007). The psychosocial consequences of pediatric multiple sclerosis. *Neurology*, *68*, S66-S69.
- Manne, S. (1999). Intrusive thoughts and psychological distress among cancer patients: The role of spouse avoidance and criticism. *Journal of Consulting and Clinical Psychology*, *67*(4), 539-546.
- Manne, S. L., Ostroff, J. L., Norton, T. R., Fox, K., Goldstein, L., & Grana, G. (2006). Cancer-related relationship communication in couples coping with early stage breast cancer. *Psycho-Oncology*, *15*(3), 234-247.
- Markus, H., & Nurius, P. (1986). Possible selves. *American psychologist*, *41*, 954-969.

- Marrie, R. A., Elliot, A., Marriott, J., Cossoy, M., Blanchard, J., Leung, S., & Yu, N. (2015). Effect of comorbidity on mortality in multiple sclerosis. *Neurology, 85*(1), 1-8.
- Marrie, R. A., Horowitz, R., Cutter, G., Tyry, T., Campagnolo, D., & Volmer, T. (2008). Comorbidity, socioeconomic status and multiple sclerosis. *Multiple Sclerosis, 14*(8), 1091-1098.
- Mathiowetz, V. (2003). Test-retest reliability and convergent validity of the Fatigue Impact Scale for persons with multiple sclerosis. *American Journal of Occupational Therapy, 57*(4), 389-395.
- Matthews, B., & Rice-Oxley, M. (2006). *Multiple Sclerosis: The Facts* (Fourth ed.). United States: Oxford University Press.
- Maurelli, M., Marchioni, E., Cerretano, R., Bosone, D., Bergamaschi, R., Citterio, A., . . . Savoldi, F. (1992). Neuropsychological assessment in MS - Clinical, neurophysiological and neuroradiological relationships. *Acta Neurologica Scandinavica, 86*(2), 124-128.
- McCabe, M. P. (2005). Mood and self-esteem of persons with multiple sclerosis following an exacerbation. *Journal of Psychosomatic Research, 59*(3), 161-166.
- McCabe, M. P., & Di Battista, J. (2004). Role of health, relationships, work and coping on adjustment among people with Multiple Sclerosis: A longitudinal investigation. *Psychology, Health & Medicine. Vol., 9*(4), 431-439.
- McCarty, C. (2002). Structure in personal networks *Journal of Social Structure*
- McDonald, I. W., Compston, A., Edan, G., Goodkin, D., Hartung, H., Lublin, F. D., . . . Wolinsky, J. S. (2001). Recommended Diagnostic Criteria for Multiple Sclerosis: Guidelines from the International Panel on the Diagnosis of Multiple Sclerosis. *Annals of Neurology, 50*(1), 121-127.
- McGuigan, C., & Hutchinson, M. (2004). The multiple sclerosis impact scale (MSIS-29) is a reliable and sensitive measure. *Journal of Neurology, Neurosurgery and Psychiatry, 75*(2), 266-269.
- McIvor, G. P., Ricklan, M., & Reznikoff, M. (1984). Depression in multiple sclerosis as a function of length and severity of illness, age, remissions, and perceived social support. *Journal of Clinical Psychology, 40*(4), 1028-1033.
- McLaughlin, J., & Zeeberg, I. (1993). Self-care and multiple sclerosis: A view from two cultures. *Social Science & Medicine, 37*(3), 315-329.
- McNair, D. M., Lorr, M., & Droppelman, L. F. (1971). *Manual for the Profile of Mood States*. San Diego: Educational and Industrial Testing Services.
- McNulty, S. E., & Swann, W. B. (1994). Identity negotiation in roommate relationships: The self architect and consequence of social reality. *Journal of Personality and Social Psychology, 67*, 1012-1023.
- Medich, C. J., Stuart, E., & Chase, S. K. (1997). Healing through integration: promoting wellness in cardiac rehabilitation. *Journal of Cardiovascular Nursing, 11*, 66-79.
- Melzack, R. (1975). The McGill Pain Questionnaire: major properties and scoring methods. *Pain, 1*(3), 277-299.

- Mills, R. J., Young, C. A., Nicholas, R. S., Pallant, J. F., & Tennant, A. (2009). Rasch analysis of the Fatigue Severity Scale in multiple sclerosis. *Multiple Sclerosis, 15*(9), 81-87.
- Minden, S. L. (2000). Mood disorders in multiple sclerosis: diagnosis and treatment. *Journal of Neurovirology, 6*(Sup2), 160-167.
- Minden, S. L., Orav, J., & Reich, P. (1987). Depression in multiple sclerosis. *General Hospital Psychiatry, 9*(6), 426-434.
- Minden, S. L., & Schiffer, R. B. (1991). Depression and mood disorders in multiple sclerosis. *Neuropsychiatry Neuropsychol Behav Neurol, 4*(1), 62-77.
- Mohr, D. C., Boudewyn, A. C., Goodkin, D. E., Bostrom, A., & Epstein, L. (2001). Comparative outcomes for individual cognitive-behaviour therapy, supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consulting and Clinical Psychology, 69*(6), 942-949.
- Mohr, D. C., Burke, H., Beckner, V., & Merluzzi, N. (2005). A preliminary report on a skills-based telephone-administered peer support programme for patients with multiple sclerosis. *Multiple Sclerosis, 11*(2), 222-226.
- Mohr, D. C., Dick, L. P., Russo, D., Likosky, W., Pinn, J., Boudewyn, A. C., & Goodkin, D. E. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology, 18*(4), 376-382.
- Mohr, D. C., Goodkin, D. E., & Likosky, W. (1997). Identification of Beck Depression Inventory items related to multiple sclerosis. *Journal of Behavioural Medicine, 20*(1), 407-414.
- Mohr, D. C., Goodkin, D. E., Likosky, W., Gatto, N., Baumann, K. A., & Rudick, R. A. (1997). Treatment of depression improves adherence to interferon beta-1b therapy for multiple sclerosis. *Archives of Neurology, 54*(5), 531-533.
- Mohr, D. C., Hart, S. L., Julian, L., Catledge, C., Honos-Webb, L., Vella, L., & Tasch, E. T. (2005). Telephone-administered psychotherapy for depression. *Archives of General Psychiatry, 62*(9), 1007-1014.
- Mohr, D. C., Likosky, W., Bertagnolli, A., Goodkin, D. E., Van Der Wende, J., Dwyer, P., & Dick, L. P. (2000). Telephone-administered cognitive-behavioural therapy for the treatment of depressive symptoms in multiple sclerosis. *Journal of Consulting and Clinical Psychology, 68*(2), 356-361.
- Mokhtari, S., Neshatdoost, H. T., & Molari, H. (2013). The effect of cognitive behavioural therapy on depression and somatic complaints of multiple sclerosis patients. In C. M. See & M. L. Y. Ng (Eds.), *Conselling in the new frontier of helping* (pp. 100-105): USM Press.
- Moller, A., Wiedman, G., Rohde, U., Backmund, H., & Sonntag, A. (1994). Correlates of cognitive impairment and depressive mood disorder in multiple sclerosis. *Acta Psychiatrica Scandinavica 89*, 117-121.
- Molton, I., Johnson, K., McMullen, K., Yorkston, K., & Jensen, M. (2010). Ageing with multiple sclerosis: Pathways of change, a focus group study. *Multiple Sclerosis, 1*(1), S182.
- Moran, P. J., & Mohr, D. C. (2005). The Validity of Beck Depression Inventory and Hamilton Rating Scale for Depression Items in the assessment of

