Better Together?
A Social Identity Approach to Psychological Adjustment Groups for People with Multiple Sclerosis

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Thesis Context

This thesis was undertaken alongside a feasibility randomised controlled trial (RCT). The RCT was conducted by a research team at The University of Nottingham, of which the thesis author was a part (das Nair, Kontou, Smale, Barker, & Lincoln, 2015). It investigated the feasibility of conducting a larger-scale RCT to compare the efficacy of individual and group psychological adjustment interventions for people with low mood and multiple sclerosis (MS). One of the aims of the doctoral research programme was to inform the design of the larger-scale RCT. Accordingly, it explored not just the question of the relative efficacy of group and individual formats, but why and for whom delivery format is important, and how this influences intervention efficacy.

The long-term goal of the doctoral research programme is for the processes identified to be tested in the proposed multi-site RCT. This will provide a more comprehensive and theoretically-informed evidence base to guide clinical policy and practice.

Abstract

People with multiple sclerosis (MS) commonly experience psychological problems including anxiety and depression. Evidence indicates that psychological interventions based on cognitive behavioural principles can help improve mental health. Such interventions are often delivered in groups and a common assumption is that the social interaction afforded by a group format is beneficial. The aim of this thesis is to explore this assumption and, drawing on social identity theory, investigate why and for whom MS psychological adjustment interventions are effective (or not) when delivered in a group.

Social identity refers to the part of an individual's self-concept that is derived from belonging to social groups. In the first study, a survey was conducted to establish an evidence base for the relationship between psychological wellbeing and social identity processes in people with MS (n=203). Continued membership of groups belonged to prior to diagnosis was associated with reduced psychological distress, highlighting the importance of social identity continuity. Increased anticipation of stigma as a result of having MS was associated with increased psychological distress. Identification with an MS group was associated with a small decrease in psychological distress when the effect of the other variables was accounted for. This raised the possibility that positive effects of MS group identification may be suppressed by an underlying negative influence of identifying with a socially devalued group.

A realist synthesis was undertaken to gain further insight into how these processes may contribute to intervention success or failure. This identified several benefits of group format, but indicated that these benefits were more readily obtained when MS was not experienced as posing a threat to identity. When the identity threat from MS was high, there were indications that a group format could have negative consequences for psychological wellbeing.

The identity-related benefits and drawbacks of individual and group interventions were explored further in a thematic analysis of interviews with

16 people with MS. Participants had taken part in a feasibility randomised controlled trial (RCT) of group versus individual cognitive behavioural therapy (CBT). Several benefits of group delivery were identified, including shared understanding, normalisation of illness and the opportunity to socialise, share information and challenge negative stereotypes. Perceived drawbacks included unhelpful group norms, putting on a mask and confrontation with a feared identity. Identity threat was found to be especially marked in the group delivery format and appeared to reduce intervention engagement. Identity threat varied depending on social identity continuity, incorporation of MS into identity, stigma, time since diagnosis, symptom progression, ageing and illness narrative. A narrative analysis of two of the interview transcripts highlighted the power of narrative perspective to influence how people respond to MS and offered an explanation for the differing responses to the prospect of taking part in group or individual interventions.

This thesis makes valuable contribution to the literature in making explicit those aspects of group intervention format that confer benefit. It also draws attention to the identity-related drawbacks of a group format. The finding that identity threat may influence perceptions of, and engagement with, interventions offers an explanation for the mixed results in the literature regarding the efficacy of group interventions. The thesis findings begin to establish a theoretical basis for clinical decisions regarding whether to offer group or individual psychological adjustment interventions. An important implication is the need to frame, design and deliver group interventions in such a way as to reduce identity threat and promote a positive shared identity.

Further research is now needed to investigate whether the proposed identity-related mechanisms impact intervention efficacy. In the planned multi-site RCT of group versus individual CBT it would be valuable to incorporate measures of MS group identification and identity threat. This would enable quantitative investigation of the degree to which these variables influence intervention engagement and efficacy.

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Author Contribution

The thesis author conceived the idea for the RCT and the programme of research presented in this thesis. The work presented in the thesis was completed between October 2012 and April 2016. The research programme was carried out in parallel with a related, but independent, doctoral research programme investigating the importance of family identity to identity change and adjustment to MS. The interviews with people with MS were conducted by both PhD students. The same topic guide was used but data analysis was carried out independently and different research questions addressed by each student.

Data collection for the survey study was also carried out alongside the other PhD student. Questionnaires informing the separate research questions were included in the same survey booklet. Application for ethical approval for the survey study was undertaken jointly, as was data entry into SPSS. Data analysis was conducted independently.

List of Abbreviations

CBT	Cognitive behavioural therapy
CIASS	Chronic Illness Anticipated Stigma Scale
CMO	Context-mechanism-outcome
GHQ	General Health Questionnaire
HADS	The Hospital Anxiety and Depression Scale
I	Interviewer
MND	Motor neurone disease
MRC	Medical Research Council
MS	Multiple sclerosis
NCCMH	National Collaborating Centre for Mental Health
NICE	National Institute for Health and Clinical Excellence
RCT	Randomised controlled trial
SD	Standard deviation
SIA	Social Identity Approach
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organisation

Chapter 1. Introduction

1.1 Summary

Multiple Sclerosis (MS) is a chronic, progressive neurological condition affecting more than two million people worldwide. In addition to physical symptoms, the mental health of people with MS is often affected, with a high prevalence of mood disorders. Evidence indicates that psychological adjustment interventions, particularly those based on cognitive behavioural principles, can lead to improvements in psychological wellbeing. Such interventions are commonly delivered in groups, and a common belief is that the social interaction afforded by a group format is beneficial. This assumption has not been explicitly examined. Taking a social identity approach to mental health offers a useful theoretical platform from which to investigate the processes underlying group psychological adjustment interventions and address this gap in the literature. Drawing on social identity theory, this thesis aims to address why and for whom MS psychological adjustment interventions are effective (or not) when delivered in a group format.

In this chapter an overview of the literature on MS and psychological distress, and psychological interventions for MS is presented. Literature on the social identity approach and its application to health and wellbeing is then introduced. Finally, the implications of the social identity approach for psychological adjustment interventions for people with MS are discussed.

1.2 Multiple Sclerosis and Psychological Adjustment

1.2.1 Multiple sclerosis

MS is a chronic, progressive disease of the central nervous system. It is thought to affect more than two million people worldwide and is one of the most common causes of neurological disability in young adults (Kingwell et al., 2013; World Health Organisation [WHO], 2008). Estimated incidence of MS is highest in Europe (3.8 per 100, 000) (WHO, 2008). MS is also more common amongst women, with an average female to male prevalence ratio of two to one (Kingwell et al., 2013; WHO, 2008).

The progression of the disease is unpredictable and can include symptoms in physical, sensory, cognitive and affective domains. Common symptoms include fatigue, balance problems, muscle weakness, spasticity, sexual dysfunction, bladder dysfunction, mood disorders and visual, speech and cognitive difficulties. The specific aetiology remains poorly understood, but MS is believed to be an autoimmune disorder (Keegan & Noseworthy, 2002) with both genetic susceptibility and contributory environmental factors (Compston & Coles, 2008; Simpson, Blizzard, Otahal, Van Der Mei, & Taylor, 2011). Symptoms arise as a result of inflammation and damage to myelin, axonal and grey matter in the brain and spinal cord, impeding transmission of electrical impulses (DeLuca & Nocentini, 2011). The pathological hallmark is focal areas of demyelination, known as plaques or lesions, although the presence of lesions alone is not sufficient for diagnosis, which can be complex.

Consequently, diagnosis is commonly reported to occur years after the onset of initial symptoms and following the exclusion of alternative diagnoses (Robinson, 1990). Recently, new criteria are allowing for earlier diagnosis (Compston & Coles, 2008; Polman et al., 2011).

The current clinical classification system broadly describes four common patterns of disease progression in MS: primary progressive, relapsing-remitting, secondary progressive and benign. Primary progressive MS is characterised by progression from onset. Within this, the disease path shows considerable variation, with some patients experiencing marked deterioration in a short period, while others plateau or progress far more slowly. Approximately 10% of patients experience this form of MS (MS UK, 2014). People with relapsing-remitting MS experience acute attacks of demyelination resulting in the worsening of original symptoms or the appearance of new symptoms. These relapses vary in duration from days to weeks or months. The period in-between relapses – remissions – are marked by a reduction in symptoms and, similarly, vary in duration, sometimes lasting for years. Over time, recovery from each episode becomes less complete, and persistent symptoms accumulate as a result of the neuronal damage (Compston & Coles, 2008). This is the most common form of MS, affecting up to 85% of people with a positive diagnosis (MS UK, 2014). Approximately 50% of people with a diagnosis of relapsing-remitting MS will eventually develop secondary progressive MS, where the disease progresses more steadily, independent of any relapses (MS UK, 2014). Benign MS starts with an initial episode, but

symptoms subside with no further attacks or lasting disability. Future relapses are possible, but these are infrequent and do not usually occur until 10-15 years after the onset of the disease. By nature, it is not possible to diagnose this form of MS until long periods of time have passed with little activity.

1.2.2 Multiple sclerosis and psychological distress

The mental health of people with MS is often affected and mood disorders such as anxiety and depression are common (Thomas, Thomas, Hillier, Galvin, & Baker, 2006). Depression is the most common psychiatric disorder in people with MS (Mendis, Rickards, & Cavanna, 2010; Wallin, Wilken, Turner, Williams, & Kane, 2006). Lifetime prevalence of clinically significant depression is estimated to be as high as 50% (Feinstein, 2011). This is higher than in other chronic illnesses or neurological conditions (E. Dalton & Heinrichs, 2005). The depression is generally stable longitudinally, unlikely to remit without treatment and can have devastating consequences for the day to day functioning of those living with the disease (Arnett, Barwick, & Beeney, 2008). Indeed, depression is implicated as a unique source of disability for people with MS, with indications that reductions in depression can lead to corresponding reductions in disability (Mohr, Hart, & Vella, 2007). In addition, the Goldman Consensus Group suggested that depression may result in decreased adherence to MS medication (Arnett et al., 2005). The socio-economic impact in terms of lifetime medical expenses, productivity loss and intangible costs to carers is also highly significant (Rosti-Otajarvi & Hamalainen, 2011).

The explanation of depression in people with MS is multi-factorial, including both neurological and psychosocial mechanisms. There is evidence indicating that the depression is partly attributable to disease processes and the direct neurological consequences of the condition. Links have been proposed between depression and demyelination (Zorzon et al., 2001) as well as the disproportionate contribution of certain affected brain areas, including parts of the pre-frontal cortex and the temporal region (Feinstein et al., 2004). Studies indicate that such endogenous disease factors account for approximately 20% of the variance in depression (Holden & Isaac, 2011). Disease factors may also contribute to depression in MS indirectly, via their influence on common MS sequelae, such as physical disability, fatigue, cognitive dysfunction and pain (Arnett et al., 2008). Psychosocial variables are also implicated. These include coping strategies, stress, uncertainty, hope, illness representations, social support and conceptions of self and illness (Arnett et al., 2008; Jopson & Moss-Morris, 2003; Lynch, Kroencke, & Denney, 2001; Omrani, Mirzaeian, Aghabagheri, Hassanzadeh, & Abedini, 2012; Pakenham, 2006; Wilkinson & das Nair, 2013). Indeed, cognitive and behavioural variables have been found to be more strongly related to psychological outcomes than have the physical effects of MS (Chalk, 2007). This finding is replicated in other studies. Dennison, Moss-Morris, Silber, Galea, & Chalder (2010) for instance, found that cognitive and behavioural factors accounted for more of the variance in psychological distress than symptom severity (37% as opposed to only 2%), with unhelpful beliefs about the self the strongest predictor. Further experimental and longitudinal studies are needed to determine causality. Nevertheless, the fact

that the behaviours and cognitions identified as important are potentially modifiable highlights the value of addressing these factors within psychological adjustment interventions (Dennison et al., 2010).

1.2.3 Psychological adjustment interventions for MS

Evidence from a recent systematic review suggests that psychological interventions for people with MS can lead to improvements in psychological wellbeing as well as physiological symptoms of the disease, particularly fatigue, pain, sleep disturbances and physical vitality (Pagnini, Bosma, Phillips, & Langer, 2014). According to guidelines from the National Institute for Health and Clinical Excellence (NICE), cognitive behavioural therapy (CBT) is one of the currently recommended psychological treatment for people with a chronic physical health condition, such as MS, and depressive symptoms (National Collaborating Centre for Mental Health [NCCMH], 2010). This is in line with the evidence discussed above, that cognitive and behavioural factors contribute significantly to psychological distress in people with MS. CBT emphasises the relationship between thoughts, feelings and behaviours and aims to provide participants with the tools to enable them to challenge underlying negative thoughts, problem solve and intentionally increase activities that bring them enjoyment (Dennison & Moss-Morris, 2010; Forman & Lincoln, 2010). It is the most researched type of psychological intervention in MS, as well as in the general population (Mohr, 2010).

A 2006 Cochrane review to assess the effectiveness of psychological interventions for people with MS was encouraging with respect to improvements in depression, particularly with cognitive behavioural approaches (Thomas et al., 2006). A more recent systematic review and meta-analysis supported the conclusion that CBT can be an effective intervention for treating depression in people with MS (Hind et al., 2014). What cannot be determined from these reviews is how much benefit is derived from the intervention content and what effects may be due to factors not specific to the intervention, including the social interaction that occurs when the intervention is delivered in a group setting. Indeed, although both group and individual interventions are used in practice and research, the majority of the literature focuses on the model of therapy as opposed to the relative efficacy of intervention format (Firth, 2014).

In a largely individualistic western healthcare system, the assumption is often that individual therapy that can be tailored to each patient is preferable to group intervention. While there is literature indicating that individual CBT is effective for people with MS, evidence to support the provision of CBT in a group format is limited by poor study quality and small sample sizes (Malcomson, Dunwoody, & Lowe-Strong, 2007; Thomas et al., 2006). A notable exception is a randomised controlled trial (RCT) (Lincoln et al., 2011) which found that group interventions based on cognitive behavioural principles improved mood in those with initial low mood, as well as reducing the impact of the disease on everyday life. Moreover, participants reported finding the

social element helpful, particularly being able to talk to other people with the same condition and similar problems (J. M. Holmes, Ford, Yuill, Drummond, & Lincoln, 2012). In accord with this, there are suggestions within the literature that group format can be beneficial over and above intervention content. However, the evidence for this remains largely anecdotal and theoretical explanation is notably lacking. Visschedijk, Collette, Pfennings, Polman and Van Der Ploeg (2004) stated that the opportunity for patients to share experiences is a "known advantage" of group format (p. 736), but provide no empirical substantiation of this claim. In a review of group psychological adjustment interventions, Firth (2014, p. 790) asserted that group delivery offers a number of benefits over individual therapy, including increased social interaction which, the author speculates, may itself improve outcome. Firth (2014) further noted that social support and the opportunity to share with others are commonly mentioned as beneficial by participants, but again, this evidence is largely anecdotal. The justification for the use of group-based treatment is similarly sparse in the Cochrane review: "Group therapy is often used to decrease feelings of alienation, facilitate expression of emotions related to the disease, and provide peer support" (Thomas et al., 2006, p.4). No reference is offered to validate this statement.

Given the paucity of empirical literature regarding delivery format, Hind et al. (2014) stressed the need for further research exploring optimal treatment modalities. Thomas et al. (2006) similarly called for research examining "the relative merits of providing treatment in groups or on a one-to-one basis" (p.

27). This is of particular importance given the priority of delivering cost-effective interventions in the current NHS climate (Firth, 2014; NCCMH, 2010). A group format is less resource heavy than one-to-one delivery (Lincoln et al., 2011; NCCMH, 2010) and allows therapists to see more people in less time, reducing waiting lists and intervention costs (Firth, 2014). Group CBT has been found to be cost effective compared to usual care for people with MS and low mood (Humphreys, Drummond, Phillips, & Lincoln, 2013), and in the general population, the costs of group CBT for major depression have been estimated to be approximately half the costs of individual therapy (Vos, Corry, Haby, Carter, & Andrews, 2005). Accordingly, interventions are now commonly delivered in groups, with a rationale that is apparently more economically-driven than theory led: "Although there is some support for individual psychological treatments, many MS services do not have the resources to provide these for all patients with MS who have low mood, and therefore group treatments have been introduced into clinical practice" (Lincoln et al., 2011, p. 1251)

Current NICE guidelines appear to reflect this resource-led rationale, recommending peer support groups as a first treatment option for people with a chronic physical health condition and mild to moderate depressive symptoms. In a stepped care approach, it is recommended individual CBT is offered when group-based CBT has been declined, or where it is not appropriate or available (NCCMH, 2010, p. 210).

It is clearly important to determine the relative efficacy of psychological adjustment interventions delivered in group and individual formats. Equally important is the need for greater understanding of the mechanisms underlying group and individual interventions and how these may differ. Increased insight may enable clinicians to target interventions more effectively. For instance, it could be that people who fall into different sub-categories (e.g. time since diagnosis, symptom severity) would benefit from a particular delivery format. Crucially, there is a need for a theoretical framework from which to address these questions. A promising candidate is the Social Identity Approach (SIA) and its recent application to health and wellbeing.

1.3 Social Identity and Psychological Adjustment Interventions for MS

1.3.1 The Social Identity Approach

Identity has become one of the most widely used terms in the social sciences, yet it only entered the discipline as a core concept in the 1950s (Wetherell, 2010). Indeed, the contemporary preoccupation with identity stands in notable contrast to the pre-modern period (Baumeister, 1999; Wetherell, 2010). This may reflect, in part, our current individualistic culture. Certainly, western individualism has important ramifications for how the term identity is understood. Within much of western culture, identity has tended to be viewed as synonymous with 'the self' - the independent, distinctive and essential nature of a person that endures with time (Ownsworth, 2014). By contrast, self-construal amongst members of collectivist cultures is more interdependent

(Meyers, 1997; Smith, 2011). Individualistic perspectives, along with the cognitive revolution in psychology, have led to a concern for establishing principles of human behaviour, cognition and emotion that are uncontaminated by or independent of culture (Gergen, 1994). It is only relatively recently that the notion of who we are in relation to other people and the implications this may have for health and wellbeing have come to the fore.

It is increasingly recognised that, as social creatures, humans gain their sense of self partly from their interactions with others (Chen, Boucher, & Kraus, 2011). As such, identity is not necessarily separate from one's social relationships or social context (Curtis & Eldredge, 1997; Gergen, 2009; Ownsworth, 2014). One aspect of this is social identity. Social identity refers to that part of the individual's self-concept that is derived from belonging to groups and the value attached to these memberships (Tajfel, 1982, p.2; Tajfel & Turner, 1979). In essence, in addition to seeing ourselves as 'I' and 'me' (personal identity) we also define ourselves as 'we' and 'us' (social identity) (Jetten, S. A. Haslam, & C. Haslam, 2012a). Social identities may be derived from any social group, including family and friendship groups, work or hobbies, as well as nationality, sexuality or religion. The Social Identity Approach encompasses both social identity theory (Tajfel, 1982; Tajfel & Turner, 1979) and the related, self-categorisation theory (Turner, Oakes, S. A. Haslam, & McGarty, 1994). The latter is concerned with the circumstances under which group memberships become contextually salient such that we define ourselves

at a group rather than an individual level. This has implications for how we relate to people: whether we perceive them as 'other' or embrace them as 'us', and whether we adopt the in-group behavioural and attitudinal norms (S. A. Haslam, Jetten, Postmes, & C. Haslam, 2009).

To borrow a simple analogy from Cruwys, S. A. Haslam, Dingle, C. Haslam, & Jetten (2014, p. 218), Lea may be a member of a sports team. Not only does she need to be able to differentiate between individual members of her team (say, Katie and Bryony) but she needs to recognise them as in-group members with whom she shares a social identity, 'us'. Psychologically speaking, group membership becomes meaningful only when it contributes to an individual's sense of self. The degree to which this group membership becomes meaningful in contributing to sense of self depends on the emotional significance attached to the membership. Lea, for instance, may greatly value her place within the team and identify highly with her team mates. Accordingly, this membership is internalised and contributes to her overall self-concept. By contrast, another player, Angela, is a member of the team on paper and shows up to training. However, she does not particularly identify with the other team members and, as such, this group does not significantly contribute to her sense of self. With regard to social identity, 'showing up' is not enough. Lea's sense of herself as a member of her team also gives meaning to her relationship with Katie and Bryony and provides them all with shared norms and goals. Importantly, people can belong to numerous groups (Lea, for instance, may also be British, female, a physiotherapist and a Christian). Consequently, an individual's most

salient social identity is liable to change with situational context (Levine, 1999; Ownsworth, 2014).

The Social Identity Approach was originally developed to help explain intergroup relations and group processes such as stereotyping and discrimination. It is only recently that researchers have begun to explore the health consequences for group-based identities (Jetten, C. Haslam, & S. A. Haslam, 2012). Research is beginning to evidence that social identities have the potential to provide individuals with a sense of belonging, security, support and significance, contributing to mental wellbeing and helping individuals to cope with challenges and life transitions, such as chronic illness (S. A. Haslam et al., 2009; Jetten, C. Haslam, et al., 2012). Thus, a social identity approach holds particular promise for contributing to a social analysis of mental health and wellbeing in chronic illnesses such as MS. It also provides a theoretical tool to inform intervention design and implementation.

1.3.2 Application of the Social Identity Approach to mental health and wellbeing

The need to belong and form social bonds with friends, family and significant others is placed directly below self-esteem in Maslow's (1968) classic hierarchy of needs. More recent work has demonstrated that this need can be fulfilled by group memberships as well as interpersonal relationships (Hornsey & Jetten, 2004). Indeed, a considerable body of research confirms that when in-group identification is defined as positive, enduring and distinct, self-esteem is

positively affected (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014; Ellemers, Kortekaas, & Ouwerkerk, 1999; Phinney, Cantu, & Kurtz, 1997). Conversely, loss of important social connections, such as occurs in bereavement or relationship breakdown, is commonly a trigger for an episode of depression (Tennant, 2002). In the same vein, social isolation is a well-established and significant risk factor for morbidity and mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; House, Landis, & Umberson, 1988). Mental health, too, is known to be affected by social isolation. A recent longitudinal study found that perceived social isolation was a strong predictor of depression and remained so even after other candidate factors, such as stress and history of depression, were controlled for (Cacioppo, Hawkley, & Thisted, 2010). Joining groups appears to protect against these effects. After reviewing the research in his book 'Bowling Alone' Putnam (2001) drew the sobering conclusion that, as a rule of thumb, joining one group (having previously belonged to none) halves your risk of dying during the next year (p. 331). Similarly, joining social groups has been found to reduce the risk of depression. Using population data from the English Longitudinal Study of Ageing, Cruwys et al. (2013) found that the number of groups a person belongs to strongly predicts subsequent depression over a four-year period, such that more group memberships predicts less depression. Moreover, joining social groups, (such as sports clubs, resident groups, church or religious groups, social clubs, education, arts or music groups), appeared to have curative as well as protective effects. Not only was the above effect strongest amongst individuals

with a history of depression, but depressive symptoms were reduced in an initially depressed sample (Cruwys et al., 2013).