- depression among patients with multiple sclerosis. *Journal of Behavioural Medicine*, 28(1), 35-41.
- Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research*, 40(2), 120-123.
- Moss-Morris, R., Dennison, L., & Chalder, T. (2010). *Supportive Adjustment for Multiple Sclerosis (saMS): An eight-week CBT programme manual*.
- Multiple Sclerosis Society. (2007). Caring for someone with MS: A handbook for family and friends. In M. S. Society (Ed.), (Second Edition ed.).
- Munger, K. L., Zhang, S. M., O'Reily, E., Harnan, M. A., Olek, M. J., Willett, W. C., & Asherio, A. (2004). Vitamin D intake and incidence of multiple sclerosis. *Neurology*, 62(1), 60-65.
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S. & Watson, P. (2008). Qualitative research methods in health technology assessment: A review of the literature. *Health Technology Assessment*, 2(16), 1-274
- Mykletin, A., Eystein, S., & Dahl, A. A. (2001). Hospital Anxiety and Depression (HAD) Scale: factor structure, item analyses and internal consistency in a large population. *British Journal of Psychiatry*, 179(1), 540-544.
- Neisser, U. (1993). *The perceived self: Ecological and personal sources of self knowledge*. New York: Cambridge University Press.
- Noblit, G. W., & Hare, R. D. (1988). *Meta-Ethnography: Synthesizing Qualitative Studies*: SAGE Publications.
- Nordin, L., & Rorsman, I. (2012). Cognitive behavioural therapy in multiple sclerosis: a randomized controlled pilot study of acceptance and commitment therapy. *Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine*, 44(1), 87-90.
- Northouse, L. L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41, 69-76.
- Noy, S., Achiron, A., Gabbay, U., Barak, Y., Rotstein, Z., Laor, N., & Sarova-Pinhas, I. (1995). A new approach to affective symptoms in relapsing-remitting multiple sclerosis. *Compr Psychiatry* 36(5), 390-395.
- Nyenhuis, D. L., Rao, S. M., & Zajacka, J. M. (1995). Mood disturbance versus other symptoms of depression in multiple sclerosis. *Journal of International Neuropsychology*, 1(1), 291-296.
- O Donnchadha, S., Burke, T., Bramham, J., O'Brien, M. C., Whelan, R., Reilly, R., . . . Tubridy, N. (2013). Symptom overlap in anxiety and multiple sclerosis. *Multiple Sclerosis*, 19(10), 1349-1354.
- Ostacoli, L., Carletto, S., Borghi, M., Cavallo, M., Rocci, E., Zuffranieri, M., . . . Picci, R. L. (2012). Prevalence and significant determinants of post-traumatic stress disorder in a large sample of patients with multiple sclerosis. *Journal of Clinical Psychology*, 20(2), 240-246.
- Owensworth, T. (2014). *Self-Identity after brain injury*. London & New York: Psychology Press.
- Oyserman, D. (2007). Social identity and self regulation. In A. W. Kruglanski & E. T. Higgins (Eds.), *Social psychology: Handbook of basic principles* (2nd Edition ed., pp. 432-453). New York: Guildford Press.

- Oyserman, D. (2009a). Identity-based motivation: Implications for action-readiness, procedural-readiness, and consumer behaviour. *Journal of Consumer Psychology, 19*, 276-279.
- Oyserman, D. (2009b). Identity-based motivation and consumer behaviour: Response to commentary. *Journal of Consumer Psychology, 19*, 276-279.
- Pakenham, K. I. (1999). Adjustment to multiple sclerosis: application of a stress and coping model. *Health Psychology, 18*(4), 383-392.
- Pakenham, K. I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine, 6*(1), 13-27.
- Pakenham, K. I. (2001). Coping with multiple sclerosis: Development of a measure. *Psychology, Health & Medicine. Vol., 6*(4), 411-428.
- Pakenham, K. I. (2002). Development of a measure of coping with multiple sclerosis caregiving. *Psychology & Health, 17*(1), 97-118.
- Pakenham, K. I., & Cox, S. (2012). Test of a model of the effects of parental illness on youth and family functioning. *Health Psychology. Vol., 31*(5), 580-590.
- Pakenham, K. I., Stewart, C. A., & Rogers, A. (1997). The role of coping in adjustment to multiple sclerosis-related adaptive demands. *Psychology, Health and Medicine, 2*(3), 197-211.
- Paliokosta, E., Diareme, S., Kolaitis, G., Tsalamani, E., Ferentinos, S., Anasontzi, S., . . . Romer, G. (2009). Breaking Bad News: Communication Around Parental Multiple Sclerosis With Children. *Families Systems & Health, 27*(1), 64-76.
- Pannebaker, J. W., & Seagal, J. D. (1999). Forming a Story: The Health Benefits of Narrative. *Journal of Clinical Psychology, 55*(10), 1243-1254.
- Pelletier, L. G., Dion, S., Tuson, K. M., & Green-Demers, I. (1999). Why do people fail to adopt environmental behaviours?: Towards a taxonomy of environmental amotivation. *Journal of Applied Social Psychology, 29*, 2481-2504.
- Pender, M. P., & Burrows, S. R. (2014). Epstein-Barr virus and multiple sclerosis: potential opportunities for immunotherapy. *Clinical & Translational Immunology, 3*(e27), 1-11.
- Pfennings, L. E., Van der Ploeg, H. M., Cohen, L., Bramsen, I., Polman, C. H., & Lankhorst, G. J. (1999). A health-related quality of life questionnaire for multiple sclerosis patients. *Acta Neurologica Scandinavica, 100*(3), 148.
- Polman, C. H., Reingold, S. C., Banwell, B., Clanet, M., Cohen, J. A., Filippi, M., . . . Wolinski, J. S. (2011). Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria. *Annals of Neurology, 69*(2), 292-302.
- Poser, S., Wikstrom, J., & Bauer, H. J. (1979). Clinical data and the identification of special forms of multiple sclerosis in 1271 cases studied with a standardized documentation system. *Journal of Neurological Science, 40*(1), 159-168.
- Pugliatti, M., Sotgiu, S., & Rosati, G. (2002). The worldwide prevalence of multiple sclerosis. *Clinical Neurology and Neurosurgery, 104*(3), 182-191.