Thus, social groups are emerging as important predictors and protectors of mental health. What is less well understood are the mechanisms underpinning these effects: why does loss of social groups have a detrimental impact on wellbeing; what is it about belonging to groups that is so beneficial, and does everyone benefit from belonging to groups? The Social Identity Approach provides a theoretical platform from which to explore the underlying processes.

From a social identity perspective, groups are central to an individual's sense of self. Thus, the loss of valued social groups may contribute to mood disorders because the individual's sense of identity and the foundation and security this provides is jeopardised. This is illustrated in the following quote by social psychologist Kurt Lewin:

> Whatever a person does… he/she must have a ground to stand upon. This is probably the primary reason why he/she is extremely affected the moment this 'ground' begins to give way…One of the most important constituents of the ground on which the individual stands is the social group to which he/she belongs (Lewin, 1948, p. 145).

This process may be of particular relevance to MS, since people living with the disease commonly experience social isolation and changes to social relationships and group memberships (Edmonds, Vivat, Burman, Silber, & Higginson, 2007; Hakim et al., 2000; Kirchner & Lara, 2011; Mohr et al., 1999; Robens, Fox, Grose, Gunn, & Freeman, 2014). Such disruption to social relationships has been shown to have detrimental effects on health and wellbeing in people with other chronic neurological conditions (Douglas, 2011). Similarly, a study with people who had recently experienced a stroke found that social identity continuity (maintaining social group memberships that existed prior to stroke) was a crucial factor in determining psychological wellbeing and life satisfaction (C. Haslam et al., 2008).

This still leaves the question of what it is about joining or belonging to social groups that can help protect against and alleviate depression. Increased social contact and the corresponding increased availability of social support is often assumed to be the key. However, evidence for the success of social support interventions is mixed, indicating that simply bringing people together does not necessarily improve mental health or wellbeing (Jetten, C. Haslam, S. A. Haslam, Dingle, & Jones, 2014). Social contact in and of itself, then, does not appear to be enough. Recently, researchers adopting a social identity approach have proposed that identification – the sense of connectedness and belonging to a group – is the active ingredient (Cruwys, S. A. Haslam, & Dingle, 2014; Cruwys, S. A. Haslam, Dingle, Jetten, et al., 2014). A growing body of evidence is providing support for this hypothesis, that it is identification with a group

that is necessary in order to gain significant psychological benefit from it. Cruwys, S. A Haslam, Dingle, Jetten, et al. (2014) tested two longitudinal intervention studies (a community recreation group and a clinical psychotherapy group), and found that social identification with a group predicted improvement in depressive symptoms over and above initial depression severity, frequency of attendance or group type. Another study explicitly comparing social contact with group identification across two groups (family and army unit) found that group identification was the better predictor of mental health (Sani, Herrera, Wakefield, Boroch, & Gulyas, 2012). Moreover, a review and meta-analysis testing the hypothesis that social identification with meaningful groups would predict lower levels of depression found this to be a consistent result across the 16 included studies (Cruwys, S. A. Haslam, Dingle, Haslam, et al., 2014).

The above review proposed that social identity is best viewed as a psychological resource that protects against depression in at least four ways: firstly it engenders a sense of belonging; secondly, it provides meaning and purpose to life; thirdly, it can facilitate social influence by adoption of group norms; and fourthly it encourages the receipt and provision of social support (Cruwys, S. A. Haslam, Dingle, Haslam, et al., 2014). In support of the first feature of social identity as a psychological resource, that of belonging, simply thinking about groups you identify with can reinforce the sense that you have a place in the world (Cacioppo et al., 2010). Knowing you are connected to others and embedded within a wider social network contributes to a feeling of existential

security, arguably a foundation for mental wellbeing (Cruwys, S. A. Haslam, Dingle, Haslam, et al., 2014; Durkheim, 2006/1987). Interestingly, merely reflecting on the groups you belong to has been shown to increase resilience when faced with stressful situations (Jones & Jetten, 2011). Feeling part of a group also furnishes individuals with a sense of purpose, meaning and direction, the second resource-related feature of social identities. According to Cruwys, S. A. Haslam, Dingle, C. Haslam, et al. (2014), this is essential for effective social-psychological functioning. The authors suggest that part of the reason is that social identities are a basis for trust, shared values and motivation that allow individuals to coordinate actions and achieve collective goals (Drury & Reicher, 1999; Ellemers, de Gilder, & Haslam, 2004; Reicher & S. A. Haslam, 2006). When an individual lacks such resources, it is argued that they are more likely to feel life is meaningless and experience the depressive symptom of anhedonia (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014).

The third mechanism has to do with the way social identity can act as a basis for social influence. When individuals see themselves as belonging to a particular group, their thoughts, feelings and behaviours are more likely to be shaped by fellow group members and salient group norms. This has been well researched in the field of health behaviours, such as eating, where an individual's eating behaviour is modelled on that of other group members (Cruwys, Bevelander, & Hermans, 2015). It is important, though, to bear in mind that group norms may be positive or negative (for instance, shared identities may encourage both healthy eating and binge drinking). Similarly,

depression, or lack of depression, may become a group norm (although equally, depending on the type of group, normative group behaviour may not be expected to influence depression one way on the other). Nevertheless, with regard to the model's third feature, the important caveat is that not all social groups are beneficial as a basis for ameliorating depression.

This may also be true in the case of groups that are negatively perceived. Since intergroup comparisons are relative, membership of a group that is negatively defined (e.g. stigmatised) has the potential to adversely affect self-esteem. In line with this, Crabtree, S. A. Haslam, Postmes and C. Haslam (2010) found that although identifying with a mental health support group enhanced self-esteem through increased social support, stereotype rejection and stigma resistance, this buffering effect was simultaneously suppressed by a negative relationship between social identification and self-esteem. Underneath the protection afforded by group membership and the associated resources, the more individuals identified with the stigmatised group, the worse they felt about themselves.

The final feature of social identity that is proposed to contribute to its position as a psychological resource comes from its capacity to facilitate receipt of social support in a variety of forms (emotional, intellectual, material etc.). There is evidence that the considerable social capital and social support that can be provided through social relationships is more readily accessed when individuals share a social identity with the provider (S. A. Haslam, Reicher, & Levine, 2012).

Individuals have similarly been found to be more likely to provide others with social support when they share a social identity with recipients (S. A. Haslam & Reicher, 2006).

It is clear from the emerging literature that belonging to social groups can have a powerful impact on an individual's mental health. This has two major implications for psychological adjustment interventions. Firstly, it draws attention to the importance of increased social connectedness as an intervention outcome. Secondly, and in support of the anecdotal evidence discussed earlier, it indicates that delivering interventions in a group format may have a significant impact on mental wellbeing over and above the content.

1.3.3 Implications of the Social Identity Approach for MS psychological adjustment interventions

In addition to affecting how identity is viewed, Western individualism has contributed to an approach to neuro-rehabilitation that is similarly individualistic (Lewis, 2007). With a few notable exceptions (e.g. BenYishay, 1996) even the widely held biopsychosocial approach is limited in its consideration of the social (Walsh, Fortune, Gallagher, & Muldoon, 2012). In light of the above evidence regarding the importance of social groups for sense of self and mental health, this is a significant omission. There is a need for the integration of clinical neuropsychology and social psychology (Walsh et al., 2012) and social identity theory is well positioned to inform clinical neuropsychology in this regard.

Depression is also known to compromise social interaction, and increased social participation is a common goal in neuropsychological rehabilitation. Although not a focus for research attention, cognitive behavioural approaches do acknowledge that social isolation can be a central feature of depression and commonly tackle this through teaching behavioural strategies aimed at increasing social activities (Cuijpers, van Straten, & Warmerdam, 2007). However, such behavioural activation is based on the assumption that it is withdrawal from meaningful activities that maintains depressive symptoms, as opposed to being social in nature (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014; Dimidjian, Martell, Addis, & Herman-Dunn, 2008). Moreover, problems with social functioning are centred with the individual and conceptualised as an individual-level deficit as opposed to being related to disruptions to the sense of self derived from group memberships (Cruwys, Haslam, Dingle, Haslam, et al., 2014). The social identity approach provides an explanatory model for the importance of social connectedness as an intervention outcome. Going one step further, the model of social identity as a psychological resource indicates that being part of a group may be equally important as an intervention input.

As outlined in the previous section, psychological adjustment interventions for people with MS are commonly delivered in a group setting, although both the evidence base and theoretical underpinning for this delivery format are lacking. Therapeutic groups are recognised to help normalise the consequences of illness and enable patients to learn from and encourage each other (Yalom &

Leszcz, 2005), but suggestions that group factors are related to psychological improvement remain largely anecdotal. Surprisingly little research has explicitly considered whether the efficacy of group interventions is attributable, in part, to the social format or who may derive greatest benefit from group delivery. This is an area that urgently needs addressing and findings could have a significant impact for the ways in which neuropsychological rehabilitation is approached.

Accordingly, the programme of research covered in this PhD aimed to explore the mechanisms underlying group and individual psychological adjustment interventions for people with MS. The particular focus was on the identity processes associated with group format. The primary research question was why are cognitive behavioural psychological adjustment interventions effective (or not) when delivered in a group format? The related question, for whom are they effective, was also considered. Taking part in a group intervention may confer emotional benefit on participants in the form of the psychological resources derived from group membership discussed earlier. Given the high levels of social isolation reported by people with MS, it may be that a group context is particularly important for this population. On the other hand, as a potentially stigmatising condition, taking part in an MS group may have a detrimental impact on mental health. Furthermore, there may also be a time-gradient of when group affiliation ceases to be detrimental and increasingly becomes valuable for the individual. As outlined in the preface, this doctoral research was conducted alongside a feasibility RCT comparing group and

individual CBT for people with MS. Thus, the results of the research are intended to inform the design and implementation of the proposed multi-centre RCT.

Chapter 2. Methodology: A Mixed Methods Approach

2.1 Summary

This thesis used a mixed methods approach to address the goals of the research programme. The aim of this chapter is to outline the rationale for mixed methods research and explain why it was chosen as the most appropriate methodology for the current research. Common critiques of mixed methods research are addressed with a brief discussion of epistemological concerns and practical challenges. Finally, the main aims of the research are stated and an outline of the research design of the studies comprising the thesis presented.

2.2 Introduction

As outlined in the introduction, psychological adjustment interventions for people with MS are commonly delivered in a group format. While there is a strong evidence base in support of cognitive behavioural content, little is known about, firstly, the impact of delivering such interventions in a group compared to an individual format and, secondly, why and how delivery format may impact outcome. The first question, regarding relative efficacy, will be addressed in the multi-site RCT proposed as a follow-on to the individual versus group feasibility RCT carried out alongside this doctoral work (das Nair et al., 2015). The second question, regarding the role of delivery format, is the focus of this thesis. Drawing on social identity theory, the aim is to begin to untangle why group interventions may or may not be effective and for whom, with a view to informing the design and implementation of the proposed larger-scale RCT.

In order to accomplish this aim both quantitative and qualitative research methods are needed. When investigating the potential impact of group format from a social identity perspective, quantitative methods are needed to establish an evidence base for a relationship between social identity processes and psychological wellbeing in people with MS. However, quantitative studies on their own are often limited in what they can offer by way of explanation; for instance, in a quantitative study whose results indicated that group psychological adjustment interventions can help improve quality of life for people with MS (Graziano, Calandri, Borghi, & Bonino, 2014), the authors recommended qualitative methods be employed to further investigate the results. In line with this, in the current research programme, qualitative methods were needed to help obtain the insight and understanding required, particularly given the explanatory focus of the research question. Accordingly, a mixed methods design was used in the current research. This chapter describes the rationale behind mixed methodology and outlines how a mixed methods design was employed in the research programme.

2.3 The Quantitative-Qualitative Debate

When undertaking research, psychologists have a wide array of research methods available to them. As outlined above, these traditionally fall into one of two camps: quantitative or qualitative. Todd, Nerlich and McKeown (2004) observed that since psychology's inception as a science in the nineteenth century, quantitative methods have been the preferred choice (p.4). In health sciences more broadly, the dominant approach has similarly been quantitative.

Quantitative methods are based on a positivist epistemology and employ deductive logic in order to test a theory to either support or refute it (Creswell & Plano Clark, 2007). Value-free inquiry is upheld (Tashakkori & Teddlie, 1998) with attempts made to eliminate bias, control variables and enable replication and generalisability of findings (Maxwell & Mittapalli, 2010). Research is valued as a means of using objective measurement to predict a reality that is independent of researchers' error-prone perceptions (Yardley & Bishop, 2015, p. 1). By contrast, qualitative methods arose out of an interpretive perspective where meaning is valued and reality is understood to be constructed in a socio-cultural context (Yardley & Bishop, 2015). Rather than numerical statistical analysis, themes are commonly identified from text (Creswell & Plano Clark, 2007). As such, qualitative methods have tended to be disregarded or considered "poor science" in comparison to their quantitative counterpart (O'Cathain, 2009, p. 3). In the field of health, qualitative methods began to gain recognition in the mid-1990s as they were able to offer insights and explore questions that prevailing quantitative methods were less able to address, such as why some healthcare interventions are effective while others are not (O'Cathain, 2009). Todd et al. (2004) succinctly summarise the difference between the two approaches as "measurement versus meaning" and "lived experience versus impersonal experiment" (p.5). Typically, researchers have become entrenched in either quantitative or qualitative approaches, seeing the other as a competing rather than complementary paradigm (Todd et al., 2004). Rather than enjoying the richness methodological pluralism may offer (cf. Sechrest & Sidani, 1995), paradigm wars ensued.

A notable turning point was an article published in the British Medical Journal heralding qualitative research methods as an essential component of healthcare research and arguing that quantitative and qualitative research methods could be complementary as opposed to antithetical (Pope & Mays, 1995, p. 42). Since this time, mixed methods research has gained both repute and momentum, not least within the health sciences (O'Cathain, 2009). Indeed, the proportion of mixed methods studies commissioned by the Department of Health Research and Development rose from 17% in the mid-1990s to 30% by the early 2000s (O'Cathain, Murphy, & Nicholl, 2007).

The biggest argument against reconciliation between quantitative and qualitative approaches is one of epistemological incommensurability: that the underlying positivist and constructivist perspectives are fundamentally incompatible (Teddlie & Tashakkori, 2010). However, many now argue that the distinction between the paradigms is less clear cut than previously thought (Johnson, Onwuegbuzie, & Turner, 2007) and that the paradigm wars have been unproductive, even hindering the progression of social science (Johnson et al., 2007; Sechrest & Sidani, 1995). Yardley and Bishop (2015) suggest that the dichotomy is less relevant in our postmodern society since few researchers still maintain the plausibility of value-free knowledge. A similar rationale is apparent in the assertion that “all research ultimately has a qualitative grounding” (Campbell, as cited in M. Miles & Huberman, 1994, p. 40). Maxwell and Mittapalli (2010) argue that what is important is a dialectic approach to research. Interestingly, even Kuhn (1962), who famously raised the problem of

incommensurability and the resultant misunderstandings that may arise between different groups of scientists, explained in a later post-script to his work that, with some effort at decoding the language of each group, there is no reason why scientists adhering to one paradigm could not understand the assumptions of the other (Kuhn, 1970). Maxwell and Mittapalli (2010) propose that critical realism can facilitate the dialogue between the differing perspectives and consequently deepen, as well as broaden, understanding. In the wake of such arguments mixed methods research has emerged as a third research paradigm (Creswell & Plano Clark, 2007; Johnson et al., 2007).

2.4 Conducting Mixed Methods Research

With the increased efforts to bridge the divide between quantitative and qualitative approaches, multiple definitions of mixed methods research have been proposed. The following provides a useful general description, reached by Johnson et al. (2007) following analysis of 19 definitions from within the field: "Mixed methods research…combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (p. 123).

Teddlie and Tashakkori (2010) stress that mixed methods research goes beyond merely utilising the relative strengths of either approach or cancelling out the weakness of one with the other. They advocate a methodological eclecticism that selects the combination of methods best suited to answering the research

questions that evolve as a study progresses. This pragmatic approach to mixed methods research, they argue, is reasonably intuitive. That said, finding and developing researchers well versed in both methodologies is not without its challenges (Todd et al., 2004), and how best to integrate the two approaches requires careful consideration. As O'Cathain, Murphy and Nicholl (2010) highlight, although health researchers are increasingly undertaking mixed methods research, some studies show a lack of integration between the two aspects and, as such, limit the knowledge that could be gleaned from such research.

Part of the difficulty in successful integration may lie in pragmatism's underestimation of the influence that philosophical assumptions and perspectives have on research methods (Maxwell & Mittapalli, 2010). An alternative is to adopt a critical realist stance towards mixed methods research, as advocated by Maxwell and Mittapalli (2010) and McEvoy and Richards (2006). Critical realism recognises that researchers' philosophical assumptions inform how they view the world and this cannot (and should not) be easily disregarded, yet, in agreement with methodological pragmatism, maintains that a research method is not necessarily tied to a particular philosophical position. The tradition of critical realism is most notably associated with Bhaskar (e.g. Bhaskar, 1989). It sits between positivism and constructivism in arguing that, although our understanding of reality is partial and constrained by not being amenable to direct measurement (since it is processed through our culture, language, brains etc.), knowledge can nevertheless accrue since

reality can be known indirectly (Wong, Westhorp, Pawson, & Greenhalgh, 2013). Applying this thinking to mixed methods research enables integration of a realist ontology (i.e. a real world exists that is independent of our perceptions of it) with a constructivist epistemology (i.e. our understanding of the world is mediated by perceptions and constructed from our perspectives) (Maxwell & Mittapalli, 2010). Contemporary mixed methods research is also characterised by a cyclical, iterative approach to research employing both inductive and deductive logic within the same research programme (Teddlie & Tashakkori, 2010).

With respect to research design, numerous mixed methods design types have been proposed. Creswell and Plano Clark (2007) have condensed these into a broad classification of four overarching types: embedded designs, exploratory designs, explanatory designs, and triangulations designs. Embedded designs are where a study is based primarily on one data type, but has another, supportive data set embedded within it. An example of this could be an experimental design where the primary data being collected is quantitative but some qualitative data is collected within this methodological framework (Creswell & Plano Clark, 2007). Explanatory or exploratory designs are also possible, whereby qualitative data either helps explain the initial quantitative results or acts in an exploratory role helping to inform the second quantitative stage of the research. The most common approach to mixing methods is the triangulation design (Creswell & Plano Clark, 2007) or what Teddlie and Tashakkori (2010) term parallel mixed designs. Here, collection and analysis of

qualitative and quantitative data are carried out separately, but both methods are given equal weighting. The qualitative and quantitative strands are planned and carried out to answer related aspects of the overarching research question and may be implemented simultaneously or with time delay (Teddlie & Tashakkori, 2010, p. 11). The results from both are then synthesised into an overall interpretation. As mentioned, integrating different sets of data in a meaningful way requires careful thought. In some instances, researchers choose to transform data, for instance transforming qualitative data into quantitative data in order to aid comparison and integration (Creswell & Plano Clark, 2007). Traditionally, there has been an emphasis on convergence of results, although more recent mixed methods research acknowledges divergence of results from different sources as equally important (Teddlie & Tashakkori, 2010).

2.5 Choice of Research Design for this Thesis

When determining the methods to use for any given study, the view endorsed by many advocates of mixed methods research is to focus on the research question (Teddlie & Tashakkori, 2010). As Teddlie and Tashakkori (2010) maintain, this can be used to determine the most appropriate tools, whether qualitative, quantitative or mixed. Koch (1995) additionally advises that rather than techniques or procedures, the necessary starting point of an inquiry is to consider the philosophical assumptions underlying a method and whether these are consistent with the view of the researcher (p. 827). In line with both these recommendations, for the current research programme a mixed

methods approach informed by a critical realist philosophy of social science was used. For critical realists, the primary goal is neither to delineate generalisable laws nor to ascertain people's lived experience (McEvoy & Richards, 2006). The primary goal is one of explanation: to gain a greater depth of understanding. The emphasis on explanation ties in with the overall goal of the research programme and the two specific research questions this thesis aims to address:

1) Why are cognitive behavioural psychological adjustment interventions for people with MS effective (or not) when delivered in a group format;
2) Who finds benefit from the group format.

The focus is on understanding what it is about the group format that may hinder or support psychological wellbeing, as well as exploring who may find group interventions beneficial. Of the four major design types outlined above, a triangulation, or parallel mixed design is most suited to the present purposes. In the current research programme this involved the collection of complementary quantitative and qualitative data in separate but related studies. Findings from both were analysed and compared, with the final conclusions based on the synthesis of both elements. The individual studies comprising the PhD are as follows:

1) *Survey study*. In this study questionnaires were completed by people with MS and data analysed using numerical statistical techniques. The aim was to build an evidence base for the relationships between mental

health and social identity; specifically, social identity continuity, MS group identity and anticipated stigma.

2) *Realist synthesis*. This method draws on the understanding of critical realism espoused by Pawson (2013) in research evaluating complex social interventions. The aim was to review and synthesise the relevant qualitative and quantitative literature in order to gain understanding of the social-identity related processes underlying group MS psychological adjustment interventions that contribute to intervention success or failure.

3) *Thematic analysis of semi-structured interviews*. Participants of both group and individual psychological adjustment interventions were interviewed to investigate factors influencing identity threat and how these may influence engagement with, and perceptions of, group and individual MS psychological adjustment interventions. Perceived benefits and drawbacks of both group and individual formats were also identified.

4) *Narrative analysis of interview transcripts*. In the thematic analysis, participants' illness narratives were highlighted as one factor influencing perceptions of, and engagement with, the intervention. Accordingly, a final study was undertaken employing a narrative analysis of two of the interview transcripts. In further support of this approach, a study investigating support group use and need amongst people with MS identified not having access to narrative data as a limitation of their study and explicitly recommended the value of a

mixed methods design in related future studies on the topic (Finlayson & Cho, 2011).