- Pujol, J., Bello, J., Deus, J., Marti-Vilalta, J. L., & Capdevila, A. (1997). Lesions in the left arcuate fasciculus region and depressive symptoms in multiple sclerosis. *Neurology*, *49* (4), 1105-1110.
- Quaranta, D., Marra, C., Zinno, M., Patanelaa, A. K., Messina, M. J., & Piccininni, C. (2012). Presentation and validation of the multiple sclerosis depression rating scale: a test specifically designed to investigate affective disorders in multiple sclerosis patients. *Clinical Neuropsychology*, *26*(4), 571-587.
- Ray, R. A., & Street, A. F. (2005). Ecomapping: an innovative research tool for nurses. *Methodological Issues in Nursing Research*, *50*(5), 545-552.
- Rabins, P. V., & Brooks, B. R. (1981). Emotional disturbance in multiple sclerosis patients: The validity of the General Health Questionnaire (GHQ). *Psychological Medicine*, *11*(2), 425-427.
- Rabins, P. V., Brooks, B. R., O'Donnell, P., Pearlson, G. D., Moberg, P., Jubelt, B., . . . Folstein, M. F. (1986). Structural brain correlates of emotional disorder in multiple sclerosis. *Brain*, *109*(4), 585-597.
- Reed, P. G. (1997). Nursing: The ontology of the discipline. *Nursing Science Quarterly*, *10*(1), 76-79.
- Riazi, A., Bradshaw, S. A., & Playford, E. D. (2012). Quality of life in the care home: A qualitative study of the perspectives of residents with multiple sclerosis. *Disability Rehabilitation*, *34*(24), 2095-2102.
- Ricoeur, P. (1991). Life in quest of narrative. In D. Wood (Ed.), *On Paul Ricoeur: Narrative and interpretation* (pp. 20-33). London: Routledge.
- Rigby, S. A., Domenech, C., Thornton, E. W., Tedman, S., & Young, C. A. (2003). Development and validation of a self-efficacy measure for people with multiple sclerosis: the Multiple Sclerosis Self-efficacy Scale. *Multiple Sclerosis*, *9*(1), 73-81.
- Robinson, I. (1990). Personal narratives, social careers and medical courses – Analyzing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine*, *30*(11), 1173-1186. s
- Rodgers, J., & Bland, R. (1996). Psychiatric Manifestations of Multiple Sclerosis: A Review. *Canadian Journal of Psychiatry*, *41*(1), 441-445.
- Rog, D., Burgess, M., Mottershead, J., & Talbot, P. (2010). *Multiple Sclerosis* (Second ed.). London: Class publishing Ltd.
- Rog, D. J., Nurmikko, T. J., Friede, T., & Young, C. A. (2007). Validation and reliability of the neuropathic pain scale in multiple sclerosis. *Clinical Journal of Pain*, *23*(6), 473-481.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ.: University Press.
- Rotstein, Z., Barak, Y., Noy, S., & Achiron, A. (2000). Quality of life in multiple sclerosis: development and validation of the 'RAYS' scale and comparison. *International Journal for Quality in Health Care*, *12*(6), 511-517.
- Roy-Bellina, S., Moitrelle, C., Camu, W., & Gely-Nargeot, M. C. (2009). Psychopathology in multiple sclerosis: Coping strategies, representation of the disease, locus of control and social support. *Journal of Neurology*, *256*, S236.
- Ryan, R. M. (1995). Psychological needs and the facilitation of integrative processes. *Journal of Personality*, *63*, 397-427.



- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*, 68-78.
- Sabatini, U., Pozzilli, C., Pantano, P., Koudriavtseva, T., Padovani, A., Millerorini, E., . . . Lenzi, G. L. (1996). Involvement of the limbic system in multiple sclerosis patients with depressive disorders. *Biological Psychiatry*, *39*(11), 970-975.
- Sadovnick, A. D., Remick, R. A., Allen, J., Swartz, E., Yee, I. M., Eisen, K., . . . Paty, D. W. (1996). Depression and multiple sclerosis. *Neurology*, *46*(3), 628-632.
- Sadovnik, A. D., Eisen, K., Ebers, G. C., & Paty, D. W. (1991). Cause of death in patients attending multiple sclerosis clinics. *Neurology*, *41*(8), 1193-1196.
- Saks, M., & Allsop, J. (2007). *Researching Health: Qualitative, Quantitative and Mixed Methods* Sage.
- Salter, K.A. (2008). The experience of living with stroke: A qualitative meta-synthesis. *Journal of Rehabilitation Medicine*, *40*(1), 595-602
- Sandelowski, M., Docherty, S., & Emden, C. (1998). Focus on qualitative methods. Qualitative meta-synthesis: Issues and techniques. *Research in Nursing and Health*, *20*(4), 365-371
- Santuzzi, A. M., & Ruscher, J. B. (2002). Stigma saliance and paranoid social cognition: Understanding variability in meta-perceptions among individuals with recently acquired stigma. *Social Cognition*, *20*(3), 171-197.
- Schiffer, R. B., & Caine, E. D. (1991). The interaction between depressive affective disorder and neuropsychological test performance in multiple sclerosis patients *The Journal of Neuropsychiatry and Clinical Neuroscience*, *38*, 28-32.
- Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. Wright, & M. Johnston (Eds.), *Measures in health psychology: A user's portfolio. Causal and control beliefs* (pp. 35-37). Windsor, UK: NFER-NELSON.
- Schwid, S. R., Covington, M., Segal, B. M., & Goodman, A. D. (2002). Fatigue in multiple sclerosis: current understanding and future directions. *Journal of Rehabilitation Research and Development*, *39*(2), 211-224.
- Scott, T. F., Allen, D., Price, T. R., McConnell, H., & Lang, D. (1996). Characterization of major depression symptoms in multiple sclerosis patients. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *8*(3), 318-323.
- Shacham, S. (1983). A shortened version of the profile of mood states. *Journal of personality Assessment*, *47*(3), 305-306.
- Sherwood, G. (1997). Meta-synthesis: merging qualitative studies to develop nursing knowledge. *Int J Human Caring*, *3*(1), 37-42.
- Showers, C. J., & Kling, K. C. (1996). Organization of self knowledge: Implications for recovery from sad mood. *Journal of Personality and Social Psychology Bulletin*, *22*, 448-460.
- Siegert, R. J., & Abernethy, D. A. (2005). Depression in multiple sclerosis: A review. *Journal of Neurology, Neurosurgery and Psychiatry*, *76*(4), 469-475.

- Simeoni, M., Auquier, P., & Fernandez, O. (2008). Validation of the Multiple Sclerosis International Quality of Life questionnaire. *Multiple Sclerosis, 14*(2), 219–230.
- Sinclair, S. J., Blais, M. A., Gansler, D. A., Sandberg, E., Bistis, K., & LoCiccero, A. (2010). Psychometric properties of the Rosenberg Self-Esteem Scale: Overall and across demographic groups living in the United States. *Evaluation and the Health Professions 33*(1), 56-80.
- Singer, J. A., & Rexhaj, B. (2006). Narrative coherence and psychotherapy: A commentary. *Journal of Constructivist Psychology, 19*(2), 209-217.
- Sjonnesen, K., Berzins, S., Fiest, K. M., Bulloch, A. G., Metz, L. M., & Thombs, B. D. (2012). Evaluation of the 9-item Patient Health Questionnaire (PHQ-9) as an assessment instrument for symptoms of depression in patients with multiple sclerosis. *Postgraduate Medicine, 124*(5), 169-177.
- Skar, A. B., Smedal, T., & Torkildsen, N. G. (2012). Recognition of self and identity is important for empowerment - A focus group-study in multiple sclerosis rehabilitation (#82). *Multiple Sclerosis, 18* (5), S58.
- Smith, G. (2012). *Psychosocial interventions in mental health nursing*. UK: University Press.
- Solari, A., Mattarozzi, K., Vignatelli, L., Giordano, A., Russo, P. M., Uccelli, M. M., . . . Grp, G. (2010). Development and validation of a patient self-assessed questionnaire on satisfaction with communication of the multiple sclerosis diagnosis. *Multiple Sclerosis, 16*(10), 1237-1247.
- Spielberger, C. D., Gorssuch, R. L., Lushenne, P. R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the State-Trait Anxiety Inventory*: Consulting Psychologists Press, Inc.
- Spielberger, C. D., & Vagg, P. R. (1984). Psychometric properties of the STAI: a reply to Ramanaiah, Franzen, and Schill. *Journal of Personality Assessment, 48*(1), 95-97.
- Stenager, E., Knudsen, L., & Jensen, K. (1994). Multiple sclerosis: correlation of anxiety, physical impairment and cognitive dysfunction. *The Italian Journal of Neurological Sciences 15*(2), 97-101.
- Stets, J. E., & Burke, P. J. (2003). A sociological approach to self and identity. In M. R. Leary & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 128-152). New York: Guilford Press.
- Stryker, S. (1980). *Symbolic interactionism: A social structural version*. Menlo Park, CA: Benjamin Cummings.
- Stuart, D. C., & Sullivan, T. J. (1982). Illness behaviour and the sick role in chronic illness - The case of multiple sclerosis. *Social Science & Medicine, 16*(15), 1397-1404.
- Stuifbergen, A. K., Seraphine, A., & Roberts, G. (2000). An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nursing Research, 60*(2), 122-129.
- Tajfel, H. (1981). *Human groups and social identity*. Cambridge, UK: Cambridge University Press.
- Taylor, S. E. (2011). Social support: A Review. In M. S. Friedman (Ed.), *The Handbook of Health Psychology* (pp. 189–214). New York: Oxford University Press.

- Tedman, B. M., Young, C. A., & Williams, I. R. (1997). Assessment of depression in patients with motor neuron disease and other neurologically disabling illness. *J Neurol Sci* 152 (Suppl 1), S75-S79.
- The MS Trust. (2014). A short guide to making sense of my MS <http://www.mstrust.org.uk/downloads/a-short-guide-to-understanding-my-ms.pdf> (pp. 1-6). <http://www.mstrust.org.uk>: The MS Trust.
- The National Multiple Sclerosis Society. (2013a). MSQLI. Retrieved from <http://www.nationalmssociety.org/ms-clinical-care-network/researchers/clinical-study-measures/msqli/index.aspx> website:
- The National Multiple Sclerosis Society. (2013b). MSQOL-54. Accessed 06/02/2013. Retrieved from <http://www.nationalmssociety.org/ms-clinical-care-network/researchers/clinical-study-measures/msqol-54/index.aspx> website:
- Thomas, P. W., Thomas, S., Hillier, C., Galvin, K., & Baker, R. (2006). Psychological interventions for multiple sclerosis. *Cochrane database of systematic reviews (Online)*(1), CD004431.
- Thompson, A. J., Hutchinson, M., Brazil, J., Feighery, C., & Martin, E. A. (1986). A clinical and laboratory study of benign multiple sclerosis. *QJM: An International Journal of Medicine*, 58(1), 69–80.
- Till, C., Udler, E., Ghassemi, R., Narayanan, S., Arnold, D. L., & Banwell, B. L. (2012). Factors associated with emotional and behavioural outcomes in adolescents with multiple sclerosis. *Multiple Sclerosis*, 18(8), 1170-1180.
- Tracy, E. M., Whittaker, J. K., Pugh, A., Kapp, S. N., & Overstreet, E. J. (1994). Support networks of primary caregivers receiving family preservation services: an exploratory study. *Families in Society* 75, 481-489.
- Tromp, C. (2006). Multiple Sclerosis, psychological problems and interventions. Between autonomy and dependency. *Gedrag & Gezondheid: Tijdschrift voor Psychologie en Gezondheid. Vol.*, 34(5), 363-373.
- Tsolaki, M., Drevelegas, A., Karachristianous, Kapinas, K., Divanoglou, D., & Routsonis, K. (1994). Correlation of dementia, neuropsychological and MRI findings in multiple sclerosis. *Dementia*, 5(1), 48-52.
- Vickery, B. G., Hays, R. D., Harooni, R., Myers, L. W., & Ellison, G. W. (1995). A health-related quality of life measure for multiple sclerosis. *Quality of Life Research*, 4(3), 187-206.
- Wade, S. L., Cassedy, A., Walz, N. C., Taylor, H. G., Stancin, T., & Yeates, K. O. (2011). The relationship of parental warm responsiveness and negativity to emerging behaviour problems following traumatic brain injury in young children. *Developmental Psychology*, 47, 119-133.
- Wallace, H. M., & Tice, D. M. (2012). Reflected Appraisal through a 21st-Century Looking Glass. In M. R. Leary & J. P. Tangney (Eds.), *Handbook of Self and Identity* (Second ed.). New York: The Guilford Press.
- White, H. (1987). *The Content of the Form: Narrative Discourse and Historical Representation*. Baltimore: The John-Hopkins University Press.
- Whitlock, F. A., & Siskind, M. M. (1980). Depression as a major symptom of multiple sclerosis. *J Neurol Neurosurg Psychiatry* 43(10), 861-865.