Further detail on the precise methods employed in each study is provided in the relevant subsequent chapters.

2.6 Quality in Mixed Methods Research

In quantitative studies, criteria for judging quality are relatively well established, including factors such as using reliable and valid measures, design that minimises confounding variables, representative samples of adequate size and appropriate statistical analyses (Yardley, 2000). Such criteria were considered with respect to ensuring the quality of quantitative elements of the research programme, but were inappropriate for the qualitative elements. Indeed, in some cases the criteria even undermine the rationale for utilising qualitative methods (Yardley, 2000). Accordingly, particular consideration was given to how to achieve and demonstrate quality and credibility in the qualitative studies. Some qualitative researchers have attempted to dismiss discussions of the reliability of methods and validity of findings as positivist concerns (Seale, Gobo, Gubrium, & Silverman, 2004). Others argue for the necessity of assessing quality in qualitative research but recognise this cannot be achieved by application of prescriptive procedures and rigid universal standards (Yardley, 2000). An alternative is to use more flexible principles as a guide to quality (Cope, 2014; Yardley, 2000). Following consultation with experts and a comprehensive review of the literature pertaining to standards

in qualitative research, Spencer, Ritchie, Lewis and Dillon (2003) produced a framework for assessing the quality of qualitative research. It is underpinned by four central principles. The first is that the research be contributory in advancing understanding in the field. The second is that the design is defensible and provides a strategy that enables the research questions to be addressed. The third principle is that the research is conducted rigorously via transparent and systematic data collection, analysis and interpretation. The final principle is that the claims of the research are credible. This is achieved by reflexivity, coherence and ensuring arguments about the evidence generated are plausible and well-founded. This framework was drawn on when addressing the quality of the qualitative studies in the research programme.

Chapter 3: Investigation of the Relationships between Social Identity Processes and Psychological Wellbeing in People with MS

3.1 Summary

As outlined in chapter one, social groups are emerging as important predictors and protectors of mental health and wellbeing. The study presented in the current chapter aimed to establish an evidence base for the effect of social identity processes on the psychological wellbeing of people with MS. This provided a foundation from which the impact of such processes on the efficacy of group psychological adjustment interventions could be explored. Three social identity-related factors and their relationships to mental health were investigated. These were social identity continuity, MS group identity and anticipated stigma.

Two hundred and one people completed online or paper-based questionnaires. Regression analyses found that, as predicted, maintaining pre-diagnosis group memberships was associated with reduced psychological distress. Also in line with predictions, increased levels of anticipated stigma were associated with increased psychological distress. There were indications that identifying with an MS group could confer psychological benefit, but exploration of the way this may interact with stigma and the potentially negative impact of identifying with a group perceived to be stigmatised require further exploration. Age also emerged as a significant predictor of psychological distress in the regression model. Exploration of how all these relationships may influence engagement with, and efficacy of, MS group psychological adjustment interventions is now needed, as addressed in the following chapters.

3.2 Introduction

The recent application of social identity theory to the field of health has begun to uncover the profound impact social networks and identities can have on health and wellbeing (S. A. Haslam et al., 2009; Jetten, S. A. Haslam, et al., 2012). This has highlighted a need for a shift away from the traditional individualistic focus within healthcare research towards a greater recognition of the importance of social groups. As Peterson, Park and Sweeney (2008) asserted: "It is within groups that we live, work, love and play, and groups should therefore be a primary focus of researchers interested in health and wellbeing" (p.19).

As outlined in the introduction to this thesis, social groups are emerging as particularly important predictors and protectors of mental health and wellbeing. Thus far, relatively little research has applied a social identity approach to the field of clinical neuropsychology to explore whether this is also the case for people with chronic neurological conditions. The few studies that have done so have largely focussed on the areas of traumatic and acquired brain injury. Thus, there is a need to build an evidence base regarding the effect of social identity processes on the psychological wellbeing of people with MS. This will provide a foundation from which to investigate the impact of such processes on the efficacy of group psychological adjustment interventions, the overarching purpose of the PhD. Accordingly, the aim of the current study was to investigate three social identity related-factors and their relationships to the psychological wellbeing of people with MS. Firstly, the effect of social identity

continuity on mental health was explored. Changes to relationships and social networks are commonly reported amongst people with MS (Edmonds et al., 2007; Hakim et al., 2000) and there are indications that loss of social functioning is associated with depression (Kirchner & Lara, 2011). However, the specific impact of loss or continuity of social group memberships needs to be established. The second relationship explored in this study was the association between mental health and identification with MS-related groups. It may be that MS group identification offers psychological benefit, in line with the resource-based model of social identity which proposes that group identification enables receipt of the social support as well as redefinition of goals and values in line with those of the in-group (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014). However, unlike other existing group memberships, MS may be more likely to be an unwanted social identity and, as such, may be less likely to confer psychological benefit. Moreover, MS is commonly perceived to be a stigmatised condition (Grytten & Måseide, 2006) which may have negative implications for psychological wellbeing. Accordingly, the third factor investigated in this study was anticipated stigma and its relationship with mental health. The existing literature informing the hypotheses of this study is outlined below.

Social identity has been conceptualised as a psychological resource that protects against depression in at least four ways: by enabling the provision and receipt of social support, by engendering a sense of belonging, by providing a sense of meaning and purpose and by facilitating social influence and the

adoption of normative group values (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014). Loss of social groups results in a lack of some or all of these resources and the loss of the foundation and security they provide, which has been proposed to result in an increased likelihood of depression (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014). There are indications that this may be true in the context of people with neurological conditions. For instance, a study of people who had sustained a traumatic brain injury (TBI) found that the consequent lack of social support was a significant predictor of depression (Douglas & Spellacy, 2000). In related research with people recovering from stroke, life satisfaction was found to be associated with multiple group memberships prior to the stroke. Path analysis revealed that this was due to the increased likelihood of maintaining at least some of the memberships after the stroke-related life-transition. Moreover, maintenance of groups that individuals belonged to prior to the stroke was directly positively correlated with life satisfaction as well as being negatively correlated with stress, indicating that social identity continuity was a crucial factor in protecting emotional wellbeing (C. Haslam et al., 2008). Whether such social identity continuity is similarly related to the psychological wellbeing of people with MS is not yet known. Given the high levels of social isolation and changes to group memberships commonly reported in people with MS (Edmonds et al., 2007; Hakim et al., 2000; Kirchner & Lara, 2011; Mohr et al., 1999; Robens et al., 2014), it seems probable that such processes may be relevant.

In addition to former group memberships providing social identity-related resources, it may be that new MS-related groups can offer similar resources to protect mental health. MS organisations, such as the UK MS Society, commonly provide such social and peer support groups, and clinicians and researchers have promoted interventions that enhance social support (Williams et al., 2004). Moreover, as discussed in the introductory chapter, psychological adjustment interventions are often delivered in a group format. Thus, the relationship between MS group identification and psychological wellbeing merits investigation and was examined in the current study. Initial empirical evidence supports the suggestion that identification with MS groups may have a positive effect on psychological wellbeing. For instance, Wakefield, Bickley and Sani (2013a) found that identification with an MS support group was associated with reduced anxiety and depression and higher levels of life satisfaction. Importantly, identification, as opposed to mere attendance, was highlighted as the critical factor (Wakefield et al., 2013a). Similarly, in a survey of people with MS and mobility difficulties, Bogart (2015) found that disability identity (identifying as a member of a disability group, or the disability community more broadly) predicted lower levels of depression and anxiety. Bogart's (2015) explanation that the beneficial effect may be partially due to adopting disability group values of interdependence, as opposed to the Western individualistic ideal of independence, is in line with the social influence pathway of the resource-based model of social identity (Cruwys, S. A. Haslam, Dingle, C. Haslam, et al., 2014).

Such results are promising with respect to the value of groups for people with MS. Nevertheless, it is important to bear in mind that not all groups will necessarily confer psychological benefit. A key difference between the groups an individual may have belonged to before developing MS and new MS-related groups, is that the former are likely to have been highly valued, and, as such, a welcome aspect of identity and source of self-esteem. This is less likely to be the case when someone is diagnosed with MS and finds themselves confronted with the prospect of a new MS social identity. Indeed, MS is commonly perceived to be a stigmatised condition, and, as such, may carry negative implications for psychological wellbeing (Grytten & Måseide, 2006). The concept of stigma is highly pertinent to social identity, as indicated by Goffman's description of stigma as socially devalued identities that disqualify individuals from full social acceptance (Goffman, 1963, preface). His, now classic, work has been followed by numerous studies in the social sciences exploring how stigma, manifested as discrimination, prejudice and negative stereotypes, discredits individuals and can result in social isolation, loss of employment and reduced psychological wellbeing (Corrigan & Penn, 1999; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Major & O'Brien, 2005). There is some evidence indicating that stigma undermines the psychological wellbeing of people living with chronic illness (B. Berger, Ferrans, & Lashley, 2001; Corrigan, Watson, & Barr, 2006; Earnshaw, Quinn, & Park, 2012; Golden, Conroy, Marie O'Dwyer, Golden, & Hardouin, 2006), but research specifically examining whether this is the case in MS is needed. Stigma has been broken down into a range of constituent elements, including enacted,

perceived and anticipated stigma (Rao et al., 2009). The terms perceived and anticipated stigma are often used interchangeably. However, some measures of perceived stigma are actually measuring knowledge of cultural stereotypes, as opposed to whether respondents anticipate others will devalue them as a result of their condition (Quinn & Chaudoir, 2009). For the purposes of the present research, the personal sense of anticipated stigma and its relationship to psychological distress was examined.

If the stigma anticipated as a result of MS is found to be associated with psychological distress, there may be related implications for identifying with an MS group. Central to social identity theory is the assertion that people make comparisons regarding the social groups they belong to (Tajfel & Turner, 1979). Accordingly, belonging to a group viewed as inferior in comparison with relevant out-groups can have a negative effect on self-esteem (Crabtree et al., 2010; Major & O'Brien, 2005). On the other hand, there are also indications that identifying with a stigmatised group can have positive effects on mental health (Crabtree et al., 2010; Quinn & Earnshaw, 2013) and that, in some cases, having a socially stigmatising illness leads people to seek the support of others with a similar condition (Davison, Pennebaker, & Dickerson, 2000; Hogan, Linden, & Najarian, 2002). One explanation of the positive effects of intentional identification with a devalued group is that the shared social identity provides the resources needed to challenge negative stereotypes and acts as a buffer against the harmful consequences of stigma (Crabtree et al., 2010; Quinn & Earnshaw, 2013). Moreover, disability affirmation may bestow a sense of pride

and enable appreciation of the benefits of living with the condition, whilst disability advocacy is thought to improve psychological wellbeing through the sense of purpose found in challenging cultural stigma (Bogart, 2015; Dunn & Burcaw, 2013; Nario-Redmond, Noel, & Fern, 2013).

Evidence that such mechanisms underlie the protective effects of identification with negatively perceived disability groups comes from a recent study by Nario-Redmond et al. (2013). The authors conducted a survey on people with a range of disabilities and found that disability identification predicted higher use of collective coping strategies, such as stereotype resistance and positive identity redefinition, and higher collective and personal self-esteem. In the context of mental health support groups, Crabtree et al. (2010) found similar evidence for positive effects of identification. Here, although identifying with a devalued group had an underlying detrimental effect on self-esteem, group identification was simultaneously found to predict increased social support, stigma resistance and stereotype rejection, which, in turn, predicted higher levels of self-esteem. Although it was beyond the scope of this study to investigate whether such stigma resistance resulted from identification of MS groups, whether belonging to MS groups buffered individuals against stigma was explored by investigating whether MS group identification moderated the relationship between anticipated stigma and psychological distress.

3.2.1 Aims

The overall aim of this study was to establish the relationships between mental health and social identity continuity, MS group identity and stigma in people with MS. Drawing on social identity theory and the literature discussed above, four hypotheses were tested:

1) Increased maintenance of pre-diagnosis group memberships would be associated with reduced psychological distress.
2) Increased identification with MS groups would be associated with reduced psychological distress.
3) Anticipated stigma would be associated with increased psychological distress.
4) MS group identity would have a moderating effect on the relationship between anticipated stigma and psychological distress, such that increased identification would reduce the detrimental effect of stigma.

3.3 Method

3.3.1 Design

The study had a cross-sectional and correlational design. Both paper-based and internet-based versions of the questionnaires and information sheets were used. The Bristol Online Survey (BOS) tool was used for the online version of the survey. The study was run in parallel with another, independent study, with a different research question and undertaken by a different researcher. The questionnaire pack included measures for both studies, with only the dependent measure common to both. Analysis was carried out independently.

The link to the online survey on the MS Society webpage was made available on several MS-related social media sites by the researcher undertaking the parallel study (this included MS-related Facebook groups and the researcher's Twitter account). The online survey was open from August 2014 – March 2015.

Ethical approval was obtained from the proportionate review sub-committee London-Bromley (NRES/REC reference: 14/LO/0703). Research and development approval was obtained from the University Hospitals of Leicester NHS Trust Research and Development (see appendix 1 for approval letters).

3.3.2 Participants

Potential participants were identified by the clinical team at the University Hospitals of Leicester NHS Trust from those attending MS clinics in Leicester. People over 18 with a clinician-confirmed diagnosis of multiple sclerosis (including benign, relapsing-remitting, secondary progressive and primary progressive) were sent a letter inviting them to take part in the study, along with a participant information sheet, questionnaire pack and demographic information sheet (see appendix 2 for participant invitation letter and information sheet). The questionnaires were completed at home and returned anonymously by pre-paid envelope.

Participants were also recruited via the MS Society website, where information about the study was displayed and people could choose to take part by clicking on the relevant link to access an online version of the information sheets and

questionnaires. Implied consent was indicated by returning the questionnaires or completing the online survey.

3.3.3 Measures

The survey included measures of maintained group memberships, MS group identity, anticipated stigma and psychological distress. Additional measures of family group identity, social support and new group memberships were also included in the questionnaire pack, which contributed to the study being undertaken by the other researcher. (See appendix 3 for the questionnaire pack).

Group membership listings: before diagnosis

Participants were asked to list any groups that they had belonged to before their diagnosis and which they may or may not still belong to. These could take any form and the instructions gave the examples of "*work, professional, friendship, family, faith, social, sporting or common interest groups*". These were not used in the analysis, but were included to make the participants think about the groups they belonged to in order to complete the subsequent maintained group memberships measure more accurately.

Maintained group memberships

Four items were used to assess the extent to which participants had maintained their pre-diagnosis group memberships. These were adapted from the corresponding measure of the Exeter Identity Transition Scales (EXITS) (C.

Haslam et al., 2008). The items were: "*After my diagnosis of multiple sclerosis I still belong to the same groups I was a member of before my diagnosis*"; "*After my diagnosis of multiple sclerosis I still join in the same group activities as before my diagnosis*"; "*After my diagnosis of multiple sclerosis I am friends with people in the same groups as I was before my diagnosis*"; and "*After my diagnosis of multiple sclerosis I continue to have strong ties with the same groups as before my diagnosis.*" Response options ranged from 1 (do not agree at all), to 7 (agree completely). An overall maintained group memberships score was created by averaging the scale items. A higher overall score indicated greater maintenance of pre-diagnosis group memberships.

Group membership listings: MS groups

Participants were asked to list any groups that they attend for people with MS. The instructions gave the examples of, "*MS Society coffee mornings, clinical groups, support groups, hyperbaric oxygen therapy*." As before, these were not used in the analysis, but were included to make the participants think about any MS groups they belonged to in order to complete the subsequent MS group identification measure more accurately.

MS group identification

Identification with MS groups was measured using the four item scale presented in Jetten, S. A. Haslam and C. Haslam (2012b), and originally developed by Doosje, Ellemers and Spears (1995). These items were: "*I see myself as a member of a group for people with multiple sclerosis*", "*I am pleased*

to be a member of a group for people with multiple sclerosis", "*I feel strong ties with members of a group for people with multiple sclerosis*", and "*I identify with members of a group for people with multiple sclerosis*". Response options ranged from 1 (not at all), to 7 (extremely). An MS group identification score was created by averaging the scale items. A higher overall score indicated greater MS group identification.

Anticipated stigma

Anticipated stigma was measured using the Chronic illness Anticipated Stigma Scale (CIASS; Earnshaw, Quinn, Kalichman, & Park, 2013). The CIASS includes 12 items divided into three subscales. These measure the extent to which respondents anticipate stigma from friends and family members, co-workers and employers, and healthcare providers. Example items include, *"A friend or family member will not think as highly of you*", "*someone at work will discriminate against you*", and "*a healthcare worker will blame you for not getting better*". Response options ranged from 1 (very unlikely) to 5 (very likely). A total anticipated stigma score was calculated by averaging all the items. A higher overall score indicated higher anticipated stigma.

Psychological distress

Psychological distress was measured using The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). This scale contains 14 four-point items, with seven questions assessing depression and seven measuring anxiety. An example item is, "*I feel cheerful"* with response options, "*not at all*",

"*not often*", "*sometimes*", and "*most of the time*". The scale was originally designed to detect anxiety and depression in a hospital outpatient clinic, but has since been shown to have broad application (Snaith, 2003). It has been validated for use with people with MS (Honarmand & Feinstein, 2009) and has been used in both MS psychological adjustment intervention studies (Lincoln et al., 2011; Rigby, Thornton, & Young, 2008) and research into disability identity in people with MS (Bogart, 2015). Given the high correlation found previously between the anxiety and depression subscales (Fortune, Smith, & Garvey, 2005) and following Fortune et al. (2005) and Walsh, Muldoon, Gallagher and Fortune (2015), the subscale scores were summed to create a general 'psychological distress' score where a higher score indicated greater psychological distress. Using a composite measure of psychological distress also enables comparison with related research in the area of stigmatised identities, which has deemed an overall measure of psychological distress to be more appropriate than separate measures of anxiety and depression (e.g. Quinn & Chaudoir, 2009).

3.3.4 Statistical analyses

Versions 21 and 22 of SPSS (Statistical Package for the Social Sciences) were used to analyse the data. Checks were conducted to determine whether the main study variables were normally distributed. Hierarchical regression was used to investigate hypotheses 1 to 3 with initial separate regression analysis carried out to explore the independent effect of each of the three main study variables of psychological distress. Age, time since diagnosis and gender were

identified as possible confounding variables from the literature (Bogart, 2015; Nario-Redmond et al., 2013). Initial analysis tested for bivariate correlations with these variables and the main study variables in order to identify which variables were suitable for inclusion in the regression model. *A priori* power calculations indicated that for an effect size of 0.15, an alpha level of 0.05 and three predictor variables, at least 119 participants were needed for the regression analysis. For the moderation analysis the PROCESS custom dialog box was installed (Hayes, 2013). The moderation effect predicted by the fourth hypothesis was tested using the PROCESS Model 1 (Hayes, 2009, 2013).

Participants were removed from the study if they had left an entire measure blank. If measures were partially completed (i.e. the participant had completed some measure items but left others blank), all missing data were replaced with the mean values for each question from the other respondents' completed answers (see missing data section in results for a detailed explanation). The only exception was for the MS Group Identity scale where missing data were replaced with the modal value from the other respondents' answers (as explained in the missing data section). In order to check whether replacing missing data affected the pattern of results, sensitivity analyses were run using data from the participants who had fully completed all the relevant measures.

3.4 Results

3.4.1 Demographic characteristics of participants

The questionnaire pack was sent to 400 people and a total of 123 participants returned it (30% response rate). Two failed to complete any of the questions in the dependent measure, the HADS, so their data were removed entirely from the sample. Eighty people completed the survey online. This resulted in 201 participants in total (51 men, 146 women). See table 1 for the demographic characteristics of participants.

Table 1. Demographic characteristics of participants

	Total (combined postal & online) (n = 201)				Postal (n = 121)				Online (n = 80)			
	N	mean	SD	range	N	mean	SD	range	N	mean	SD	range
Age (years)	197	48.2	10.9	23-85	118	49.7	11.0	25-85	79	46.0	10.4	23-70
Psychological distress (HADS)	201	18.0	8.0	0-38	121	16.6	7.4	0-38	80	20.0	8.5	2-38
Maintained group memberships	201	14.2	8.1	4-28	121	16.5	8.2	4-28	80	10.8	6.7	4-28
MS group identity	201	11.6	8.5	4-28	121	9.9	7.6	4-28	80	14.1	9.3	4-28
Anticipated stigma	201	28.4	9.6	12-56	121	25.9	8.5	12-47	80	32.1	9.8	14-56

		n	%	N	%	n	%
Gender (n = 197)	Men	51	25.9	35	29.9	16	20
	Women	146	74.1	82	70.1	64	80
	Missing	4					
Time since diagnosis in years (n = 198)	< 1	10	5.1	3	2.5	7	8.8
	1-3	38	19.2	18	15.3	20	25
	3-5	24	12.1	13	11	11	13.8
	5-10	39	19.7	23	19.5	16	20
	10-15	47	23.7	32	27.1	15	18.8
	> 15	40	20.2	29	24.6	11	13.8
	Missing	3					

MS type (n = 193)	Relapsing-remitting	106	54.9	68	60.2	38	47.5
	Primary Progressive	34	17.6	18	15.9	16	20
	Secondary Progressive	43	22.3	21	18.6	22	27.5
	Benign	10	5.2	6	5.3	4	5
	Missing	8					
Ethnicity (n = 196)	White British	160	81.6	98	84.5	62	77.5
	White other	14	7.1	5	4.3	9	11.3
	Black British	2	1	2	1.7	0	0
	Black other	3	1.5	1	0.9	2	2.6
	Indian	5	2.6	5	4.3	0	0
	Chinese	3	1.5	1	0.9	2	2.5
	Other	9	4.5	4	3.6	5	6.4
	Missing	5					

3.4.2 Missing data

Of the 201 participants, five participants did not complete all of the demographic information. The missing demographic information included gender (n=197), age (n=197) and time since diagnosis (n=198), and since these variables were included in the regression model as potential confounders, the data from these participants were excluded from the regression analyses where these factors were entered in the first step (such that n=196 for the final regression model). Thirty nine participants failed to complete some of the items on the measures in the questionnaire pack. This broke down as follows. Two participants missed one question from the HADS. Ten respondents missed out some or all four of the questions on the maintained group membership scale. Twenty seven participants failed to complete part or all of the CIASS. On the MS group identity measure, 16 respondents missed out some or all four of the questions. The majority of the missing data from the measures appeared to be a result of a systematic interpretation of or response to certain questionnaires or sub-sections of questionnaires, as detailed below. Given this pattern and the relatively large number of missing items, rather than exclude the data from the regression analyses, the decision was taken to systematically replace all of the data missing from the measures, as outlined below.

On the MS group identity measure, missing answers were often accompanied with “N/A” in the section where the participant was asked to list any MS groups he/she belonged to. The implication was that this meant the respondent didn’t see him/herself as part of an MS group. In this case, the score would have been

1 (the lowest score) for each of the four questions. This was also the modal value from the other respondents' answers. Accordingly, these missing data were replaced with the mode for each question from the other respondents.

Twenty four of the twenty seven participants who failed to complete the CIASS missed out all of the second subsection, relating to anticipated stigma from employers or co-workers. This was often accompanied with "N/A" implying that when respondents did not think they would return to work, the subscale was deemed to be irrelevant. The missing data on this measure were replaced with the mean values for each question from the other respondents' completed answers. All missing data from the remaining measures were similarly replaced with the mean values for each question from the other respondents' completed answers. To check that replacing the data in this way did not affect the pattern of results a sensitivity analysis was run using data from the participants who had fully completed all the measures (such that n=158 for the final regression model).

3.4.3 Measures

Cronbach's alpha was calculated to provide a measure of internal consistency for each of the scales. This was 0.93 for maintained group memberships, 0.97 for MS group identification, 0.88 for anticipated stigma and 0.89 for psychological distress.

3.4.4 Inter-correlations

Psychological distress and anticipated stigma were approximately normally distributed. Maintained group membership was not normally distributed and neither was MS group identity, with 41% of respondents scoring the lowest value of 4 on the latter scale (33% before missing data were corrected for). Accordingly, both parametric and non-parametric tests were used for the preliminary correlation analysis as appropriate. Bivariate correlations are reported in table 2 (all 2-tailed tests). Age was not significantly correlated to maintained group membership (r_s = 0.06, p = 0.43) or MS group identity (r_s = 0.08, p = 0.29) but it was significantly correlated with both psychological distress (r_p = -0.26, p <0.001) and anticipated stigma (r_p = -0.22, p = 0.002). Similarly, time since diagnosis was not significantly correlated to maintained group memberships (r_s= 0.08, p = 0.25) or MS group identity (r_s = -0.04, p = 0.55) but was significantly correlated with both psychological distress (r_s = -0.16, p = 0.022) and anticipated stigma (r_s= -0.16, p = 0.021).

T-tests revealed the same pattern with respect to gender. Women showed significantly greater levels of psychological distress (mean = 18.8, SD = 8.0) than men (mean =15.2, SD=7.6), t (195) = -2.84, p < 0.01, CI [-6.18, -1.11]. Women also showed significantly higher levels of anticipated stigma (mean =29.3, SD = 9.9) than men (mean = 25.7, SD= 8.5), t(195)= -2.33, p<0.05, CI [-6.66, -0.55]. Mann-Whitney U test indicated there were no significant difference between men (Mdn = 15) and women (Mdn = 13) in maintained group memberships: U = 3578, Z = -0.42 p = 0.68, r = -0.03. Neither was there a significant difference

between men (Mdn = 8) and women (Mdn = 6.5) in MS group identity; U = 3335, Z = -1.15 p = 0.25, r = -0.08.

There was a significant negative correlation between maintained group memberships and psychological distress (r_s = -0.43, p < 0.01 (1-tailed)). There was also a significant positive relationship between anticipated stigma and psychological distress (r_p = 0.54, p<0.01 (1-tailed)). MS group identity was not found to be significantly correlated to psychological distress (r_s = -0.07, p = 0.17 (1-tailed)).

Table 2. Bivariate correlations

	Maintained group memberships	Anticipated stigma	MS group identity	Psychological distress
Age (years)	$r_s = 0.06$ ($p = 0.43$)	$r_p = -0.22^{**}$ ($p = 0.002$)	$r_s = 0.08$ ($p = 0.29$)	$r_p = -0.26^{**}$ ($p < 0.001$)
Time since diagnosis (years)	$r_s = 0.08$ ($p = 0.25$)	$r_s = -0.16^{*}$ ($p = 0.021$)	$r_s = -0.04$ ($p = 0.55$)	$r_s = -0.16^{*}$ ($p = 0.022$)

** $p < 0.01$ *$p < 0.05$

3.4.5 Regression analyses

Initially, the relationship between each continuous independent variable and the dependent variable was checked to ensure linearity assumptions were met (Field, 2013). The maximum absolute standardised residual value was less than 3.29, indicating there were no outliers influencing the regression model (Field, 2013; Pallant, 2013). This was further confirmed by checking that Cook's distances were less than 1. The maximum Cook's distance was 0.07, indicating that there were no cases with undue influence over the regression parameters (Field, 2013; Pallant, 2013). There was no indication of multi-collinearity from inspection of the collinearity matrix. In addition, all the variance inflation factor (VIF) values were all well below 10 and the tolerance statistics were all well above 0.2, confirming there was no collinearity (Field, 2013). Accordingly, a linear regression was conducted.

In separate regression analyses (with age, gender and time since diagnosis included in first step), maintained group membership was associated with reduced psychological distress ($\beta = -0.42$, $p < 0.01$) and accounted for 17.7% of the variance. Anticipated stigma was associated with greater psychological distress ($\beta = 0.496$, $p < 0.01$) explaining 22.7% of the variance. The negative association between MS group identity and psychological distress was not statistically significant ($\beta = -0.12$, $p = 0.096$).

Hierarchical regression was performed to enable an examination of the unique contribution of each variable on psychological distress. Age, time since

diagnosis and gender were identified by the correlation analyses as potential confounding variables so were entered into step one of the hierarchical regression. Together they explained 9.7% of the variance in psychological distress. Maintained group membership, MS group identity and anticipated stigma were entered in the second step. This enabled an assessment of the variance in psychological distress explained by all three predictor variables in addition to the variance explained by age, time since diagnosis and gender. Each predictor variable showed a statistically significant association with psychological distress. For anticipated stigma this was a positive association ($\beta = 0.388$, $p < 0.001$) and for maintained group memberships this was a negative relationship ($\beta = -0.288$, $p < 0.001$). In contrast to the separate regression analyses, MS group identity showed a small negative association with psychological distress ($\beta = -0.133$, $p = 0.019$). Together the three variables accounted for an additional 31.3% of the variance. (See table 3 for hierarchical regression statistics). To check whether being recruited online or via the postal survey acted as a confounding factor this variable was added into the model. In the second step of the hierarchical regression, the addition of recruitment method was not significant and made no material difference to the regression coefficients or to the probability values, such that the overall conclusion remained the same (see appendix 4).

Further checks were carried out to ensure the underlying assumptions were met. Inspection of the histogram of the regression standardised residual and the normal probability plot (P-P) of regression standardised residual for the

dependent variable revealed that the residuals were approximately normally distributed. The assumption of homoscedasticity was confirmed upon inspection of the scatterplot of the standardised residuals. This showed a roughly rectangular array of points randomly dispersed throughout the plot. Inspection of the partial plots did not indicate any non-linear relationships. Independence of errors was indicated by a Durbin-Watson value of 1.85 which fell within the guideline values of 1 to 3 (Field, 2013).

When MS group identity was investigated as a moderator of the relationship between anticipated stigma and psychological distress, it was found to have a small negative effect (such that it slightly reduced the negative effect of stigma on psychological wellbeing). This difference was not statistically significant and confidence intervals crossed zero (n=201, b = -0.005, 95%CI [-0.016, 0.007], t = -0.771, p = 0.442).

In sensitivity analyses the pattern of results for the hierarchical regression remained unchanged, except that in the final model, age was not found to be a statistically significant predictor of psychological distress (see table 4). The moderation analysis also yielded the same pattern of results (n = 162, b = -0.006, 95%CI [-0.018, 0.006], t= -0.95, p=0.34).

Table 3. Hierarchical regression predicting psychological distress

n = 196	Predictor variable	Outcome variable: psychological distress (HADS)						
		b (SE)	Beta	p	95% CI		R2 change	Total R2
Step 1	**Age**	-0.149 (0.056)	-0.202**	0.009	-0.260	-0.038	0.097**	0.097
	Time since diagnosis	-0.380 (0.393)	-0.073	0.334	-1.155	0.394		
	Gender	3.048 (1.269)	0.166*	0.017	0.544	5.551		

Step 2	**Age**	-0.094 (0.047)	-0.127*	0.046	-0.186	-0.002	0.313**	0.410
	Time since diagnosis	-0.114 (0.322)	-0.022	0.724	-0.750	0.522		
	Gender	1.763 (1.046)	0.096	0.094	-0.301	3.828		
	Maintained group memberships	-0.284 (0.060)	-0.288**	<0.001	-0.402	-0.166		
	Anticipated stigma	0.324 (0.052)	0.388**	<0.001	0.221	0.427		
	MS group identity	-0.127 (0.053)	-0.133*	0.019	-0.232	-0.021		

*p<0.05 **p<0.01

Table 4. Sensitivity analysis of hierarchical regression predicting psychological distress

n =158	Predictor variable	Outcome variable: psychological distress (HADS)						
		b (SE)	Beta	p	95% CI		R2 change	Total R2
Step 1	**Age**	-0.172 (0.067)	-0.218*	0.011	-0.304	-0.039	0.118**	0.118
	Time since diagnosis	-0.655 (0.450)	-0.123	0.147	-1.543	0.233		
	Gender	2.689 (1.388)	0.148	0.055	-0.053	5.431		

Step 2	**Age**	-0.082 (0.055)	-0.104	0.141	-0.191	0.028	0.323**	0.441
	Time since diagnosis	-0.387 (0.365)	-0.073	0.290	-1.108	0.333		
	Gender	1.210 (1.134)	0.067	0.288	-1.031	3.451		
	Maintained group memberships	-0.285 (0.066)	-0.290**	<0.001	-0.415	-0.156		
	Anticipated stigma	0.324 (0.057)	0.400**	<0.001	0.211	0.436		
	MS group identity	-0.122 (0.057)	-0.130*	0.035	-0.235	-0.008		

3.5 Discussion

This study aimed to establish the relationships between mental health and maintained group memberships, MS group identity, and anticipated stigma. As predicted by hypothesis 1, increased maintenance of pre-diagnosis group memberships was associated with reduced psychological distress. This is consistent with a similar finding in the context of acquired brain injury (C. Haslam et al., 2008) and is also in line with literature on identity motives that suggests one way people strive to achieve positive self-esteem is via identity continuity (Vignoles, 2011). The finding emphasises both the detrimental impact of social identity loss and the importance of maintaining social groups in facilitating psychological wellbeing in people with MS. More broadly, it demonstrates the theoretical contribution that a social identity approach can make to the field of clinical neuropsychology (C. Haslam et al., 2008).

The second hypothesis was that there would be a negative relationship between MS group identity and psychological distress. There was some evidence in support of this hypothesis. Although the negative correlation between MS group identity and psychological distress did not reach statistical significance on its own, when the other identity-related factors and potentially influential demographic variables were held constant in the regression model, MS group identity was found to explain a small but significant amount of additional variance in psychological distress. This shows some consistency with previous research which found that disability identity predicted lower anxiety and depression in people with MS (Bogart, 2015). That the effect of MS group

identity only became significant when maintained group memberships and anticipated stigma were held constant may indicate the occurrence of social identity-related processes acting in opposing directions. Indeed, there was evidence of social identity processes that were detrimental to mental health; as predicted by hypothesis 3, increased levels of anticipated stigma were associated with increased levels of psychological distress. Taken together, these findings are in line with Crabtree et al.'s (2010) result, that positive effects of group identification were suppressed by an underlying negative influence of identifying with a socially devalued group. A co-occurring negative effect could also account for the relatively small beneficial effect of MS group identity. In order to better understand the precise nature of the underlying processes and whether they do, indeed, operate in simultaneously positive and negative directions, further research including potential mediating variables is needed (as discussed in the next section).

The hypothesis that identification with MS groups may act as a buffer against the negative effects of stigma was also tested in this study. Contrary to expectations, the relationship between stigma and psychological distress was not found to be moderated by group identification. This stands in contrast to Nario-Redmond et al.'s (2013) findings that people with MS who identified highly with disability groups showed increased use of collective strategies endorsing social change, and a corresponding bolstering of collective and personal self-esteem (Nario-Redmond et al., 2013). As before, one reason may be that there are identity processes not measured in this study acting in

opposing directions, masking any moderation effects. Alternatively, it may be that certain groups of people derive greater benefit from shared identification, such that a moderation effect is only relevant to a subset of the population. One possibility is that the buffering effect of MS groups may apply predominantly to people who have decided to identify with MS groups for self-protective reasons. People who experience stigma as less threatening to valued social identities, sense of self and self-esteem, may perceive less need for in-group support to challenge negative stereotypes.

An additional noteworthy finding was that the majority of respondents scored the lowest value possible on the MS group identity scale. This appears to indicate a general reluctance to identify with other people with MS or take part in MS groups. Although the study did not explicitly investigate whether people adopted a protective strategy of non-identification, the literature on stigmatised identities does suggest that people often resist identification with devalued groups (Crabtree et al., 2010; Dunn & Burcaw, 2013) and that involvement can limit wider 'normative' networks (Markowitz, 2015). One way of avoiding the unwanted association is to attempt to conceal the stigmatising attribute (Dunn & Burcaw, 2013). In the context of MS, Nario-Redmond et al. (2013) found that lower endorsement of disability identity amongst people with MS was related to greater adoption of strategies aimed at escaping association with the disability group and working to conceal disability status. This raises the interesting possibility that the desire to conceal MS and the degree to which symptoms can be concealed may be relevant factors. Social

identity theory recognises that group boundaries are not always permeable and that it may not always be possible to avoid being associated with negatively perceived groups. In the case of MS, this may be the case as symptoms become more visible. Those who are largely able to conceal their MS and who are, thus, more able to pass as 'normal' members of healthy majority groups may be less inclined to identify with an MS group. Conversely, people with more obvious impairment who are no longer able to hide the illness may be more likely to identify with MS groups and adopt collective strategies, such as disability redefinition and stereotype resistance in order to obtain the associated protective effects. Support for this suggestion is found upon closer inspection of the sample demographics in Bogart's (2015) study. The authors found that increased disability identity predicted reduced anxiety and depression. Interestingly, in light of the above suggestion, all the participants had self-reported mobility impairment, widely considered to be a stigmatising aspect of MS (Dennison, Yardley, Devereux, & Moss-Morris, 2011) and difficult to conceal. Further support for the adoption of differing identity strategies depending on visibility status comes from comparison of the two samples in Nario-Redmond et al.'s (2013) study. Here, those with more visible disabilities were more likely to be advocates of social change for disability rights, whereas those whose disabilities were less visible were more likely to try to minimise and deny the illness.

A final interesting finding was that age emerged as a significant predictor of psychological distress in the regression model (with increased age predicting

reduced psychological distress). Although this effect did not reach significance in the sensitivity analysis, the direction of the effect remained the same. One explanation, in line with the comparative nature of social group evaluations, is that as people age, their peer groups are also more likely to have illnesses or disability. Consequently, social comparisons between peer groups and MS groups then become more equal and having MS less stigmatising, which may result in a reduction in the associated psychological distress. This suggestion finds some support in the empirical literature on ageing with MS (DiLorenzo, Becker-Feigeles, Halper, & Picone, 2008).

3.5.1 Clinical implications

The study confirms the importance of social identity processes for the mental health of people with MS. Such processes are currently given limited consideration in clinical practice and greater understanding of both the positive and negative implications of social identity change and identification with MS groups may have significant implications for the way neuropsychological rehabilitation is considered and implemented. Certainly, the common blanket assumption that MS groups in and of themselves are beneficial (e.g. Visschedijk et al., 2004) finds only marginal support from this study. Instead it is evident that with respect to social identities, the experience of MS is complex. There was some evidence that identifying with an MS group can confer psychological benefit, and research is now needed to explore more precisely what aspects of group identification confer most benefit and for whom. Importantly, stigma may have both positive and negative implications for group participation. In

line with empowerment approaches, belonging to MS groups may foster stereotype rejection (Corrigan et al., 2005; Nario-Redmond et al., 2013). On the other hand, MS group participation may cultivate internalised stigma, with implications for the degree to which social identity resources may be gleaned without underlying cost to self-esteem (Crabtree et al., 2010; Markowitz, 2015). The finding that anticipated stigma was associated with increased psychological distress, and the apparent reluctance of respondents to identify with MS groups may also have implications for intervention engagement. Better understanding of the precise processes, the directions in which they operate and to whom they apply may go some way towards explaining the mixed findings of the value of MS support groups (Uccelli, Mohr, Battaglia, Zagami, & M. Mohr, 2004). It will also be valuable in informing intervention targeting and design.

3.5.2 Limitations and further research

The clearest limitation of this survey is the cross-sectional design, which limits conclusions regarding the causal nature of the identified relationships. For instance, there may well be a degree of reciprocity, whereby increased psychological distress reduces the likelihood of maintaining group memberships and increases negative appraisals of MS groups and anticipated stigma, which in turn increases psychological distress. A longitudinal study would provide a stronger test of the hypotheses. The study design also limits more in depth exploration of underlying processes, particularly with respect to exploring the intriguing possibility of social identity processes acting both to

reduce and increase psychological distress. Given the complexity of the relationship between stigmatised identities and psychological wellbeing, it is necessary to look not only at the quantitative associations, but to explore what the identity means to different people and how this may operate in tandem with stigma to render them more or less vulnerable to associated distress (Quinn & Chaudoir, 2009). Qualitative research would help gain greater insight into the identity strategies people adopt, reasons why they may or may not choose to identify with MS groups, and their perceptions of doing so. The explanatory power of the study could also be increased by including scales measuring different aspects of stigma. For instance, measures of internalised stigma (Molina, Choi, Cella, & Rao, 2013), sensitivity to stigma (Major & O'Brien, 2005), and stigma resistance (Crabtree et al., 2010) as well as identity centrality and salience (Quinn & Earnshaw, 2013) may help clarify whether these factors are affected positively or negatively by being part of an MS group. Further measures were not included in the current design, partly due to the greater number of participants this would have required for sufficient power. Another reason for not including more stigma-related measures was to avoid potential bias from response fatigue. This was especially true since additional measures were already being included for the purposes of the parallel study. This in itself should be noted as a possible source of bias, although systematic effects are highly unlikely since the measures used by the two studies were intermixed and there is no reason to suppose that responses from one would influence those of the other.

Part of the rationale for including postal as well as online versions of the questionnaire was to broaden the range of respondents, increasing the representativeness of the sample and improving generalisability. In line with this, the age range of postal survey respondents was slightly older than those who completed the online questionnaire. This may be particularly relevant given the indications of increasing prevalence of MS in the older population (Solaro et al., 2015). It may also be that people attending MS clinics are more likely to have relapsing-remitting MS, as opposed to a longer-standing progressive form of the disease (whose care may be more likely to be managed by general practitioners or rehabilitation medicine consultants). This potential form of bias was, again, addressed by inclusion of the online survey. There were more female than male respondents, with numbers broadly in line with the estimated male-to-female incidence ratio for MS (Alonso, Jick, Olek, & Hernan, 2007; Mackenzie, Morant, Bloomfield, Macdonald, & O'Riordan, 2013). There were also a greater number of respondents who reported relapsing-remitting MS. This is in line with relapsing-remitting being the most prevalent type of MS (MS UK, 2014) and with higher documented incidence rates than the primary progressive form (Alonso et al., 2007).

Given the nature of the questionnaire, it may be that fewer people with cognitive or visual impairment completed the study. Alternatively, and as reported anecdotally in a comparable study (Williams et al., 2004), more assistance may have been provided by carers in such instances, which may have

introduced bias: for instance respondents may have been less willing to report psychological distress.

The study did highlight areas in which two of the measures could be improved. The MS group identity scale was left blank by many of the respondents. Several of those who left the scale blank reported not belonging to any MS groups and often wrote “N/A” next to the scale, implying that people who did not consider themselves members of any MS groups felt the scale was irrelevant. Although the scale has been used for people with neurological disabilities (C. Haslam et al., 2008), it was originally designed in the context of university students. This study indicates that further consideration may need to be given to the scale wording when used with people with MS to avoid missing data. A similar problem was evident with the CIASS. The subset of questions relating to how individuals felt they might be treated by employers or co-workers was left blank by many respondents. Again, the “N/A” that commonly accompanied the missing data implied that when respondents did not think that they would return to work, the subscale was deemed to be irrelevant. Here wording could be adjusted to include hypothetical scenarios.

A small typographical error with the HADS also needs acknowledgement. On one of the questions on the anxiety subscale, the fourth response read as “not at all” as opposed to “only occasionally” and on one question in the anxiety subscale, the answer read as “seldom” as opposed to “very seldom”. However, given the similarity in meaning, as well as the publisher’s guidelines that the

scale may be considered valid when data are missing from one item on either subscale (GL Assessments, n.d.), it is unlikely that the overall pattern of results was affected.

The extent to which findings and implications can be applied to the specific context of MS group interventions is also limited. For the purposes of this thesis, further research related to how the identified relationships may affect engagement with, and efficacy of, MS psychological adjustment groups is now needed. Ultimately, it would be valuable to incorporate measures of stigma and MS group identification as baseline and outcome measures in a psychological adjustment intervention RCT. This would increase understanding of the role of identification with group members on intervention outcome, whilst a longitudinal design including pre- and post-intervention measures would allow firmer conclusions regarding causality. Inclusion of a variety of stigma-related measures as well as factors such as MS visibility status would elucidate more precisely the nature and direction of the underlying processes. In order to determine the most appropriate measures to include, particularly with respect to the most relevant aspects of stigma, further exploratory research is needed.

An informative next step would be to review and synthesise the existing literature using a social identity framework. Exploration of related qualitative research from this perspective may uncover valuable insight regarding identity-related processes relevant to how MS groups may affect mental health.

Similarly, looking at the quantitative research on the efficacy of group psychological adjustment interventions through a social identity lens may offer clues regarding the characteristics of people who gain greatest or least benefit from this format. Accordingly, an approach to literature review and synthesis that can bring together work from both qualitative and quantitative approaches is needed. The relatively new realist synthesis method is a promising candidate. This approach has a focus on explanation and is particularly suited to gaining understanding of how complex social interventions work. Accordingly, a realist synthesis of the identity processes underlying group psychological adjustment interventions for people with MS was undertaken, as presented in the following chapter.