- Whittemore, R. (2005). Analysis of integration in nursing science and practice. *Journal of Nursing Scholarship, 37*, 261-267.
- Whittemore, R., Chase, S. A., Mandle, C. A., & Roy, C. (2002). Lifestyle change in type 2 diabetes: a process model. *Nursing Research, 51*, 18-25.
- Whittemore, R., & Dixon, J. (2008). Chronic illness: the process of integration. *Journal of Clinical Nursing, 17*(0), 177-187.
- Wilkinson, H., & Das Nair, R. (2013). The Psychological Impact of Living with an Unpredictable Illness: A Meta-Synthesis of Qualitative Research Literature in Multiple Sclerosis. *British Journal of Neuroscience Nursing, 9*(4), 172-178.
- Wilkinson, H. R., & das Nair, R. (2013). The psychological impact of the unpredictability of multiple sclerosis: a qualitative literature meta-synthesis. *British Journal of Neuroscience Nursing, 9*(4), 172-178.
- Wineman, N. M. (1990). Adaptation to multiple sclerosis – The role of social support, functional disability, and perceived uncertainty. *Nursing Research, 39*(5), 294-299.
- Wright, L. M., & Leahey, M. (2000). *Nurses and Families: A Guide to Family Assessment and Intervention*. Philadelphia, PA.: FA Davis Co.
- Zajicek, J., Freeman, J., & Porter, B. (2007). *Multiple Sclerosis Care: A Practical Manual*. United States: Oxford University Press.
- Zeldow, P. B., & Pavlou, M. (1984). Physical disability, life stress, and psychosocial adjustment in multiple sclerosis. *Journal of Nervous and Mental Disease, 172*(2), 80-84.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370.
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment, 52*, 30-41.
- Zorzon, M., deMasi, R., Nasuelli, D., Ukmar, M., Mucelli, R. P., & Cazzato, G. (2001). Depression and anxiety in multiple sclerosis. A clinical and MRI study in 95 subjects. *J Neurol, 248*(5), 416-421.

## **Appendix 1: Interview Schedule**

### **MS Interview Themes**

#### **1) How found the intervention**

- i. What do you feel you gained from taking part?
- ii. Content/format – relational aspect
- iii. What do you feel were the strengths of being part of a (group/individual) intervention?
- iv. Did you have a preference of group or individual beforehand?

#### **2) Social group memberships**

- i. Eco-mapping – relationship, strength, type of support, direction, frequency, changes

#### **3) Degree of identification with social groups (including intervention)**

#### **4) Impact of social groups and changes on emotional adjustment**

## **Appendix 2: Example Transcript**

### **From Participant CS**

I: Ok so erm, just to begin with, how, how did you find the intervention?

R: Alright

I: Yeah?

R: Yeah

I: Ok erm, ...

R:...I wonder if I was, I wasn't relapsing...

I: ...Yeah...

R: ...and Im currently on Mat Leave (Maternity), so all the things that would affect me normally, didn't so it was a bit of a...

I:...yeah....

R:...wasn't the right time to be doing it but I suppose you cant really choose when to do it...

I:...yeah...

R:...if youre going to be put through to research, that was the only thing that I really found it was a bit pointless because I wasn't in the...

I:...yeah....

R:...do you know what I mean? I wasn't in the place to be having MS problems or at work so got outside influences causing your problems.

I: Ok, erm, was there any aspects of the content or the format that you found worked well or didn't work well?

R: I think, im not, im not one for turning the smile upside down...

I:...yeah...

R:...looking at my negative thoughts and making, im just not what it, so, yeah it was alright.

### Appendix 3: One Theme

#### All quotes on sub-theme: family support

##### Family Support

P	260-261	My family, they are pretty much as they've always been so...	Still part of family – secure base
P	131-133	Friends and family, well theres my wife, (Name), obviously, I tell her the majority of things or ask her questions around different things..	Talks to wife most – more comfortable? Proximity?
KB	148-151	I've only got the one sister and she's just being a nightmare. She's drunk herself into a state of dementia. She caused an awful lot of problems over the last few years, awful, awful lot and caused a lot of stress.	Family support not always useful or provided, can lead to worse coping, a lot of problems. Coping needs to be aligned?
KB	219-222	. We've always been quite a close family without actually seeing each other very often. But when there's any kind of a crisis everybody just pulls together.	Perceived family support is used for coping. Family pulls together in a crisis to support. SIMIC
KF	238-	Theres an element of it where I have	Feels an expectation to

	242	to be slightly careful because....erm....although they will, I think they get quite upset if I dont share things with them, but then on the other hand if I share something about having a bad day I know that that can upset them	share and receive support with parents but doesn't want to upset them, open dialogue aligned support needed.
JT	195	"It breaks my mums heart, I know it does"	May not choose to receive family support due to unintentional guilt MS has caused
JK	193-194	"They're being great at the moment in helping me deal with it."	Family is a source of positive coping. Support whilst she "deals" with it
CS	97-101	"Immediate family have to spend time with me no matter what.....what mood im in, and whats going on yeah, that's the best support there is..."	The family is always there to provide support and this is seen as a good thing
KB	331-341-342	"Yes, theyre always there for me if I need them" "But hes doing his thing so he cant be there all the time, hes there when I need him"	Family are seen as a constant source of support, theyre always there, this is a perceived support
BD	114-116-190-191	"(Ok, so erm, are, are there any important groups or people that you can think of?) err, well family and friends really" "well you need somebody you can, in any walk of life you need somebody to ring up and whinge at or..."	Family and friends are important to the participant. Family (brother) are seen as a source of perceived social support.
BD	351-353-354-362-363	"I'd say 3, the same..." "But I spent most of the time away, but when you was home, you know exactly the same" "Err, excellent because I knew I could ring, [name], my brother, I could ring him up"	Perceived support is important
K3	252-267	"And the games maid said, 'Do you want a wheelchair?', and I said, 'No. I'm alright.' And walking across the grass they had put matting on it so you could walk on it. And then we went to the actual...the next day we went to the Olympic Park, and the distance was so vast there and as you go in there there was a thing saying for disability you could have	Family accepted the wheelchair use in a friendly unjudgemental manner. Made the participant feel that the wheelchair use is less stigmatised than she had imagined.