Chapter 4. The Role of Group Delivery Format in Psychological Adjustment Interventions for People with MS: A Realist Synthesis

4.1 Summary

The survey study in the previous chapter confirmed the relevance of social identity process to the mental health and wellbeing of people with MS. In order to gain a better understanding of how such processes relate to group psychological adjustment interventions, a useful next step was to review and synthesise the existing literature using a social identity framework. Given the need for an explanatory focus and the insight that could be gained from both quantitative and qualitative papers, a realist synthesis was undertaken. This is an interpretive type of systematic review that is both theory-driven and theory-generating, and has an ultimate goal of providing the understanding needed to shape and target complex social interventions. Drawing on social identity theory, the aim of the current realist synthesis was to generate mid-range theories addressing the question: what are the processes underlying group MS psychological adjustment interventions that contribute to intervention success or failure. The focus was on group format as opposed to intervention content. Given the finding in the previous chapter of the detrimental effect of stigma on mental health, how perceived stigma may affect these processes was also investigated. Finally, who may derive greatest or least benefit from group interventions was considered.

Thirty five papers were identified by the search strategies. Overall, the findings indicated that a group format can offer benefits distinct from intervention content and which would not be achieved from one-to-one delivery. The important caveat is that obtaining these benefits depends, in part, on the degree of identity threat posed by MS. Identity threat was found to exist on a continuum and was influenced by perceived stigma, social identity continuity, integration of MS into identity, time since diagnosis and age. Results indicated that when people experience MS as posing a threat to

identity, some mechanisms, such as being confronted with a feared future identity, may have a negative effect on psychological wellbeing. When identity threat is high, interventions may be avoided entirely to protect psychological wellbeing. The mechanisms and associated outcomes relating to psychological wellbeing are presented for differing levels of identity threat. These constitute mid-range theories which now require further testing and refinement.

4.2 Background

As outlined in the introduction, psychological adjustment interventions for people with MS are becoming increasingly common. This is in response to the high prevalence of psychological distress amongst people with MS (Feinstein, 2011). Research into the efficacy of such interventions has tended to focus on the therapeutic model, and findings are particularly encouraging with respect to interventions based on cognitive behavioural therapy (Firth, 2014). In clinical practice, MS psychological adjustment interventions are often delivered in a group setting, but few studies have investigated the impact of delivery format. There is a need to review and synthesise the existing literature in order to gain understanding of the effect of delivering such interventions in a group format and elucidate the underlying processes.

Reasons for group delivery of MS psychological adjustment interventions appears to be due more to lack of resources, than to being evidence-based or theory-led (Lincoln et al., 2011). A commonly held assumption is that a group format offers participants additional benefits by virtue of the concomitant

social support. However, little empirical research has tested this claim in an MS population, or explicitly investigated which aspects of group format may offer benefit (or, indeed, be unhelpful) and why. Anecdotal reports indicate that, in addition to improvements due to the intervention content, psychological benefit may be derived from a group format due to factors such as increased peer support and reduced feelings of alienation (Thomas et al., 2006). Some empirical support for this comes from a study examining the relative efficacy of group and individual psychological adjustment interventions for people with MS. Rigby et al. (2008) compared a brief (3-week) cognitive behavioural, psychological group intervention with a non-structured social discussion group and a control condition where participants received an information booklet. Their results indicated that group participation in and of itself may have a beneficial impact on mood (and counteract the decline in mood that occurred in the booklet-only group). However, high levels of attrition render this conclusion a tentative one and an additional control group would be needed for confirmation. Since the intervention was only brief, the authors speculated that with longer interventions additional benefits deriving from the psychological content may be found, which may lead to differentiation of results between the social and psychological groups. Seemingly contradictory results were found in a study investigating the efficacy of peer support groups for people with MS (Uccelli et al., 2004). Here, no consistent improvement in depression was found across patients. Interestingly, the results indicated that group participation may actually be detrimental for those with better baseline

mental health, highlighting the importance of considering the optimal treatment modalities for participants with different baseline characteristics.

A systematic review of the effectiveness of CBT for depression in people with MS identified seven RCTs which included three individual CBT studies, three group CBT interventions, and one using computerised-CBT (Hind et al., 2014). The meta-analysis revealed CBT to be beneficial overall, but in the indirect comparison of group and individual interventions there was not enough evidence to suggest a difference in outcome between the formats. Part of the reason for this insufficient evidence is down to the large heterogeneity across studies, in both the participant demographics and intervention content and format. This is an inevitable problem for standard systematic reviews when examining complex social interventions.

Another reason for the conclusion, common to many systematic reviews, that 'more primary research is required', is that underlying theories are rarely articulated prior to trials of complex interventions (see Greenhalgh, Kristjansson, & Robinson, 2007). Furthermore, in standard systematic reviews, study inclusion rests on the basis of methodological standards without consideration of theoretical quality. This limits the advances that could be made in understanding how complex social interventions work; the underlying processes remain hidden in the intervention 'black box'. When considering the type of review method needed to explore the question of group processes, a standard systematic review was deemed to be of limited value, since it would

be unable to draw on existing theory or go much beyond questions of efficacy to provide satisfactory explanations regarding why group interventions are found to beneficial in some cases and not in others. Furthermore, standard reviews cannot elucidate process to suggest what aspects of group format are either beneficial or detrimental to psychological wellbeing. Finally, since systematic reviews are limited by strict inclusion criteria regarding intervention type, participant groups and study designs, potentially valuable insights from studies investigating different types of MS groups, such as peer support groups, would be overlooked. Clearly a different approach to review and synthesis was needed. The most appropriate candidate was a realist synthesis.

4.2.1 Realist synthesis

Realist syntheses have gained increasing recognition in recent years, largely due to their ability to provide the explanation that is lacking in standard systematic reviews. Based on a realist philosophy of science (see chapter 2), they are an interpretive type of systematic review with an explanatory focus. They are both theory driven and theory generating, with the ultimate goal being to provide the understanding needed to shape and target interventions and provide recommendations to policy makers (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013). Whereas the focus of standard, Cochrane-style systematic reviews is whether or not an intervention works, realist reviews are concerned with understanding why. Thus, the standard research question 'what works' is replaced by the realist question: "what is it about this kind of intervention that works, for whom, in what circumstances

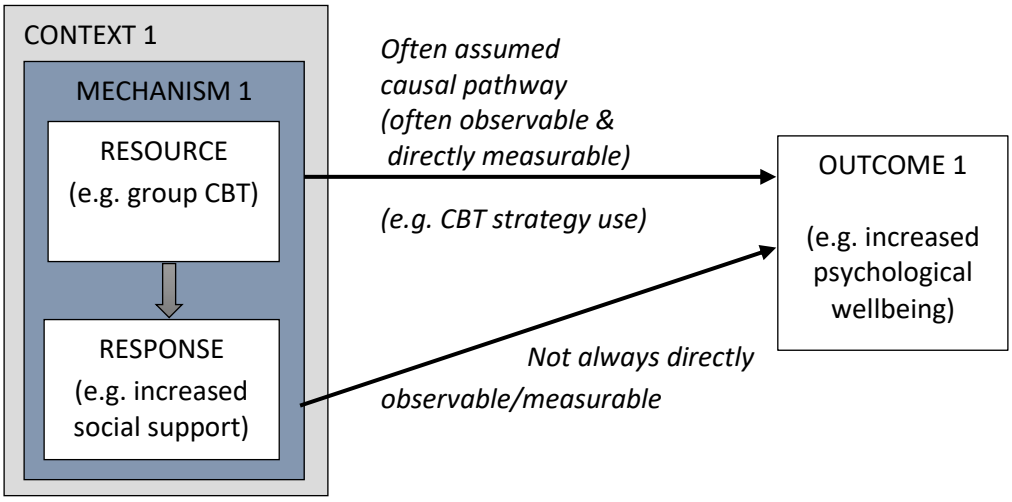
and why?" (Pawson, Greenhalgh, Harvey, & Walshe, 2004, p. 2). Depending on their scope, realist syntheses may choose to hone in on certain aspects of this broader question.

The need to go beyond questions of efficacy in the synthesis of clinical research was recognised in a NICE document entitled: "Moving beyond effectiveness in evidence synthesis" (Popay, 2006). In its discussion of the methodological issues this entails, realist syntheses were included as a potential new type of systematic review with an explanatory focus (Pawson & Bellamy, 2006). The focus on understanding in realist synthesis is also in accord with the updated Medical Research Council (MRC) guidelines for developing and evaluating complex interventions (Craig et al., 2008). In comparison to earlier guidelines, there is more of a focus on process and an increased recognition of the need for good theoretical understanding of how interventions cause change (Craig et al., 2008, p.588). The proposed stages are also recognised as being less linear, and more iterative than in previous guidelines. This ties in with the iterative stages of the realist synthesis.

The initial stage of a realist synthesis involves articulating the key candidate theories to be explored (Wong, Greenhalgh, et al., 2013; Wong, Westhorp et al., 2013). Substantive theory is used to develop an initial rough programme theory which is then refined iteratively during the course of the synthesis. Upon completion, no quantifiable summative judgement of intervention effectiveness is produced, nor is absolute certainty established. Instead, the

aim is to develop mid-range theories in the form of context-mechanism-outcome (CMO) patterns. (In realist language, 'mechanism' is the term for the processes that underlie the intervention. Mechanisms are often divided into two parts, resource and response). The level of theory generated is termed 'mid-range', in that it is at a level of abstraction that allows for some generalisation but close enough to the data and with sufficient detail from which testable hypotheses can be derived (Wong, Greenhalgh, et al., 2013; Wong, Westhorp, et al., 2013). The working assumption of the approach is that mechanisms are context sensitive, such that they are triggered in certain contexts to generate outcomes of interest (see figure 1). If the context is altered, the mechanism may not come into play, or a different mechanism may be actualised, producing differing outcomes. Thus, the different results observed in a sample of primary studies may be explained by the interplay between context and mechanism.

Figure 1. Schematic representation of CMO configurations (adapted from Dalkin, 2014)



Multiple sources of evidence may be included, with quantitative and qualitative studies both seen as valuable in uncovering potential underlying mechanisms (Pawson, Greenhalgh, Harvey, & Walshe, 2005). Moreover, the approach enables synthesis across intervention type since mechanisms rather than programmes are the basic unit of analysis (Wong, Westhorp, et al., 2013). Indeed, different studies are likely to address only part of identified CMO patterns and theory is refined in the synthesis process as the findings in one study are able to provide an explanation for the results of another (Pawson et al., 2004).

In addition, in realist syntheses the value of informative 'nuggets' is recognised (Wong, Westhorp, et al., 2013). Accordingly, some articles included in a synthesis may provide large amounts of relevant data, others only a few sentences of speculation. Data extraction is not, therefore, carried out using uniform extraction sheets, but requires subjective decision-making. Study inclusion is decided on the basis of relevance to the research question, where relevance is not a straightforward 'in or out', but seen as more of a continuum (McLean et al., 2014). Standardised checklists of methodological quality or hierarchies of evidence are not used. Indeed, in the attempt to standardise interventions, the RCT, at the top of the hierarchy of methodological quality, actually washes out key explanatory ingredients. Instead evidence is appraised in terms of 'fitness for purpose' – the degree to which the paper is able to provide information from which to refine the initial programme theory.

4.2.2 Initial programme theory

As outlined in the introduction, the social identity approach offers a useful theoretical platform from which to investigate the aspects of group format that may influence psychological wellbeing. Drawing on this approach, the initial programme theory hypothesised that being part of an MS group could improve psychological wellbeing through engendering a sense of belonging, providing meaning and purpose, adopting positive group norms, perspectives and goals, and encouraging the receipt and provision of social support (see particularly Cruwys, S. A. Haslam, Dingle, C. Haslam et al., 2014). On the other hand, chronic illness is commonly seen as a stigmatised condition (Earnshaw et al., 2012) and it may be that perceived stigma is a key, and largely overlooked, contextual factor. Implicit in social identity theory is the assertion that self-esteem is enhanced by favourable comparison with relevant out-groups (Abrams & Hogg, 1988). As such, maintaining a positive sense of self can be especially difficult for people who have, or are perceived to have, a devalued attribute, such as illness (Major & O'Brien, 2005, p.395). Thus, it may be that identification with an MS group that is seen as inferior by comparison triggers identity processes that decrease psychological wellbeing (Crabtree et al., 2010; Major & O'Brien, 2005). In view of this, the additional hypothesis was that in contexts where group members perceive MS to be stigmatised, different mechanisms operate with consequent negative outcomes with respect to psychological wellbeing.

4.2.3 Aims & objectives

The overarching aim of the realist synthesis was to generate mid-range theories, in the form of CMO configurations, addressing the question: what are the processes underlying group MS psychological adjustment interventions that contribute to intervention success or failure? The focus was on group format rather than intervention content. How perceived stigma may affect these processes and who may derive greatest or least benefit from group interventions was also explored. In realist synthesis terminology, the specific objectives were to draw on the social identity approach to:

1) develop a more in-depth understanding of the mechanisms that underlie MS psychological adjustment group interventions;
2) explore how the context of perceived stigma influences when these mechanism are actualised;
3) refine the proposed context (i.e. perceived stigma) to suggest who may derive greatest or least benefit from group interventions;
4) identify potential outcomes of context-mechanism pathways with respect to psychological wellbeing.

4.3 Methods

This synthesis followed Pawson et al.'s (2005) realist synthesis methods and key stages outlined in methods guidance papers (Pawson et al., 2004). Table 5 provides an outline of the stages. In contrast to Cochrane-style systematic reviews, the process is iterative and the stages may be revisited as the synthesis progresses.

Table 5. Key Stages in realist synthesis (adapted from Pawson et al., 2004)

Realist synthesis (iterative) stages
1) Clarify the scope of the review ➢ identify the research question ➢ refine the purpose of the review ➢ articulate the key theory/theories to be explored and refined
2) Search for relevant evidence, refining inclusion criteria as appropriate in light of the emerging data.
3) Quality appraisal to assess relevance and rigour and using judgement regarding 'fitness for purpose'.
4) Extract relevant data from different studies using an iterative approach.
5) Synthesis of data to refine programme theory i.e. to determine what works for whom, how and under what contexts.
6) Make recommendations regarding future implementation/policy with particular reference to contextual issues.

4.3.1 Search strategy

In a realist synthesis, the search process is not intended to be exhaustive, but to gather a representative body of literature from which theory can be tested and refined (Wong, Pawson, & Owen, 2011). Thus, searching is both purposive and iterative, and involves tracking back and forth from retrieved articles to the developing theory. This avoids the limitations of using fixed search protocols and allows for progressive focussing and searches that can respond flexibly to

emerging findings (Best et al., 2012). The iterative search process allows for search terms to be refined to those which produce both manageable numbers for the scope of the review and the most relevant focus. In line with this, several initial scoping searches were carried out to gain an idea of the breadth and volume of relevant literature and the most relevant search terms. Scoping searches included combinations of keywords relevant to: multiple sclerosis; cognitive behavioural therapy; psychological adjustment, mood disorders, psychological wellbeing or quality of life; identity, social identity, self-categorisation or identity change; support group, peer or group therapy; stigmatised identity or stigma. Initial search terms were determined and three iterative searches performed. (See appendix 5 for the final search strategies and terms). Five databases were used for these searches: OVID Medline, EMBASE, PsycINFO, CINAHL and ASSIA. These were chosen to incorporate research across disciplines of medicine, nursing, psychology and sociology. Only articles written in English were included. The final numbers of included articles following the iterative search process are outlined in figure 2 (last search update May 28th 2015).

The aim of the first search was to seek out studies of psychological adjustment interventions for people with MS. Following the initial scoping searches, in order to restrict the volume of returned articles to a manageable number, and given the evidence for the efficacy of CBT, the decision was taken to limit the search scope to interventions based on CBT principles. The intervention needed to be specific to psychological adjustment/mood (as opposed to CBT

for fatigue or pain management) and employ a mood-based outcome measure. Other inclusion criteria were that the study included a group component and that the intervention was specific to MS (as opposed to including a combination of neurological disorders or chronic conditions). Sibling studies offering additional contextual or empirical information regarding the primary study were considered for inclusion, as were commentaries. Given their length, dissertations were not included, and conference abstracts were not included due to the lack of detail or theoretical insight in this overview.

Some papers were relevant in that they reported a CBT-based psychological adjustment intervention with a group component, but provided little contextual information. Although these were not necessarily included in the final numbers, in order to find the contextual detail sought after by realist synthesis, cluster searching was used to identify sibling studies. This procedure was modified from Booth et al.'s (2013) suggested systematic method for cluster searching and included: checking reference list of primary articles for relevant citations by the authors; checking the reference database for additional relevant articles by the authors; searching for the lead author (and other authors where appropriate) and seeking out publication lists or institutional repositories; and conducting citation searches on the primary citations using Web of Science and Google Scholar. Also in accord with Booth et al.'s (2013) recommendations, in addition to searching for sibling papers to add 'contextual thickness', mention of potential explanatory theory in included articles was noted in order to build up 'conceptual richness' (Booth et al., 2013).

The second search aimed to find papers exploring social identity and MS. Particularly relevant papers provided information regarding whether people join MS groups or not, whether they identify with other people with MS, and how their social identity may have changed following diagnosis. Since this search had a more theoretical leaning, articles were considered for inclusion if the paper considered social identity in chronic illness more generally, provided that a clear subset of people with MS were included. Although potentially of some relevance, given the large volume of articles on the experience of MS, adjustment and coping with the disease, articles with this focus were only considered for inclusion if specific reference to identity or meeting others with the disease was made in the abstract.

The third search was conducted to find papers providing information regarding how people with MS viewed other people with the disease, how they felt about meeting them and potential benefits of peer support and MS groups. Stigma was included as a search term in order to identify articles discussing negative perceptions of meeting others with MS. Inclusion did not extend to articles discussing perceived stigma in other contexts, such as in the workplace. Particularly relevant papers provided information on perceived or actualised benefits or drawbacks to meeting others with the condition, particularly in a group format, as well as whether or not participants felt MS was a stigmatised identity and the implications this may have for meeting others with the condition. Due to the scope of the synthesis, articles focusing on being a support-group facilitator or an official 'peer-supporter' were not included

unless there was also some discussion of the experience of regular group attendees. All articles needed to be specific to MS.

References lists of all included articles were hand-searched to identify further relevant papers, according to the above criteria. This enabled identification of potentially valuable information that would otherwise be missed. (A systematic review conducted according to realist principles (Greenhalgh & Peacock, 2005) found that 51% of empirical studies used in the final report had been identified through such 'snowballing', while database searching using the original protocol identified only 30%). By its nature, iterative searching could continue indefinitely, hence, decisions need to be taken regarding the search endpoint. This was established partly by consideration of saturation, and partly by time constraints. After the third search, it was determined that little would be added to the understanding of the underlying mechanisms by further searches or search refinement and the decision taken to stop searches. In total, 35 articles were included in the synthesis. The characteristics of included articles are reported in table 6. Further information on the participants and design of included empirical studies is presented in table 7.

The filter of quality utilised in traditional systematic reviews is replaced by a filter of relevance in realist syntheses. Since this is relatively subjective, 20% of the full articles selected from the first screen of each iterative search were selected for discussion regarding inclusion or exclusion with one research supervisor. Where the thesis author had any queries regarding inclusion, these

articles were selected for discussion, otherwise selection proceeded according to stratified random sampling, ensuring that both included and excluded articles were discussed. Following this, 10% of included and excluded articles were discussed with a second research supervisor.

Where possible, electronic versions of included articles were imported into NVivo software (NVivo Version 10, 2012). Relevant information from any part of the article was highlighted and coded at nodes in NVivo. If electronic versions were unavailable, coding was carried out by hand and verbatim sections uploaded into NVivo. As further documents revealed supportive or rival ideas, additional codes were developed and bracketed together as appropriate. Once all the articles had been coded, the coded sections were revisited in order to create a final list of possible contexts, mechanisms and outcomes and proposed CMO configurations.

Figure 2. Flow diagram illustrating search process and article inclusion

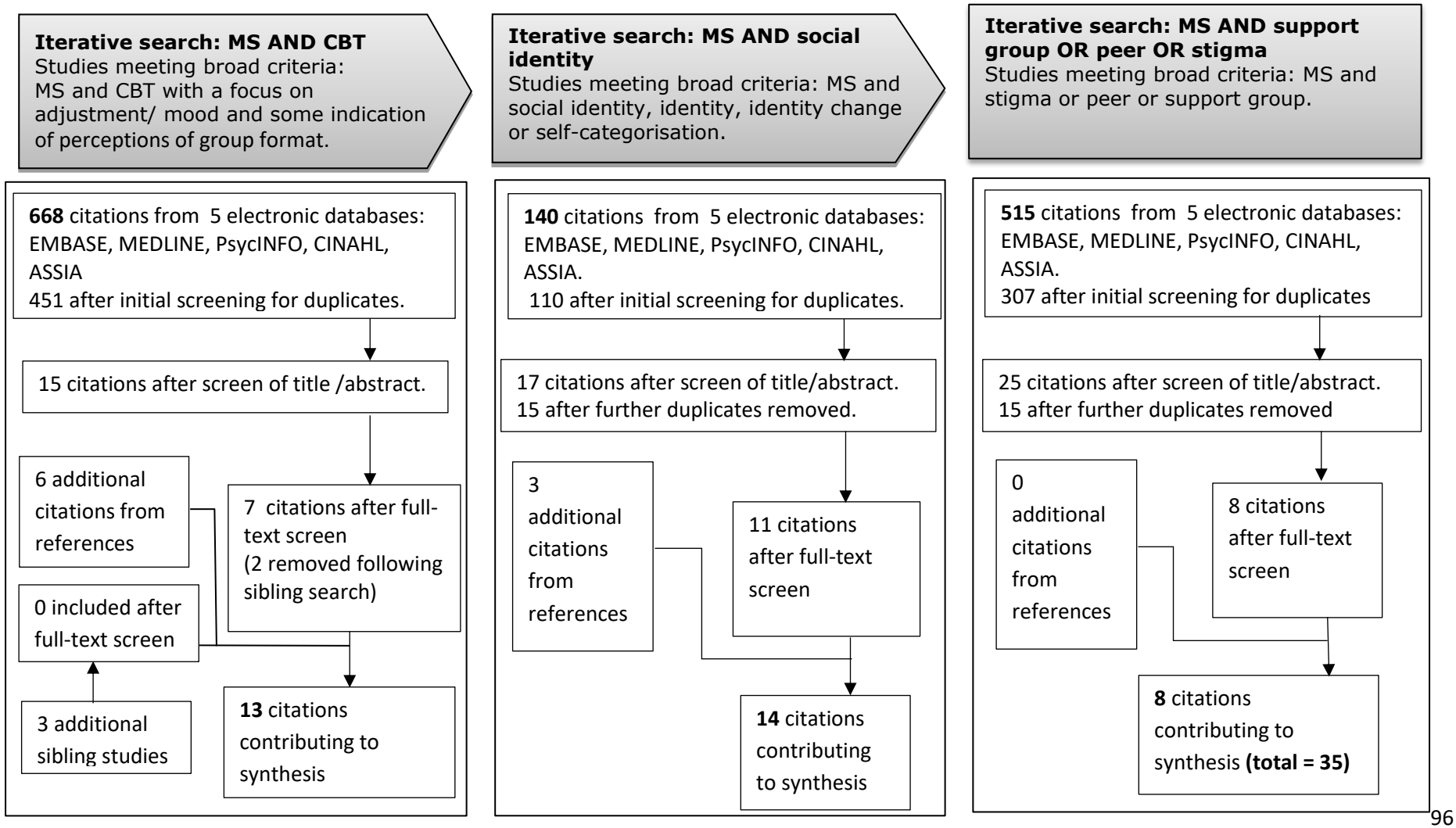


Table 6. Characteristics of included papers

	Author(s)	Year	Title	Type of Paper: Methodology
1	Abma, Osesburg, Widdershoven, Goldsteen and Verkerk	2005	Two women with multiple sclerosis and their caregivers: conflicting normative expectations.	Empirical: qualitative
2	Boeije, Duijnstee, Grypdonck and Pool	2002	Encountering the downward phase: biographical work in people with multiple sclerosis living at home.	Empirical: qualitative
3	Bogart	2015	Disability identity predicts lower anxiety and depression in multiple sclerosis.	Empirical: quantitative
4	Dennison et al.	2011	Experiences of adjusting to early stage Multiple Sclerosis.	Empirical: qualitative
5	DiLorenzo et al.	2008	A qualitative investigation of adaptation in older individuals with multiple sclerosis.	Empirical: qualitative
6	Finlayson and Cho	2011	A profile of support group use and need among middle-aged and older adults with multiple sclerosis.	Empirical: qualitative

7	Fitzgerald and K. A. Paterson	1995	The hidden disability dilemma for the preservation of self.	Empirical: qualitative
8	Forman and Lincoln	2010	Evaluation of an adjustment group for people with multiple sclerosis: a pilot randomized controlled trial.	Empirical: quantitative & qualitative
9	Gallagher, O'Donnell, Minescu and Muldoon	2013	A commentary on 'The effects of identification with a support group on the mental health of people with multiple sclerosis'.	Commentary /letter (on Wakefield et al., 2013a)
10	Graziano et al.	2014	The effects of a group-based cognitive behavioral therapy on people with multiple sclerosis: a randomized controlled trial.	Empirical: quantitative
11	Grytten and Måseide	2005	'What is expressed is not always what is felt': coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis.	Empirical: qualitative
12	Grytten and Måseide	2006	'When I am together with them I feel more ill.' The stigma of multiple sclerosis experienced in social relationships.	Empirical: qualitative

13	Hartings, Pavlou and Davis	1976	Group counselling of MS patients in a programme of comprehensive care.	Discussion paper
14	J. M. Holmes et al.	2012	Attendance at a psychological support group for people with multiple sclerosis and low mood.	Empirical: quantitative & qualitative
15	L. Hunt, Nikopoulou-Smyrni and Reynolds	2014	'It gave me something big in my life to wonder and think about which took over the space… and not MS': Managing well-being in multiple sclerosis through art-making.	Empirical: qualitative
16	Irvine, Davidson, Hoy, and Lowe-Strong	2009	Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition.	Empirical: qualitative
17	Matuska and Erickson	2008	Lifestyle balance: how it is described and experienced by women with multiple sclerosis.	Empirical: qualitative
18	McCabe, Ebacioni, Simmons, McDonald and Melton	2015	Unmet education, psychological and peer support needs of people with multiple sclerosis.	Empirical: quantitative

19	A. Miles	1979	Some psycho-social consequences of MS: problems of social interaction and group identity.	Empirical: qualitative
20	Mohr, Boudewyn, Goodkin, Bostrom and Epstein	2001	Comparative outcomes for individual cognitive-behavior therapy, supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis.	Empirical: quantitative
21	Ng, Amatya and Khan	2013	Outcomes of a peer support program in multiple sclerosis in an Australian community cohort: a prospective study.	Empirical: quantitative
22	Peters, Somerset, Campbell and Sharp	2003	Variables associated with attendance at, and the perceived helpfulness of, meetings for people with multiple sclerosis.	Empirical: quantitative
23	Radice	1995	Nursing and peer support: A winning combination.	Discussion paper
24	Rigby et al.	2008	A randomized group intervention trial to enhance mood and self-efficacy in people with multiple sclerosis.	Empirical: quantitative

25	Salminen, Kanelisto and Karhula	2014	What components of rehabilitation are helpful from the perspective of individuals with multiple sclerosis?	Empirical: qualitative
26	Schwartz and Fox	1995	Who says yes? Identifying selection biases in a psychosocial intervention study of multiple sclerosis.	Empirical: quantitative
27	Schwartz	1999	Teaching coping skills enhances quality of life more than peer support: results of a randomized trial with multiple sclerosis patients.	Empirical: quantitative
28	Sinclair and Scroggie	2005	Effects of a cognitive-behavioral program for women with multiple sclerosis.	Empirical: quantitative
29	Skår, Folkestad, Smedal and Grytten	2013	‘‘I refer to them as my colleagues’’: the experience of mutual recognition of self, identity and empowerment in multiple sclerosis.	Empirical: qualitative
30	Spiegelberg	1980	Support group improves quality of life.	Empirical: qualitative

31	Twomey and Robinson	2010	Pilot study of participating in a fatigue management programme for clients with multiple sclerosis.	Empirical: qualitative
32	Uccelli et al.	2004	Peer support groups in multiple sclerosis: current effectiveness and future directions.	Empirical: quantitative
33	Visschedijk et al.	2004	Development of a cognitive behavioral group intervention programme for patients with multiple sclerosis: an exploratory study.	Empirical: quantitative
34	Wakefield et al.	2013a	The effects of identification with a support group on the mental health of people with multiple sclerosis.	Empirical: quantitative
35	Wakefield, Bickley and Sani	2013b	A reply to Gallagher, O'Donnell, Minescu, & Muldoon's commentary on 'The effects of identification with a support group on the mental health of people with multiple sclerosis.	Commentary/letter (Response to Gallagher et al. (2013))

Table 7. Design and participants of included empirical studies

	First Author & Year	Study Design	Participants	Recruitment
1	Abma (2005)	Interviews (unstructured)	• MS • n = 2 • male/female: 0/2 • age (years): 39 & 48 • years since diagnosis: >17, >20	Selected from 15 patients interviewed following a project on responsibilities in the care of chronically ill people.
2	Boeije (2002)	Interviews (semi-structured)	• People with MS (PWMS), advanced stage & family caregivers • n = 43, (PWMS, 22; caregivers, 21) • male/female: (PWMS, 9/13) • age (years): mean: PWMS, 55 range: PWMS, 31-78 • years since diagnosis: mean: PWMS, 19 range: PWMS, 4-54	Access to MS patients gained through 5 care organisations & 9 members of a research steering committee

3	Bogart (2015)	Survey (internet)	• MS (self-reported diagnosis) • n = 106 • Male/female: 55%/ 45% • Age (years): mean (SD): 58.30(8.85) range: 36-77 • MS duration (years): mean (SD): 20.14 (12.20) • Self-reported walking impairment	Organisations including Multiple Sclerosis Foundation and The National Multiple Sclerosis Society & via newsletters, e-mail, discussion board posts and social media. (sub-sample of larger Internet-based study of people with mobility difficulties)
4	Dennison (2011)	Interviews (telephone)	• MS, early stage • n = 30 • Male/female: 27%/ 73% • Age (years): 70% in 40s-50s • Years since diagnosis: mean (SD) = 3.8 (2.1) range = 2 months – 8 years	UK MS Society website & NHS MS services.

5	DiLorenzo (2008)	Interviews (telephone; open-ended 'Perceptions of Ageing Interview')	• MS • n = 13 • Male/female: 23% / 77% • Age (years): mean = 68.3 range = 62 – 75 • MS duration (years): mean = 22.5 range = 8 - 42	MS Comprehensive Care Centre and newsletters of two local chapters of the National Multiple Sclerosis Society. (Recruited from larger study on MS and ageing).
6	Finlayson (2011)	Interviews (telephone)	• MS • n = 1,275 • Male/female: 23.9% / 76.1% • Age (years): mean (SD) =63.8 (9.4) • Years since diagnosis: mean (SD) = 20.1 (11.49)	Direct mailing, flyer distribution, consumer newsletter advertising.
7	Fitzgerald (1995)	Interviews (semi-structured)	• MS • n = 15 • Male/female: 0% / 100% • (Also 8 women with Temporomandibular Joint Syndrome; data not used) • Age (years): mean = 43.8 range = 33 – 56 • No obvious outward sign of illness	Not reported

8	Forman (2010)	Pilot RCT 6 week adjustment group vs waiting list control Feedback sheet (open-ended questions)	• MS • n = 40 • Male/female: 8/32 • Age (years): mean (SD) = 47.7 (9.7) range = 25 - 68 • Years since diagnosis: mean (SD): intervention = 7.3 (5.4); control = 12.4 (11.4) • Low mood (>7 HADS subscales, or >2 GHQ-12)	MS outpatients clinic MS Society newsletter & poster
9	Graziano (2014)	RCT Group-based CBT vs control (informative sessions)	• MS • n = 82 • Male/female: 36%/ 64% • Age (years): mean (SD) = 40.5 (SD= 9.4) • Years since diagnosis: mean (SD): intervention = 8.6 (5.2); control = 7.2 (5.3)	MS Clinic Centre

10	Grytten (2005)	Interviews (unstructured)	• MS • n = 8 people with MS; 6 relatives • Male/female: 5/9 • Age (years): mean = 51 range = 33 – 60 • MS duration (years): 25	Local MS Society, MS support group, specialist hospital practice
11	Grytten (2006)	Interviews (unstructured)	• As in Grytten & Måseide (2005)	As in Grytten & Måseide (2005)
12	J. M. Holmes (2012)	Survey of intervention attendance & telephone (feedback) questionnaire	• As in Lincoln et al. (2011) • n = 72 • Sample of n = 20 completed additional telephone feedback questionnaire	Recruited as part of RCT (Lincoln et al., 2011)

13	L. Hunt (2014)	Interviews (semi-structured)	• MS • n = 5 • Male/female: 2/3 • Age (years): range = 40 – 65 • Years since diagnosis: 1 – 30	Local branch of MS Ireland
14	Irvine (2009)	Focus Group	• MS • n = 8 • Male/female: 1/7 • Age (years): mean = 49 • range = 36 – 63 • Years since diagnosis: mean (SD) = 12.8 range = 5 – 20	Branch of local MS charity
15	Matuska (2008)	Focus Group & follow-up interviews	• MS • n = 13 • Male/female: 0/100% • Age (years): mean 41.9 range = 29 – 60	Recruited from people enrolled on 6 week Multiple Sclerosis Society course on lifestyle balance

16	McCabe (2015)	Questionnaire	• MS • n = 2,805 • Male/female: 21%/ 71% • Age (years): mean (SD) = 52.10 (11.82) range = 19 – 92 • Years since diagnosis: mean (SD) = 11.28 (9.18)	Recruited from the Australian MS Longitudinal Study
17	Miles (1979)	Interviews	• MS • n = 22 married couples • Male/female: 10 male patients and their wives, 12 female patients and their husbands • Age (years): range = middle 20s – early 50s • Years since diagnosis: ≥ 3 years	Recruited fom records of a general hospital.
18	Mohr (2001)	Quasi experimental CBT vs supportive expressive group therapy (SEG) vs sertraline	• MS • n = 63 • Male/female: 27%/ 73% • Age (years): mean (SD) = 43.9 (10.0) • Years since diagnosis: 3 months – 31.2 years	Referred by neurologists, other health care professionals, the National Multiple Sclerosis Society, advertising or other means.

19	Ng (2013)	Quasi-experimental repeated measures design Group peer support program	• MS • n = 33 • Male/female: 36.4%/ 63.6% • Age (years): mean (SD) = 51.8 (9.3) range = 28 – 66.6 • MS duration (years): median (IQR) = 16 (9-23)	Community-based MS group identified from Royal Melbourne Hospital MS database.
20	Peters (2003)	Questionnaire (postal)	• MS • n = 318 • Male/female : 30%/ 70% • Age (not reported)	People registered with general practitioners in 8 randomly selected health authorities/boards across England and Scotland.
21	Rigby (2008)	RCT Brief group CBT vs social discussion group vs information booklet control	• MS • n = 147 • Male/female: 37% / 63% • Age (years): mean (SD) = 44 (9.6) range = 20 – 65 • Years since diagnosis: mean (SD) = 9.0 (7.5)	Patient research database at Walton Centre for Neurology and Neurosurgery, Liverpool.

22	Salminen (2014)	Focus groups	• MS • n = 68 (16 focus groups) • Male/female: 32%/ 68% • Age (years): mean (SD) = 47 (9.1) range = 28 – 61 • MS duration (years): median = 12 range = 0-33	Participants in multi-professional group-based out-patient rehabilitation program.
23	Schwartz (1995)	Measuring participation in RCT (Schwartz, 1999)	• MS • n = 325 • Male/ female: 111/ 213 (1 missing) • Age (years): mean (SD) = 46.7 (11.0)	MS clinic patient registry of teaching hospital in Boston
24	Schwartz (1999)	RCT Coping skills group + follow-up telephone support vs peer-telephone support	• MS • n = 132 • Male/female: 27%/ 73% • Age (years): mean (SD) = 43 (9.0) • MS duration (years): mean = 8.2 range = 1-37 years	As in Schwartz and Fox (1995)

25	Sinclair (2005)	Quasi-experimental Repeated measures group CBT intervention	• MS • n = 37 • Male/female = 0/100% • Age (years): mean = 38 range = 22 -59 • Years since diagnosis: mean = 5 range = a few weeks – 20 years	Local neurologists Middle Tennessee Multiple Sclerosis Society
26	Skår (2014)	Focus groups	• MS • n = 10 • Male/female: mixed (not reported) • Age (years): mean = 52.6 range = 45 – 61 Years since diagnosis: mean = 13.2 range = 7 – 22	Recruited from a physiotherapy rehabilitation study
27	Spiegelberg (1980)	Report on MS support group	• MS • Demographic characteristics not reported	MS support group

28	Twomey (2010)	Interviews (semi-structured) Following participation in 8 week fatigue management programme	• MS • n = 8 • Male/female: 2/6 • Age (years): mean = 42.9 range = 29 – 55 • Years since diagnosis: mean = 10.1 range = 1 -20	Participants for fatigue management programme recruited through Multiple Sclerosis Society of Ireland Newsletter and information sheet sent to local health professionals.
29	Uccelli (2004)	Quasi-experimental Intervention: peer support group	• MS • n = 42 • Male/female = 17/25 • Age (years): not reported • Time since diagnosis: mean (SD) = 6.9 (6.14)	Peer group organisers nominated by neurologists. Peer group participants recruited by organisers, local branch of MS society & by neurologists at outpatient clinics.

30	Visschedijk (2004)	Quasi-experimental Intervention: CBT to improve coping with MS	• MS • n = 14 • Male/female = 8/3 (excluding people who dropped-out) • Age (years): group 1, mean = 34; group 2, mean = 42 • Recently diagnosed (within 3 years) • Exclusion criteria: wheelchair bound	Referral by neurologist or MS nurse specialist.
31	Wakefield (2013a)	Questionnaire	• MS • n = 152 • Male/female = 56/96 (36.84% / 63.16%) • Age (years): mean (SD) = 52.01 (11.08) • MS duration (years): mean (SD) = 13.55 (9.94)	UK MS support groups

4.4 Results

4.4.1 Included study characteristics

The iterative searches provided a total of 35 studies to be included in the synthesis. Study characteristics are outlined in tables 6 and 7. The studies dated from 1979 to 2015 and all came from developed nations including Australia, Finland, Ireland, Italy, The Netherlands, Norway, The United Kingdom and The United States of America. Thirty one included empirical research and of these 13 were quantitative, 16 were qualitative and two reported quantitative and qualitative findings. One paper was a commentary on an intervention, and one a reply to the commentary including some updated calculations. The remaining two articles were discussion papers.

4.4.2 Summary of CMO configurations

The initial programme theory hypothesised that being part of an MS group may have a differing impact on psychological wellbeing depending on whether the context was one where participants perceived MS as stigmatised. This context was refined during the synthesis to whether MS posed a threat to an individual's identity. This incorporated, but went beyond the concept of stigma. Identity threat appeared to exist on a continuum ranging from high to low identity threat. During the synthesis, the resource element of the mechanisms was also refined into being invited to attend an MS group (where people considered the prospect of meeting others with MS) and actually attending an MS group.

In summary, in contexts where MS posed a high threat to identity, for instance, when individuals had only recently received a diagnosis or where they perceived MS to be highly stigmatising, responses tended to lead to avoidance of MS groups, apparently in an attempt to protect psychological wellbeing. Where the threat to identity was somewhat reduced and people took part in groups (medium identity threat), some mechanisms, such as being confronted with a feared identity, had a negative effect on psychological wellbeing, whereas others, such as having negative stereotypes challenged, appeared to have more positive outcomes with respect to psychological wellbeing. In contexts where MS posed less of a threat to identity (low identity threat), the majority of mechanisms, including shared understanding and normalisation of illness, appeared to give rise to outcomes resulting in increased in psychological wellbeing. The proposed CMO configurations are outlined in figures 3, 4 and 5.

4.4.3 Context: identity threat posed by MS

The identity threat posed by MS was identified as a key contextual factor. Five factors that influenced identity threat were identified: perceived stigma; social identity continuity; integration of MS into identity; age; and time since diagnosis (see table 8). Identity threat appeared to exist on a continuum, but for the purposes of representation has been divided into three: people for whom MS posed a high, medium, or low threat to identity. These divisions are, to a certain degree artificial, but were useful for presentation purposes and to aid understanding at this stage of the research process. In particular, dividing identity threat into contexts of high, medium and low threat aided

understanding of the influence identity threat may have on intervention engagement by enabling the underlying processes to be disentangled. There is some evidence for such stratification, most notably from Dennison et al. (2011), who observed that the emotional adjustment of people with early stage MS appeared to be precariously balanced and contingent on a reasonable current health. Some threats, such as loss of ability to walk, drive or work were perceived as intolerable and unacceptable. However, amongst their interviewees, the actual experience of such challenges appeared to form a 'critical incident', which contributed to them being able to move forward to more stable and positive adjustment where MS posed a reduced threat.

Conditions of high identity threat were deemed to be those where the threat prevented people from even attending MS groups (such that the resource aspect of the mechanism was designated as 'invited to attend MS group' (figure 3)). In contexts of medium and low identity threat participants attended MS groups (such that the resource aspect of the mechanism was 'meet other people in MS group'). The difference between these categories was less clearly delineated but related to the degree of identity threat experienced and the differing responses that could be triggered in each context as a result (as detailed in the following section). Broadly speaking, a classification of medium identity threat was used where people attended an MS group despite some threat to identity. This threat was evidenced, for instance, by discussion of negative and stigmatised perceptions of people with MS, a reluctance to assume such an illness identity, or a desire to challenge such stigma. By

contrast, contexts of low identity threat were deemed to be those where people appeared to experience very little identity threat from taking part in MS groups. This was evidenced, for instance, by a willingness to obtain support from others with MS, and rather than a focus on challenging stigma, an emphasis on the positive aspects of meeting others with the illness.

Table 8. Factors influencing the identity threat posed by MS

Factors influencing identity threat	**Context: identity threat posed by MS**		
	high identity threat	➞	**low identity threat**
1. Perceived stigma	MS perceived as stigmatised	➞	Positive aspects of living with MS recognised
2. Social identity continuity	Existing valued social group memberships threatened by MS	➞	Former valued social identities maintained despite disclosure
3. Integration of MS into identity	MS not integrated into sense of self	➞	Openness to identity redefinition
4. Time since diagnosis	Recently diagnosed	➞	Longer time since diagnosis
5. Age	Younger age	➞	Older age

Perceived stigma

MS posed a greater threat to identity when the disease, or aspects of the condition, were perceived as stigmatised. Such stigma could be anticipated or enacted (Irvine et al., 2009). Mobility aids were seen as especially stigmatising: "symbols of having assumed the identity of somebody who is disabled, old and incapable" (Dennison et al., 2011, p. 484). Respondents described attempting to avoid the associated stigma and identity threat by refusing to use walking sticks, wheelchairs or disabled car stickers, despite the functional difficulties this created (Dennison et al., 2011; Irvine et al., 2009). Another alternative was to avoid exposing disability by withdrawing from social contact and staying at home when symptoms were more evident (Skår et al., 2014). With respect to theory, Goffman's (1963) classic work on spoiled identities was referred to in several papers. Fitzgerald and K. A. Paterson (1995), for instance, highlighted how reluctance to publicly reveal disability was linked to individuals attempting to avoid becoming discredited by acquiring socially devalued identities.

By contrast, the threat to identity appeared to be reduced when participants became able to appreciate the benefit of such aids:

> …he realized that such aids could enlarge his shrunken world and he stopped caring about other people's reactions to his appearance or his performance. He incorporated the aids into his biography. He even saw it as a challenge to be allocated a scoot mobile (Boeije et al., 2002, p. 887).

Similarly, some people were able to redefine MS, appreciating the positives and how they had grown through living with the illness: “Anne does not deny the painful aspects of having MS, but endows the illness with a different meaning. Her narrative is about personal growth, gaining awareness and self-understanding. Anne talks in terms of what she has learned” (Abma et al., 2005, p. 487).

Social identity threat

Where societal and cultural attitudes surrounding disability and chronic illness were perceived to be negative, and this stigma was internalised, former identities as healthy, competent and valuable members of society were often seen as under threat (Dennison et al., 2011; Grytten & Måseide, 2005). The underlying fear was identified as being “deprived of social belonging” (Grytten & Måseide, 2005, p. 231). In order to preserve endangered social identities, one response was to conceal the disease and avoid associations with it (Dennison et al., 2011; Grytten & Måseide, 2005).