		<p>hired one of those little motorised chairs. It was fantastic. That's really amazing; because I had never used one before. And I thought, 'Oh, gosh! Trust me to get introduced to...baptism of fire with crowds of people trying to control this thing' - but it was great. My daughters quite liked it and the...I think she Facebooked me a picture of me in this thing. 'Yusain Bolt, eat your heart out. [name] is on the way', sort of thing. So we laughed at it. And that was great and I had a good time so...it makes me realise that things are available there to help and in the past I haven't utilised them because I'm quite independent and haven't utilised what's available."</p>	
K3	368-373	<p>"In fact I didn't tell my daughters until after they had done their A levels and were at university because I didn't want to upset them.</p> <p>I: Right. Okay.</p> <p>R: But they haven't known that long actually. I've had it 11 years. They've only known for the past five years.</p> <p>"</p>	<p>Friends were important because she didn't want to upset her family, instead opened up to family when she felt ready.</p>
K2	93-97 118-120	<p>"Um, because it's like...I was like really, really lucky because like my family, like my parents and my boyfriend have been like incredibly supportive and like my friends and everything, but they don't have it themselves so they can't understand it cos they can't totally like get into my head or anything so..."</p> <p>"at the moment, I'm living with my parents again and I've got everything that's...like all the support network</p>	<p>The participant sees the family as being more understanding and supportive than friends. Family is a really supportive environment for the participant</p>

		that I need really. “	
K2	574-584	I just went back for like a year [I: yeah] and my boyfriend...it's like when I first became ill... like, how it happened is like I lost all feeling in my whole body [I: right] and apparently I was like dragging my feet and stuff. So, um, my boyfriend, um, called my mum and she was like, 'Bring [name N] back home now.' So he drove down there and picked me up and everything and so him he was like, 'Oh no. You're not going back to [city 1] now'. Cos they just wanted to like look after me and everything. And I was just like, 'I need to go back for like at least a year because how am I going to like find another job if...', because I couldn't even remember my job. I had no idea what I did or anything.	The family wanted to look after her when she first became ill, first support available.
K2	645-650	“Yeah. If it wasn't for parents, fiancé and my [city2] friends I don't know where I'd be. Especially like parents and fiancé obviously. “	Family are really important cant imagine not having their support
K2	1025-1027 1031-1033	“Then for my brother it's like...he doesn't want, he doesn't like me having a blue badge or anything or like a bus pass or anything like that because it's like, I'm like his little sister.” “So for him it's like...he's like really like struggled coming to terms with it and I think he still hasn't come to terms with it.”	Family members can struggle with the identity change – coping needs to be aligned in the family group
K1	56-59	“I was able to get some feedback from my sisters. Because all the relationships I have had is with the support of my six sisters. I don't think I would be here without them, so they've been an amazing support system.”	Family is a very important source of support for the participant.
K1	203-211 221-223	“I think the support has reduced somewhat, because, erm, about three years ago I was dependent upon everyone for everything, I: Mmm	Support may have reduced due to coming to terms and adjusting, however, support is still perceived to be there.

		<p>R: so that was literally everything. But now not so much. But I know they are there so if I do need something I ask them.</p> <p>I: Yes.</p> <p>R: But I think the support system has gone down so much. I don't really ask so much now; because I'm into...I've got a car, which is a big thing for me. Because I wasn't able to drive for two years."</p> <p>"Because I used to live with my parents when I was poorly, very poorly, and I have moved back to my house, again, which has kind of made me independent."</p>	
K1	96-99	<p>"doctors can only sympathise, they can't empathise. And that was a big thing for me to be able to talk about experiences, because I can't talk about that with my sisters cos they haven't got a clue what I go through:"</p>	<p>Group interventions are more important once a person has come to terms with their diagnosis. Family is useful for initial support, however, people seek out people who have had similar experiences following the exacerbation of symptoms.</p>

## **Appendix 4: Invitation to Participate**

**[TO BE PRINTED ON TRUST HEADED PAPER]**

*Participant Address*

*Trust Address*

*Date*

Dear (*Participants name*),

### **RE: Multiple Sclerosis Research Project Invitation**

We are contacting you to invite you to take part in a research study being undertaken in partnership with the University of Nottingham. We are investigating whether mood is impacted by changes to the

groups people with MS are part of (e.g. work, family, friendship, common interest groups).

You have been invited to take part because you have a diagnosis of multiple sclerosis. We are sending this invitation letter to all those who have been attending clinics in Leicester and are 18 years or over. We are also inviting people to take part through the MS Society website.

Please read through the Participant Information Sheet, which provides more detailed information about the study, If you would like to contribute to the research please then complete the enclosed questionnaires and return them in the pre-paid envelope provided. The questionnaires will ask you about the groups you belong to, the support you receive, your mood and how you feel others see you. They are anonymous and should take no more than 20 minutes to complete.

If you have any questions please feel free to contact Professor Nadina Lincoln, as outlined in the enclosed information sheet.

Thank you in advance,

Yours sincerely,

Dr Nikfekar Esmail

## **Appendix 5: Information for Participants**



### **PARTICIPANT INFORMATION SHEET** (Version 1.1: 22.04.2014)

### **Investigation of social identity and mood in people with multiple sclerosis**

**REC ref: 14/LO/0703**

**Name of Researchers:** Professor Nadina Lincoln Kathryn  
Smale Dr Roshan das Nair  
Alex Barker Dr Nigel Hunt

**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. Please take time to read the following information carefully and discuss it with others if you wish. Please contact us if there is anything that is not clear, or if you would like more information.

**What is the purpose of the study?**

Research has shown that many people with MS experience changes to the social groups they belong to, such as family, friendship, professional, clinical and common interest groups. We are interested in whether such changes affect mood and psychological wellbeing.

We are exploring several aspects of group membership. These include the loss of existing relationships as well as the effect of continuation of group memberships. The effect of joining new groups following diagnosis and how groups for people with MS are viewed will also be investigated.

**Why have I been chosen?**

You have been invited to take part because you have multiple sclerosis. We are sending this information sheet to all those who have been attending clinics for people with MS in Leicester and are 18 years or over. Participants are also invited to respond via an online survey on the MS Society website.

**Do I have to take part?**

You can decide whether or not to take part in the study.