Where previous social identities could be maintained despite disclosure, the threat from MS was reduced such that, for some people, it was possible for the two to co-exist:

> Marc thought it would be a challenge to maintain his social network and is surprised that his friends do not treat him as a disabled person. He

> appreciates them for this. It helps him to contextualize MS, while at the same time maintaining aspects of self that have nothing to do with the illness (Boeije et al., 2002).

Integration of MS into identity

As the above example indicates, some participants were able to accept the illness and integrate it into their life. Where participants were able to integrate MS into their identity without letting it define them, the disease appeared to pose less of a threat and was less all-consuming (e.g. DiLorenzo et al., 2008). As one woman explained:

> I am not solely an MS patient. I am also Anne who wants to do other things in life, in my spare time. I do not always want to be involved with MS, that is just a part of me (Abma et al., 2005, p. 486).

There were indications that accepting the illness to some degree was needed before individuals could move forward and focus on other things (e.g. L. Hunt et al., 2014). Being open to identity reconstitution and redefinition of life purpose appeared to be key. This enabled participants to find benefits of living with the condition, such as it opening doors, enabling personal growth and a new outlook on and appreciation for life (e.g. DiLorenzo et al., 2008; L. Hunt et al., 2014; Irvine et al., 2009).

By contrast, some people failed to integrate MS into their identity and strove to separate themselves as far as possible from the MS. For some people who rigidly attempted to preserve their former identity, MS appeared to pose a greater threat to identity: "Kathy thinks in terms of a fixed identity that is under threat …She [Kathy] operates in accordance with nondisabled full-time work values and therefore this loss is a significant issue for her" (Abma et al., 2005).

Another interviewee hated MS so much she would not even pronounce the words. MS had not been given a place in her life, but, ironically, the lack of integration meant that the threat from MS was ever present and overwhelmed her life (Boeije et al., 2002, p. 890).

Time since diagnosis

For many people, integration of MS into identity appeared to be related to time since diagnosis:

> when I was first diagnosed, I found it very scary. As far as my self-image was concerned, I almost let it define me ...the MS was what I always saw as a part of my life and I saw that as big, negative, scary, something that made me different, that was going to hold me back, and so what it did with my self image ...I became less sure of myself. As I got older, I realized that wasn't necessarily the case so that now I wouldn't say it affects my self-image in any negative way, it just kind of is (DiLorenzo et al., 2008, p. 1092).

That some individuals experienced a greater threat to identity from MS soon after diagnosis was further evidenced by Irvine et al.'s (2009) summary: "Initially, diagnosis was met with negative reactions; denial, concealment and diminished confidence" (p. 1). Such reactions indicate that this is a period of challenging internal transition; the individual is facing changes in how they see themselves and how others might see them. With time, the identity threat often appeared to reduce, with participants stating they had learned to live with it.

Age

In addition to reduced threat over time, there was evidence that, for some people, as they aged, the identity threat from MS reduced. With respect to integration of MS, DiLorenzo et al. (2008) commented that, "Most participants described a process whereby they integrated MS into their self-identities as they aged" (p. 1092).

Social comparison theory (Festinger, 1954, as cited in DiLorenzo et al., 2008) was a proposed explanation for this. Generally, as people age, their reference group is also ageing and, as such, are also likely to have health problems, thus reducing the threat of alienation due to illness (DiLorenzo et al., 2008). In a quantitative study of attendance at meetings for people with MS, social comparison was similarly suggested as a reason meeting others with the condition appeared to be especially threatening for younger people: "the fact that younger people (who were less likely to have progressive disease in the

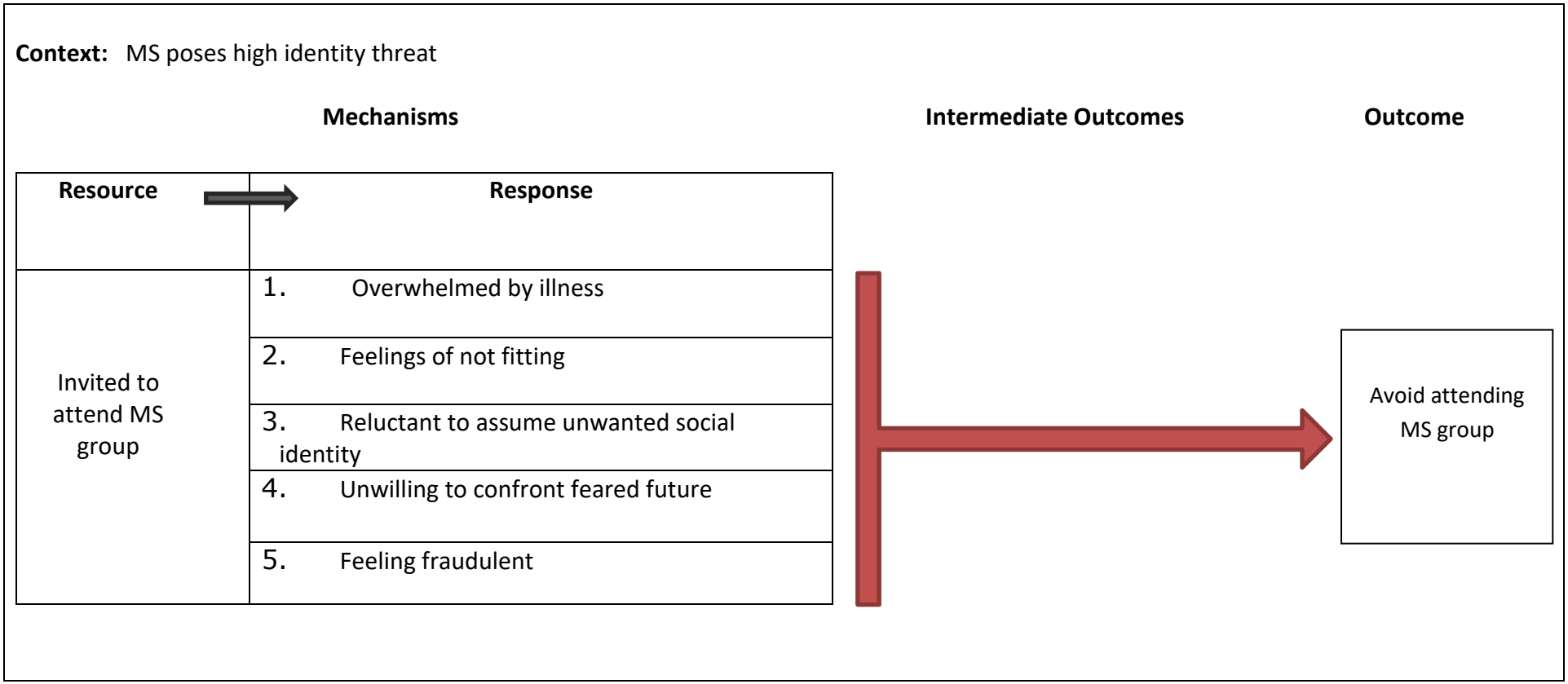
present sample) were less likely to attend suggests that the prospect of social comparison was not viewed positively by this group of individuals" (Peters et al., 2003, p. 25).

As indicated in this extract, type of MS, along with current level of impairment and symptom interference may also be factors influencing identity threat. However, there was no strong evidence regarding how these may affect identity threat.

4.4.4 Mechanisms triggered in contexts of high identity threat

In contexts where MS posed a high threat to identity and the resource (in realist synthesis terminology) was being offered a group intervention, five response mechanisms were identified: overwhelmed by illness; feelings of not fitting; reluctant to assume an unwanted social identity; unwilling to confront a feared future; and feeling fraudulent. All five mechanisms appeared to lead to avoidance of MS groups, apparently in an attempt to protect psychological wellbeing (see figure 3).

Figure 3. CMO configurations for contexts of high identity threat



Overwhelmed by illness

There was evidence that MS was so overwhelming for some individuals that meeting others with the disease was too big a challenge to contemplate. For example, one man who was "wholly absorbed" by MS having "let it take control over him" (Boeije et al., 2002, p. 889), saw himself as less active and as coping worse than other people with the disease, which kept him from engaging with the MS Society. Described by the author as having been unable to put his life back together or achieve any degree of identity reconstitution, he was unable to bring himself to have any contact with other people with MS.

Such feelings of being overwhelmed were apparent in other respondents, particularly following diagnosis and in the early stages of the disease (Dennison et al., 2011). In further support of this, in a paper exploring lifestyle balance in women with MS, one respondent commented: "It's all just pretty overwhelming. I didn't go get help right away and I didn't talk about it, and I didn't really want to hear about it. [now I'm] just taking the steps to learn" (Matuska & Erickson, 2008, p. 22).

Feelings of not fitting

Following an exploration of adjustment to MS, Irvine et al. (2009) concluded that the period following diagnosis appeared to be one of identity crisis due to the dissonance caused by the realisation that individual now has something in common with chronically ill people. In line with this, some early stage participants described feeling that they did not fit in with other people with MS

and saw people who attended MS groups as “unlike themselves” (Dennison et al., 2011, p. 484). A lack of identification was further evidenced by an interviewee in Boeije et al.’s (2002) study:

> When he first heard he had MS, Marc did not want to have anything to do with the disease. He ignored invitations from the MS Society, because he could not identify with the people with their wheelchairs and crutches (p. 887)

Negative stereotypes appeared to put people off engaging with MS groups: “I’m not, I’m not dribbling or, you know. It sounds awful but I’m not a, I’m not classically disabled” (Dennison et al., 2011, p. 484).

Them-and-us language further indicated that some respondents saw themselves as different to people at MS-related organisations: “But get in with a whole load of ‘em. I couldn’t. No, I couldn’t go to [name of local club], thank you very much” (Dennison et al., 2011, p. 483).

In the same vein, in a telephone feedback questionnaire following a psychological adjustment group for people with MS, one non-attender (classified as attending three of fewer sessions out of six) felt that it was “not for me” (J. M. Holmes et al., 2012, p. 4). However, information was not provided on whether it was the group aspect, the cognitive behavioural

content or the fact that it was a psychological adjustment group that was being referred to in this comment.

Reluctant to assume an unwanted social identity

In addition to feelings of not fitting with other people with MS, some people reported not wanting to identify with MS groups. Becoming involved with MS-related organisations was seen not only as admission of being ill, but as constituting a loss of former social identities and acceptance of other people with MS as one's relevant social group. Attending MS groups appeared to be considered unfavourably due to the negative identity attendance was seen to confer: "Many participants expressed a desire to avoid membership of what they evidently thought of as a stigmatized group and an alien, unwanted identity" (Dennison et al., 2011, p. 485).

In the same way, when considering taking part in a group psychological adjustment intervention, one person reported fearing that they would be the most disabled person there (Visschedijk et al., 2004, p. 743). The implication was that this would confirm the individual's status as someone who is disabled.

With respect to theory, literature on the loss of self that chronic illness can bring about was referred to (Charmaz, 1983). Theories of identity management were especially relevant. Grytten and Måseide (2005), for instance, commented that while individuals can manipulate identity through tactics of protective disclosure and impression management, identities can also be

imposed relationally in certain social situations, which helps explain motivations for avoidance of MS groups. Dennison et al. (2011) made a similar argument, using Scambler and Hopkins' (1986, as cited in Dennison et al., 2011) theory that people with chronic illness strive to maintain former selves and avoid acquiring "spoiled identities" (Dennison et al., 2011, p. 486), to explain findings that participants distance themselves from the unacceptable threat presented by association with stigmatised aspects of MS.

One result of attempting to maintain a valued self-identity was failure to take advantage of available services (Fitzgerald & K. A. Paterson, 1995). This was corroborated by one of Grytten and Måseide's (2005) respondents:

> 'When I am done as a working man, and I have nothing to hide, maybe then [I'll accept healthcare].' The informant distinguishes between the identity of a worker being self- supporting and the sick person being unfit to work and needing healthcare (p. 237).

The indication was that avoidance was an attempt to protect psychological wellbeing. One lady, described as experiencing MS as highly threatening to her sense of self, avoided all contact with fellow sufferers and reported becoming terribly upset when she had to talk about and face up to it (Boeije et al., 2002). Dennison referred to the shifting perspectives model of illness (B. Paterson, 2001) to explain how avoiding reminders of present disability may be protective of emotional wellbeing. The model posits that people shift between

holding wellness or illness in the foreground and that keeping the illness in the background helps sustain a sense of wellbeing. Accordingly, reminders of present disability are deemed unhelpful because they bring illness to the foreground.

Unwilling to confront feared future

When considering meeting others with MS, individuals not only had to face the prospect of being reminded of their present disability, but also the prospect of being confronted with a feared future identity. Meeting others with worse symptoms at a more advanced stage appeared to be a particularly potent reminder of what might happen and who they might become. In both older and more recent papers, fear of encountering decline and disability was offered as one of the main reasons behind decisions not to attend MS groups (Dennison et al., 2011; A. Miles, 1979). Dennison et al. (2011) commented that such reluctance to engage with the threat of disease progression was particularly apparent in young participants who were relatively newly diagnosed. Participants in their study described avoiding MS groups in order to protect themselves emotionally against thoughts of a feared future they did not feel able to tolerate: "It's almost like a different world. You know, which, you kind of know that you'll probably have to join sometime, but you're just kind of thinking well not yet please" (Dennison et al., 2011, p. 483).

Again, identity threat was especially apparent from MS resulting in visible impairment, loss of independence or reliance on mobility aids, as a different

participant explained:

> I've not really seen anybody in a wheelchair that's got MS, because I choose not to go down that route. I just don't think I could stand to sit in a room with people that have got MS on the understanding that I could end up like that (Dennison et al., 2011, p. 483).

Interestingly, an Australian study examining country-wide satisfaction with psychological and peer support services for people with MS found that young people were significantly more likely to report a desire for greater varieties of peer support (McCabe et al., 2015). This included groups for younger people with MS. Although reasons are not provided, the evidence from studies such as Dennison et al. (2011) suggest that one possibility is that a group for younger people with MS may help avoid confrontation with people at more advanced stage of illness.

Feeling fraudulent

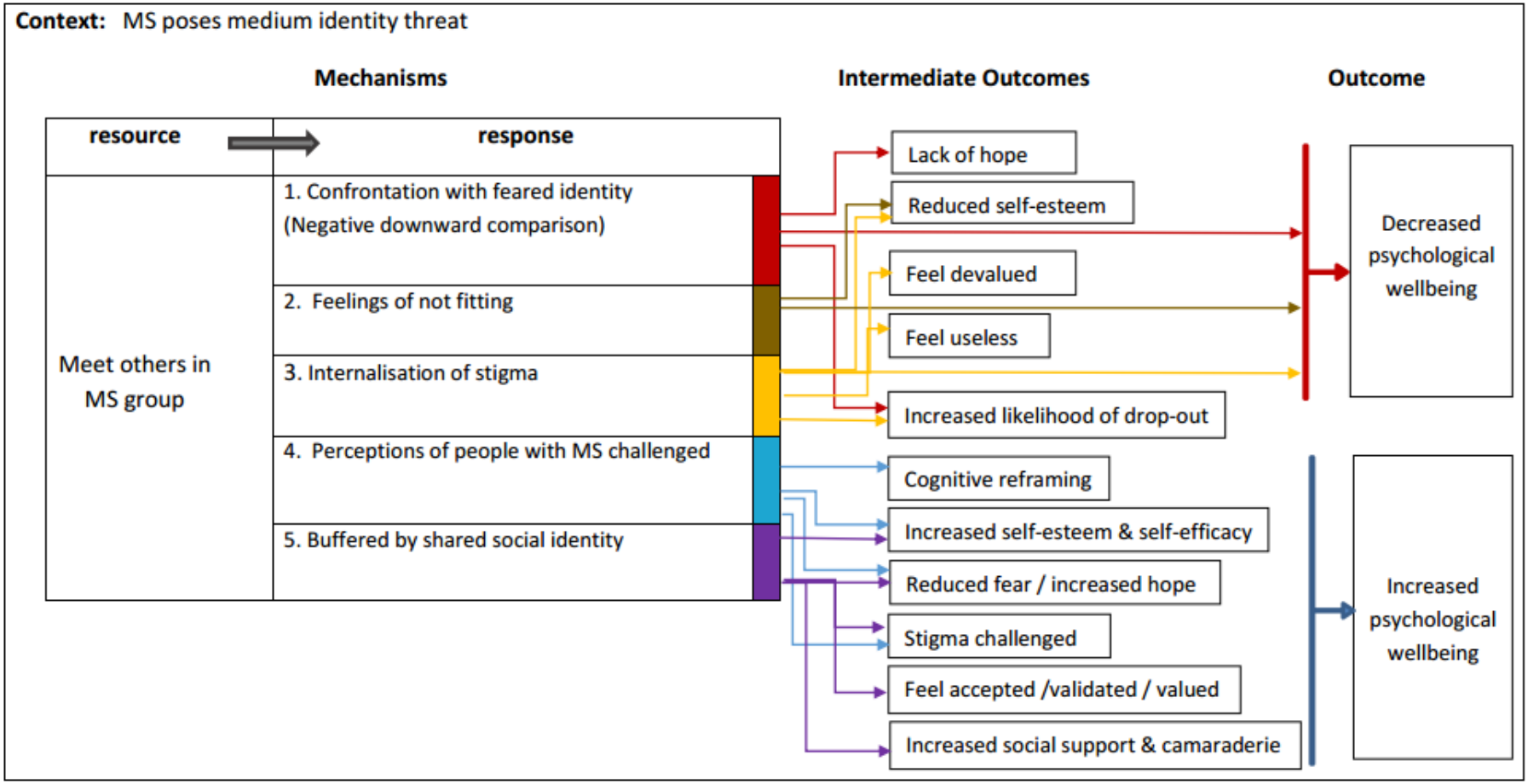
At the other end of the spectrum, one participant confided that, in addition to not wanting to be confronted by reminders of what might happen, she did not feel her relatively mild symptoms merited attendance at her local MS group: "I almost feel as if I'm slightly a fraud, when you get people with wheelchairs and they're struggling badly and I can walk" (Dennison et al., 2011, p. 483).

Although not referring directly to attending MS groups, this sentiment was echoed by a participant in Fitzgerald and K. A. Paterson's (1995) study, who admitted to feeling guilty at claiming a disabled identity when using her disabled parking space when others suffered worse symptoms than her.

4.4.5 Mechanisms triggered in contexts of medium identity threat

When identity threat was reduced to a degree where people attended MS groups (medium identity threat) five possible responses were identified. Some of these paralleled the anticipatory mechanisms in conditions of higher identity threat. The proposed mechanisms were: confrontation with feared identity; feelings of not fitting; internalisation of stigma; perceptions of people with MS challenged; and being buffered by shared social identity. The first three mechanisms appeared to have a negative impact on psychological wellbeing, while the latter two acted to positively influence wellbeing (see figure 4).

Figure 4. CMO configurations in contexts of medium identity threat



Confrontation with feared identity (negative downward comparison)

As outlined above, one of the reasons people avoided meeting others with the condition was to avoid reminders of their current disease status and protect themselves from thoughts of what might happen. For some people, there was evidence that when they actually did meet others with the condition, the result was, indeed, upsetting. For instance, in a group psychological adjustment intervention, two people stopped attending because the confrontation with MS was too emotionally upsetting: "one patient dropped out after the second session, and another dropped out after the third session, both due to emotional problems associated with intensive exposure to MS" (Visschedijk et al., 2004, p. 739). Since the group was aimed at people with a recent diagnosis of MS and purposefully did not include people in wheelchairs, it seems that in this instance, even meeting people with less severe symptoms could cause emotional upset. In other examples, meeting people with more advanced symptoms appeared to result in negative downward comparison. This was apparent even amongst participants who had volunteered to act as peer-supporters: "We found, for instance, that seeing patients who had late-stage MS made some volunteers question their own fate" (Radice, 1995, p. 1383).

That such negative downward comparison could have a detrimental impact on psychological wellbeing was supported by Peters et al.'s (2003) reference to other chronic illness research in which downward social comparison is associated with depression and decreased self-esteem.

Feelings of not fitting

As outlined above, in contexts of high identity threat, many participants avoided involvement in MS groups because they felt they were unlike other people with the disease and did not identify with them. Irvine et al.'s (2009) study of adjustment to MS suggested that such lack of identification can influence individuals' rehabilitative potential. One way this may play out with respect to MS support groups is suggested in a study by Wakefield et al. (2013a). Their survey, investigating the effects of identification with an MS support group on mental health found that group identification was associated with lower levels of depression and anxiety and higher levels of satisfaction with life. The authors warn that not only is it unlikely that psychological benefit will be observed in support groups where there is little or no identification between members, but that when participants do not identify with other group members, attending such groups could actually be detrimental for mental health, due to interpersonal interactions that promote feelings of negativity and conflict (Wakefield et al., 2013a).

Internalisation of stigma

There were indications that by attending MS groups, people internalised stigma surrounding MS. Fitzgerald and K. A. Paterson (1995), for instance, commented that if individuals decided to reveal their illness publicly they "must assume a socially devalued self-identity, that of sick and disabled, and all that these identities entail" (p. 13). In line with this, one participant reflected: "I try really

hard … but I just kind of think, 'Am I just making myself part of a cripple club'" (Dennison et al., 2011, p. 483).

Although it is not clear whether the participant is referring here to having attended an MS group or is expressing a reason for avoiding such groups, the indication is that taking part in such groups confers an unwanted social identity and the stigma that goes along with it.

Perceptions of people with MS challenged

In contrast, some people who had initially been unwilling to attend MS groups found their perceptions of people with MS were challenged upon meeting positive role models.

> One participant described her initial reluctance to participate in a group programme for people with MS: 'I got to see 11 other people with MS that are ... that all have their disabilities but are still normal happy people. I had this vision in my head that they were going to be pure sick and pure miserable and it was just going to drag me down' (Twomey & Robinson, 2010, p. 796).

Cognitive reframing of the disease and people with it was evident. One man found that as his negative preconceptions of people with MS were challenged upon meeting others in an MS group, he could identify with other group members, and became able to contemplate integrating MS into his identity:

> After attending their meetings once or twice, he discovered that the members were more than just their illness and were actually very nice people, many of them young. At that moment he realized that MS was going to be a part of his life too (Boeije et al., 2002, p. 887).

For some, reduction of threat was a significant outcome of such encounters: "I saw that life did not end even though I would end up in a wheelchair. They could smile and laugh and have fun, even if they were sitting in a wheelchair ... I was not afraid anymore" (Grytten & Måseide, 2006, p. 203).