**What will happen to me if I take part?**

If you agree to take part you will be asked to complete a series of questionnaires. The questionnaires will ask about the groups you belong to, the support you have, your mood and how you feel others see you. It should take no more than 20 minutes to complete.

**What are the possible disadvantages and risks of taking part?**

There are no physical risks to you for taking part in this survey. However, completing the questionnaire will require you to give up some of your time. Some of the questions will ask you to think about your psychological wellbeing and some people may find thinking about these issues upsetting. If you feel upset and wish to talk to someone about any issues answering this questionnaire has raised, you can contact Nadina Lincoln on 0115 823 0230

**What are the possible benefits of taking part?**

There is no individual benefit of taking part in this survey. However, we hope that the information you provide will increase our understanding of the impact of changes to social groups on people living with multiple sclerosis. It may also have implications for different methods of delivery of clinical interventions and the social context in which these take place.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The Chief Investigator's contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) on 08081 788337.

**Will my taking part in the study be kept confidential?**

Yes. All information that you provide will be kept strictly confidential. You do not need to supply your name, address or any other information that could identify you. The written responses that you provide will be coded, anonymised and stored securely at the University of Nottingham. Only authorised persons will have access to this data.

**What will happen to the results of the study?**

We aim to submit the results of the study in psychology doctoral theses at the University of Nottingham and as paper(s) for publication in a scientific journal. Your individual responses or participation will not be personally identifiable.



**Who is organising the study?**

The study is being organised by researchers at The University of Nottingham. The research is funded by the Multiple Sclerosis Society.

**Who has reviewed the study?**

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee London - Bromley.

**Further information and contact details**

Think about whether or not you would like to take part in the study. Once you have decided, please complete the enclosed questionnaires. Once the questionnaires have been completed, please send them to us in the enclosed pre-paid addressed envelope.

**If you have any questions about this study please contact:**

Professor Nadina Lincoln  
Chief Investigator and Professor of Clinical Psychology  
Division of Rehabilitation and Ageing, Medical School  
Queen's Medical Centre  
University of Nottingham  
Nottingham  
NG7 2UH  
Email: [nadina.lincoln@nottingham.ac.uk](mailto:nadina.lincoln@nottingham.ac.uk)  
Tel: 0115 823 0230

**Thank you very much for your time and consideration**

## **Appendix 6: Demographic Information Sheet**



### **DEMOGRAPHIC INFORMATION SHEET** (Version 1.0: 10.04.2014)

**Investigation of social identity and mood in people with multiple sclerosis**

**REC ref: 14/LO/0703**

**Name of Researchers:** Professor Nadina Lincoln Kathryn Smale  
Dr Roshan das Nair  
Alex Barker Dr Nigel Hunt

**Please provide us with the following information:**

**Age:** \_\_\_\_\_  
\_\_\_\_\_

**Gender (male/female):**  
\_\_\_\_\_

**Date of multiple sclerosis diagnosis if known (year/month):**  
\_\_\_\_\_

**Years since diagnosis:** Please tick  the corresponding box

Less than 1 year	<input type="checkbox"/>	5-10 years	<input type="checkbox"/>
1-3 years	<input type="checkbox"/>	10-15 years	<input type="checkbox"/>
3-5 years	<input type="checkbox"/>	More than 15 years	<input type="checkbox"/>

**Type of multiple sclerosis:** Please tick  the corresponding box

Relapsing remitting	<input type="checkbox"/>	Primary progressive	<input type="checkbox"/>
Secondary progressive	<input type="checkbox"/>	Benign	<input type="checkbox"/>

**Marital status:** Please tick  the corresponding box

Married/with partner	<input type="checkbox"/>	Single	<input type="checkbox"/>
Divorced/separated/widowed	<input type="checkbox"/>		<input type="checkbox"/>

**Living arrangements:** Please tick  the corresponding box

Living with partner	<input type="checkbox"/>	Living with family	<input type="checkbox"/>
Living alone	<input type="checkbox"/>	Living with friends	<input type="checkbox"/>

Other

Please describe:

---

**Nationality:** \_\_\_\_\_

**Ethnic Origin:** Please tick  the corresponding box:

**White**

British

Irish

Any other white background

**Black**

Black British

African Caribbean

Any other black background

**Mixed**

White and Asian

White and Black African

White and Black Caribbean

Any other mixed background

**Asian or Asian British**

Bangladeshi

Indian

Pakistani

Arab

Chinese

Any other Asian background

**Other**

Any other ethnic background: \_\_\_\_\_

## Appendix 7: Questionnaire Booklet



### QUESTIONNAIRE BOOKLET

Below is a series of questionnaires which should take about 15 minutes to complete. **Please answer all the 57 items** and do not leave any blank; answer the closest fit to how you feel.

#### Multi-dimensional Scale of Perceived Social Support

We are interested in how you feel about the following statements.  
Read each statement carefully. Indicate how you feel about each statement.

Circle the '1' if you *Very Strongly Disagree*      Circle the '5' if you *Mildly Agree*

Circle the '2' if you *Strongly Disagree*      Circle the '6' if you *Strongly Agree*

Circle the '3' if you *Mildly Disagree*  
*Strongly*  
 Circle the '4' if you are *Neutral*

Circle the '7' if you *Very*  
*Agree*

	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7

7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

**Please list any groups you belonged to before your diagnosis.**

For example: work, professional, friendship, family, faith, social, sporting or common interest groups. Include any groups you considered yourself part of (you may or may not still belong to them).

.....

.....

.....

.....

.....

.....

Now please indicate the extent to which you agree with the following statements from (1) "do not agree at all", to (7) "agree completely".

<b>Maintained Group Memberships</b>	
1. After my diagnosis of multiple sclerosis I still belong to the same groups I was a member of before my diagnosis	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>
2. After my diagnosis of multiple sclerosis I still join in the same group activities as before my diagnosis	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>
3. After my diagnosis of multiple sclerosis I am friends with people in the same groups as I was before my diagnosis	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>
4. After my diagnosis of multiple sclerosis I continue to have strong ties with the same groups as before my diagnosis	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>

<b>New Group Memberships</b>	
1. After my diagnosis of multiple sclerosis, I have joined one or more new groups	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>
2. After my diagnosis of multiple sclerosis, I have joined the activities of new groups	<i>do not agree at all</i> 1   2   3   4   5   6   7 <i>agree completely</i>
3. After my diagnosis of multiple sclerosis, I am friends with people in one or more of these new groups	



<i>do not agree at all</i>	1	2	3	4	5	6	7	<i>agree</i>
<i>completely</i>								
4. After my diagnosis of multiple sclerosis, I have strong ties with one or more new groups								
<i>do not agree at all</i>	1	2	3	4	5	6	7	<i>agree</i>
<i>completely</i>								

**Please write down who you think of as your family members** e.g. father, sister, cousin etc.

.....  
 .....  
 .....

Now please indicate the extent to which you agree with the following statements from (1) "not at all", to (7) "extremely".

<b>Social Identification Scale: Family Groups</b>									
1. I see myself as a member of the family group	<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>
2. I am pleased to be a member of the family group	<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>
3. I feel strong ties with members of my family group	<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>
4. I identify with members of my family group	<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>

**Please write down any groups that you attend for people with multiple sclerosis**

E.g. MS Society coffee mornings, clinical groups, support groups, hyperbaric oxygen therapy.

.....  
 .....  
 .....  
 .....

Now please indicate the extent to which you agree with the following statements from (1) "not at all", to (7) "extremely". Please answer with reference to the groups listed above.

<b>Social Identification Scale: Multiple Sclerosis Groups</b>									
1. I see myself as a member of a group for people with multiple sclerosis									
<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>	
2. I am pleased to be a member of a group for people with multiple sclerosis									
<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>	
3. I feel strong ties with members of a group for people with multiple sclerosis									
<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>	
4. I identify with members of a group for people with multiple sclerosis									
<i>not at all</i>	1	2	3	4	5	6	7	<i>extremely</i>	

### **The Chronic Illness Anticipated Stigma Scale (CIASS)**

Please read these statements below and mark how likely you think it is that they could happen to you in the future.

*First, think about how your friends and family members will treat you in the future. How likely is it that they will treat you in the following ways **because of your MS?***

	Very Unlikely	Unlikely	Some what Likely	Likely	Very Likely
1. A friend or family member will be angry with you.	1	2	3	4	5
2. A friend or family member will blame you for not getting better.	1	2	3	4	5
3. A friend or family member will think that your illness is your fault.	1	2	3	4	5

4. A friend or family member will not think as highly of you.	1	2	3	4	5
---------------------------------------------------------------	---	---	---	---	---

Now, think about how your coworkers and employers will treat you in the future. If you are not currently employed, think about coworkers and employers that you might have in the future. How likely is it that they will treat you in the following ways **because of your MS?**

	Very Unlikely	Unlikely	Some what Likely	Likely	Very Likely
5. Your employer will not promote you.	1	2	3	4	5
6. Someone at work will discriminate against you.	1	2	3	4	5
7. Your employer will assign a challenging project to someone else.	1	2	3	4	5
8. Someone at work will think that you cannot fulfil your work responsibilities.	1	2	3	4	5

Finally, think about how healthcare providers such as doctors, nurses, technicians, and secretaries who work at hospitals and doctors' offices will treat you in the future. How likely is it that they will treat you in the following ways **because of your MS?**

	Very Unlikely	Unlikely	Some what Likely	Likely	Very Likely
9. A healthcare worker will be frustrated with you.	1	2	3	4	5
10. A healthcare worker will give you poor care.	1	2	3	4	5
11. A healthcare worker will blame you for not getting	1	2	3	4	5

better.					
12. A healthcare worker will think that you are a bad patient.	1	2	3	4	5

### Hospital Anxiety and Depression Scale

Please read each item and place a tick in the box opposite the reply which comes closest to how you have been feeling in the **past week**. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up': Most of the time <input type="checkbox"/> A lot of the time <input type="checkbox"/> Time to time, occasionally <input type="checkbox"/> Not at all <input type="checkbox"/>	I feel as if I am slowed down: Nearly all the time <input type="checkbox"/> Very often <input type="checkbox"/> Sometimes <input type="checkbox"/> Not at all <input type="checkbox"/>
I still enjoy the things I used to enjoy: Definitely as much <input type="checkbox"/> Not quite so much <input type="checkbox"/> Only a little <input type="checkbox"/> Hardly at all <input type="checkbox"/>	I get a sort of frightened feeling like 'butterflies' in the stomach: Not at all <input type="checkbox"/> Occasionally <input type="checkbox"/> Quite often <input type="checkbox"/> Very often <input type="checkbox"/>

<p>I get a sort of frightened feeling as if something awful is about to happen: <input type="checkbox"/></p> <p>Very definitely and quite badly <input type="checkbox"/></p> <p>Yes, but not too badly <input type="checkbox"/></p> <p>A little, but it doesn't worry me <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>	<p>I have lost interest in my appearance: <input type="checkbox"/></p> <p>Definitely <input type="checkbox"/></p> <p>I don't take so much care as I should. <input type="checkbox"/></p> <p>I may not take quite as much care <input type="checkbox"/></p> <p>I take just as much care as ever <input type="checkbox"/></p>
<p>I can laugh and see the funny side of things: <input type="checkbox"/></p> <p>As much as I always could <input type="checkbox"/></p> <p>Not quite so much now <input type="checkbox"/></p> <p>Definitely not so much now <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>	<p>I feel restless as if I have to be on the move: <input type="checkbox"/></p> <p>Very much indeed <input type="checkbox"/></p> <p>Quite a lot <input type="checkbox"/></p> <p>Not very much <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>
<p>Worrying thoughts go through my mind: <input type="checkbox"/></p> <p>A great deal of the time <input type="checkbox"/></p> <p>A lot of the time <input type="checkbox"/></p> <p>From time to time but not too often <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>	<p>I look forward with enjoyment to things: <input type="checkbox"/></p> <p>As much as I ever did <input type="checkbox"/></p> <p>Rather less than I used to <input type="checkbox"/></p> <p>Definitely less than I used to <input type="checkbox"/></p> <p>Hardly at all <input type="checkbox"/></p>
<p>I feel cheerful: <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p> <p>Not often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Most of the time <input type="checkbox"/></p>	<p>I get sudden feelings of panic: <input type="checkbox"/></p> <p>Very often indeed <input type="checkbox"/></p> <p>Quite often <input type="checkbox"/></p> <p>Not very often <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>
<p>I can sit at ease and feel relaxed: <input type="checkbox"/></p> <p>Definitely <input type="checkbox"/></p> <p>Usually <input type="checkbox"/></p> <p>Not often <input type="checkbox"/></p> <p>Not at all <input type="checkbox"/></p>	<p>I can enjoy a good book or radio or TV programme: <input type="checkbox"/></p> <p>Often <input type="checkbox"/></p> <p>Sometimes <input type="checkbox"/></p> <p>Not often <input type="checkbox"/></p> <p>Seldom <input type="checkbox"/></p>