Goals may also be redefined in this process. For instance, in a study examining the impact of disability identity on mental health, Bogart (2015) discussed how new meaning can be given to illness through disability advocacy, and goals revised to fit those of the disability community as opposed to wider societal views. The example they give is that interdependence may come to be valued in contrast to the majority Western culture value of independence (Bogart, 2015, p. 107).

Buffered by shared social identity

Following on from this, there was evidence that when people did identify with members of an MS group, the ensuing sense of shared social identity enabled individuals to challenge external stigma and acted as a buffer against the stresses of living with the disease. For instance, a survey of UK MS support groups found that higher levels of identification with such groups were

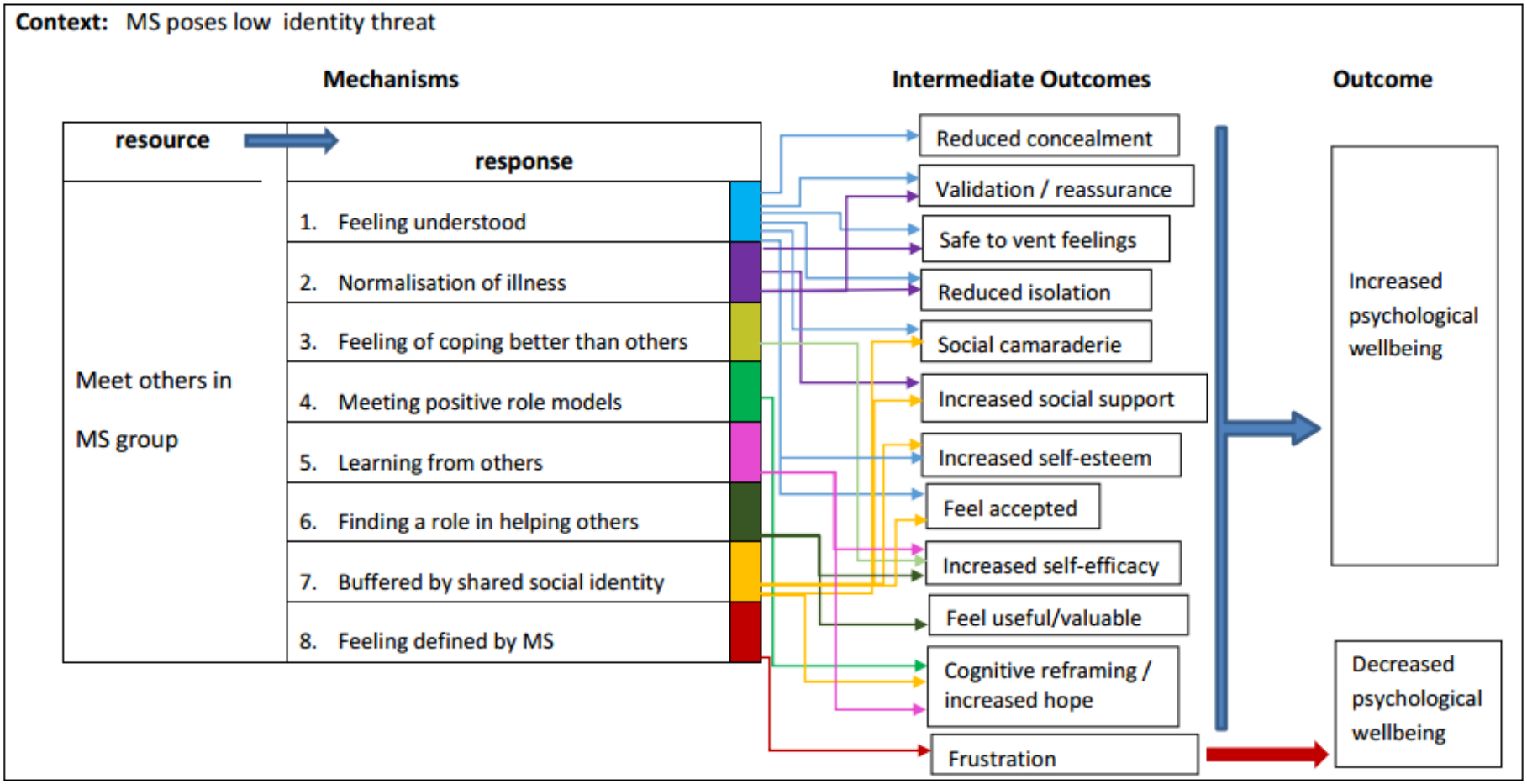
associated with lower levels of anxiety and depression (Wakefield et al., 2013a). Accordingly, the authors suggested that a sense of shared identity is a critical but largely overlooked factor determining the success (with respect to mental health) of such groups.

This was supported by the results of another survey study, which found that stronger disability identity was a significant predictor of less depression and anxiety in people with MS and mobility impairment (Bogart, 2015). The authors explained their findings with reference to literature on minority groups and suggested that disability identity is affirmed through social support from the disability community and reduction of stigma through disability pride. A 'minority' group of similar others provided a place to belong, feel valued and accepted, improving self-esteem.

In line with this, participants reported enjoying the sense of empowerment created by feeling part of a collective group. Twomey and Robinson (2010) and Skår et al. (2014) concluded that identity, recognition and empowerment counteract the stigma encountered by people with MS in everyday life. Further support that shared social identity can reaffirm one's value and provide the support to challenge negative stereotypes was echoed by Grytten and Måseide (2006), who likened identification with MS groups to the process of disclosure of a homosexual identity:

Similar to those with a gay identity, people with MS come out to affirm their identity as being worthy of value, dignity and pride. Coming out is associated with disclosure and visibility and with the process of social affirmation of the self (Grytten & Måseide, 2006, p. 204)

Figure 5. CMO configurations in contexts of low identity threat



4.4.6 Mechanisms triggered in contexts of low identity threat

Seven mechanisms were identified as responses to meeting other people in MS groups in contexts of low identity threat. These were: feeling understood; normalisation of illness; feeling of coping better than others; meeting positive role models; learning from others; finding a role in helping others; buffered by shared social identity; feeling defined by MS. With the exception of the last of these, all the mechanisms appeared to have a positive impact on psychological wellbeing (see figure 5). The indication was that these mechanisms are enabled when the threat posed by meeting others with MS was reduced, although for some mechanisms, particularly, feelings of coping better than others, the evidence for this was less clear cut and it may be that it can also be triggered in contexts of higher identity threat.

Feeling understood

In a study investigating what aspects of rehabilitation people with MS found most helpful, meeting peers with MS and having the opportunity for discussion with them were described as helpful by 88% (n = 60) of respondents (Salminen et al., 2014). This appeared to be true regardless of intervention content: “In any form of rehabilitation it is important to get support from other people who are similar to you and then get support and information from your own peers” (Salminen et al., 2014, p. 1986).

The benefit of meeting others with shared experiences was a recurring theme, both in the context of peer support groups and psychological adjustment

interventions. In a cognitive behavioural psychological adjustment group, for instance, many participants "enjoyed talking to others and sharing experiences" (Forman & Lincoln, 2010, p. 218). Findings from other studies indicated that this may be partly because people with MS understand from subjective experience what it is like to live with the disease (Spiegelberg, 1980). One respondent commented: ''I know what they're talking about and they know what I am talking about''. 'When I have a problem, the others understand', Grace said. Among peers they appreciated the comfort of being seen and understood" (Skår et al., 2014, p. 675).

In Salminen et al.'s (2014) study, many participants discussed the importance of acceptance, understanding, and being heard: "…here [in group-based rehabilitation] we somehow all agree that you can be here just as you are" (p. 1987). Such understanding was reported as providing relief, affirmation and validation (Fitzgerald & K. A. Paterson, 1995; Spiegelberg, 1980). Skår et al. (2014) suggested that feeling understood by other group members led to an increase in self-esteem. This stood in contrast to the often expressed feelings of alienation, frustration, guilt, discreditation and invalidation when often invisible, symptoms were not taken seriously or were disbelieved by significant others (Fitzgerald & K. A. Paterson, 1995; Grytten & Måseide, 2005; Spiegelberg, 1980; Twomey & Robinson, 2010). The importance of understanding and legitimisation was recognised in the design of a fatigue management programme for people with MS where family members were invited to attend a session (Twomey & Robinson, 2010).

Some people expressed fears and guilt around burdening family members, and the consequent value of a group of peers in providing a safe place, not only to be understood, but to express their feelings: “only those who have been there can truly identify and can permit one to accept one’s own unacceptable feelings. Monthly group sessions are a safe place to ventilate shock, fear, outrage, dismay, disappointment, and grief” (Spiegelberg, 1980, p. 11). Additional psychological benefits may come from the feeling of social camaraderie and opportunity for laughter and inside humour afforded by the social interaction of MS groups (Sinclair & Scroggie, 2005; Skår et al., 2014).

Normalisation of illness

The mechanism of normalisation was referred to in several papers. For instance, in a study exploring perceptions of inpatient rehabilitation, the authors noted: “In the sense of community created among participants it was ‘normal’ to have impairment” (Skår et al., 2014, p. 676). Participants across studies referred to value of MS groups for realising that they were not the only one out there with the disease, as the following extract from a group fatigue management programme highlights:

> …all the participants described the group context as useful in reducing feelings of isolation and uniqueness: ‘…to meet people with the same problems, the important thing you realize is you are not on your own ...' (Peter). ‘... knowing that you are not the only one out there ...

because we are quite a lonely bunch of individuals on our own' (Kevin) (Twomey & Robinson, 2010, p. 795).

Given the diversity of symptoms, it appeared that for some participants, meeting others with the same specific symptoms, such as memory loss, was helpful (Skar et al., 2013). Psychological wellbeing appeared to be influenced through the comfort and security afforded by knowing they were not alone (Hartings et al., 1976) and the opportunity to gain perspective on previously unspoken fears: “Speaking these fears makes them less real, less crazy, less alienating” (Spiegelberg, 1980, p. 11). In line with this, Forman and Lincoln (2010) stated that part of their rationale for the choice of a group-based intervention was that meeting other people in similar situations helps to normalise the patients’ circumstance and shows that they are not alone (p. 212).

With regard to theory, Yalom and Leszcz’s (2005) work on the therapeutic factors of group therapy was referred to in several papers. For instance, Salminen et al. (2014) pointed out the parallels with Yalom and Leszcz’s (2005) concept of universality and the realisation that one’s problems are not unique but experienced by others (Salminen et al., 2014, p. 1988).

Feeling of coping better than others (positive downward comparison)

In contrast to the negative downward comparison observed in contexts of medium identity threat, there were indications that when identity threat was

low, some participants were able to compare themselves positively with people with worse symptoms. When the condition is less overwhelming, and individuals are able to accept MS without letting it define them, they may be less inclined to jump to the feared conclusion that because others have certain symptoms it inevitably means the same will happen to them. Moreover, if less stigma is attached to symptoms, fear of the future may become less overwhelming such that people are more able to appreciate their current relatively good state of health. Such positive downward comparison appeared to have a corresponding positive influence on psychological wellbeing, as explained by Ng et al. (2013) in their discussion of peer support literature: "downward comparison with those worse off can also make people feel better about their own situation" (p. 4).

This was corroborated by Schwartz and Fox (1995), who discussed how negative role models can facilitate downward social comparison and lead to a more positive appraisal of their situation. DiLorenzo et al. (2008) noted a similar mechanism in older people with MS, whereby individuals tend to compare themselves to people who are more ill to ensure positive assessments and enable them to feel better about themselves (p. 1092).

Meeting positive role models

There was also evidence that when identity threat was reduced, people were able to derive benefit from meeting others who were coping well and living a full life despite having a more advanced stage of the disease (Radice, 1995).

This closely parallels the mechanism of having negative perceptions challenged in contexts where MS is perceived as a greater threat to identity. The slight difference is that the emphasis is less on challenging stigmatised views and more on people with "better attitudes" serving as a source of inspiration (DiLorenzo et al., 2008, p. 1092). Encouragement and hope were offered as positive psychological outcomes: "Seeing others coping well with the condition can provide hope" (Ng et al., 2013, p. 5).

Similarly, a participant in an inpatient rehabilitation group explained to a peer: "Seeing you manage [the wheelchair], and you as well, gave me assurance – it is possible to manage" (Skår et al., 2014, p. 676).

Learning from others

Another mechanism identified in the synthesis was that of the group context enabling participants to learn from others. Visschedijk et al. (2004) saw this as a crucial element of the intervention, commenting: "We observed that bringing together patients with the same disease (at about the same stage of the disease process) enabled patients to learn a great deal from each other" (p. 743). However, the inclusion criteria that participants were recently diagnosed is noteworthy, since this is likely to reduce the potential threat posed by meeting others with a more advanced stage of the disease. Moreover, people in wheelchairs were deliberately not included in this intervention, further reducing the potential threat.

The opportunity to glean advice and information from other people with the condition, particularly with respect to solutions for seemingly small problems encountered in everyday life, was highlighted as helpful by respondents of the survey of rehabilitation (Salminen et al., 2014). Uccelli et al.'s (2004) discussion indicated the value of this mechanism for improving mental health. The findings of their study appear to point to the importance of coping skills, such as those taught in cognitive behavioural therapies over and above the value of generic peer support groups. However, their suggestion that intentionally including a focus on coping skills in more structured peer support programmes indicates the potential value of learning such skills from peers, as opposed to or in addition to professionals. In line with this, in some articles, the support and advice offered by other people with MS was reported as being perceived as more trustworthy (Gallagher et al., 2013), different to, and even superior to information from professionals (Dennison et al., 2011; Twomey & Robinson, 2010). In the context of a fatigue management programme, one participant commented: "The sharing of expertise was described as beneficial because 'you were learning from others as well as [from] the people who were giving the course; you learned as much nearly from the people around you'" (Twomey & Robinson, 2010, p. 795).

The opportunity afforded by a group of peers to talk about more sensitive issues was also valued: "Almost universal problems like constipation, rarely discussed even in intimate privacy, can be brought up and solutions suggested in group meetings" (Spiegelberg, 1980, p. 11).

Finding a role in helping others

In addition to learning from others, many respondents appeared to derive benefit from the opportunity to help others with the illness. As Spiegelberg (1980) observed: "Providing and giving to one another makes each provider feel more competent, less powerless" (p. 11).

In an intervention designed to encourage participation and ownership was reported to produce a sense of empowerment: "You could contribute ... you were a part of it" (Twomey & Robinson, 2010, p. 795). Similarly, those purposefully placed in the role of peer-supporter were reported to feel rewarded by the knowledge that they were helping others (Radice, 1995).

Grytten and Måseide (2006) suggested that becoming an expert in MS might help reduce the insecurity associated with the unpredictability of the disease. Some people who had lost roles, particularly with respect to profession, found new purpose in supporting others. For instance, one lady who had been forced to retire early and was frustrated by her lack of professional career, found some satisfaction and status in becoming a spokesperson and politically active member of her regional society for people with MS (Abma et al., 2005).

Buffered by shared social identity

There was evidence that this mechanism operated in conditions of low as well as medium identity threat. The difference may be that, as indicated by the literature on minority groups, when membership of existing 'majority' social

groups is threatened by illness, membership of a disability group provides a place to belong, and a base and shared identity that enable stigma to be challenged. Where perceived stigma is already reduced, a similar mechanism may operate, but here the positive outcomes from a sense of shared identity may result primarily from increased social support. This is supported by Gallagher et al.'s (2013) comments on the finding by Wakefield et al. (2013a) that increased identification with MS support groups was associated with better mental health. Gallagher et al. (2013) referred to literature indicating that one is more likely to accept social support and advice from similar others and suggest that social support may mediate the positive relationship between support group identification and mental health. In response, Wakefield et al. (2013b) proffered a loop of reciprocal causality, acknowledging the possibility that social identity may exert its influence on mental health by facilitating social support, but suggesting that the resulting increased social support then further promotes feelings of shared identification.

A paper reporting on an art-based group for people with MS raised the interesting possibility that identity threat may be reduced when MS is not the only common ground (L. Hunt et al., 2014). Participants in this group reported social camaraderie as a very important part of the programme, but interestingly MS was not a regular topic of conversation. In this context, the identifying factor appeared to be a common interest in arts and crafts.

Feeling defined by MS

There was some evidence that, although reduced identity threat enabled people to interact with others with MS, some participants reported feeling obliged to help others with the condition. For one woman, interviewed in Abma et al.'s (2005) study, this became limiting and led to feelings of frustration at being defined by the disease. She reported wanting to be recognised as a professional woman, not just a volunteer. Significantly, she also expressed a desire to relate to people without MS.

4.4.7 Context: Gender

Another contextual factor that appeared to be of relevance with respect to peer-group meetings was gender. However, how this related to identity threat was not explored in any of the included articles. There was some evidence that men were more reluctant to attend MS groups than women and, in line with this, McCabe et al. (2015) found that women perceived a greater need for support groups. J. M. Holmes et al. (2012) found drop-out rate was higher amongst men and similarly, Schwartz and Fox's (1995) demographic analysis revealed that in the sample of eligible patients, women were represented more heavily (although, this may be confounded by the greater proportion of women having MS). Interestingly though, in the RCT by Graziano et al. (2014), at a six-month follow-up, psychological wellbeing was increased for men and slightly decreased for woman. With respect to identity processes, women reported greater MS group identification than men (Wakefield et al., 2013a) which was suggested to be due to women's ability to relate to others more easily and, by

comparison with men, to look more often to those outside their spousal relationship for support (Antonucci & Akiyama, as cited in Wakefield et al., 2013a). Grytten and Måseide (2005) similarly suggested that, in general, women may be more willing to disclose information about themselves to others, indicating that some of the mechanisms here relating to sharing information may be most applicable to women.

4.5 Discussion

While the literature indicates that MS psychological adjustment interventions can be beneficial, evidence regarding the efficacy of group format is mixed. Qualitative reports, too, offer seemingly contradictory accounts, with some studies finding interaction with other people with MS to be highly valued, while others report ambivalent or adverse responses towards involvement with MS groups. This synthesis goes some way towards explaining the mixed findings by identifying potential mechanisms underlying MS group interventions. Some of these lead to outcomes related to positive psychological wellbeing, others act to protect wellbeing, while others appear to have a detrimental impact on mental health. Thus, although the mechanisms proposed in figures 3-5 should be seen as preliminary and non-exhaustive, they begin to shed light on the mixed findings in the empirical literature. The key proposal made by the synthesis is that identity threat posed by MS is a crucial, but often overlooked, contextual variable that influences which of these mechanisms are actualised.

The notion that illness can threaten individuals' self-concept and existing social identities is not new. Both Charmaz's (1983) writings on chronic illness and biographical disruption and Goffman's (1963) discussion of stigma and 'spoiled identities' are classic works in the area. The suggestion that such identity threat may be significant in influencing individuals' responses to group interventions is a more novel application. Support for this proposal can be found not only in the social identity literature, but also in research and theory on identity motives, minority groups and disability identity. Fundamental to all these areas is the argument that individuals are motivated to have a positive self-concept and self-esteem, and that when this is threatened, coping strategies to counteract the threat are employed. According to social identity theory, much of an individual's self-concept and self-esteem is derived from social group memberships (Tajfel & Turner, 1979). The evaluations people make regarding the social groups they belong to are essentially relative in nature (Tajfel & Turner, 1979). Thus, while favourable comparisons can improve self-esteem, unfavourable comparisons, resulting from being identified with a negatively viewed group, can result in reduced self-esteem. As indicated by the synthesis, this may provide much of the motivation for avoidance of MS groups. Empirical support for identity threat as a motive for group avoidance comes from a recent study by Nario-Redmond et al. (2013). The authors found that disability identity was negatively associated with individualistic strategies of minimising, concealing or attempting to overcome the stigmatised attribute; when individuals did not identify with a disability group due to the threat posed to

valued social identities, they adopted strategies that dissociated them from such groups.

The CMO configurations related to avoidance of MS groups are especially interesting in view of the relatively high rates of attrition and initial non-attendance often reported in MS group psychological adjustment interventions (das Nair et al., 2015; J. M. Holmes et al., 2012). Data collection on such variables is often precluded by study design, but tends to be attributed to logistical difficulties, such as work commitments as well as transportation and mobility difficulties (Graziano et al., 2014; J. M. Holmes et al., 2012; Ng et al., 2013). Synthesising data from across study design enabled the identification of additional identity-related motivational factors. The literature on identity motives highlights further motivating factors as identity continuity, self-efficacy, meaning and belonging (Vignoles, 2011). All of these find parallels in the CMO theories proposed in this synthesis.

Researchers in disability studies suggest that when disability is seen according to a social model, it has much in common with other stigmatised minority groups (Olkin, 2002). In light of this, it is interesting to consider Grytten and Måseide's (2006) allusion to MS disclosure as similar to the process of coming out as a sexual minority individual. Indeed, with respect to the reduction of identity threat over time, parallels are found in models of same-sex identity development and the coming out process (Dillon, Worthington, & Moradi, 2012). The predominant identity development models are stage based,

although progress through the stages is recognised as occurring in back and forth, or spiralling patterns rather than a straightforward linear process (Troiden, 1988). Typically, earlier phases include identity confusion and identity comparison, as individuals begin to compare themselves with similar others and weigh up the potential costs of identification (Cass, 1984; Troiden, 1988). In later stages come identity acceptance and identity pride, the latter being comparable with the mechanism identified in the synthesis whereby shared identity empowered group members to challenge stereotypes and provided the support needed to cope with the stigma of illness. Research into disability identity further supports the existence of this process in the context of rehabilitation. The study by Nario-Redmond et al. (2013), for instance, reported that greater identification with disability groups was associated with increased adoption of collective strategies that positively redefine stigmatised traits. Identity synthesis is proposed as the final stage of the same-sex identity development models, and is suggested to occur only once the individual has had positive contact with members of the gay community (Troiden, 1988). Again, parallels can be drawn here with mechanisms identified in the synthesis, notably having negative perceptions challenged through meeting positive role models. Interestingly, identity development models stress that in this final stage, integration or identity synthesis occurs where individuals see being gay as a part, but not exclusive aspect of their identity (Cass, 1984; Dillon et al., 2012; Savin-Williams, 2012; Troiden, 1988). This also appeared to be the case for some MS participants. One lady in particular no longer appeared to experience MS as threatening her identity, but expressed frustration at feeling

defined by MS. Interestingly she expressed a desire to relate to people without MS, a desire mirrored in Cass's (1984) model with respect to socialising with heterosexual individuals. Further literature on adjustment to MS also supports this experience (Mozo-Dutton, Simpson, & Boot, 2012).

Another theory referenced in included articles was B. Paterson's (2001) shifting perspective model of illness. The suggestion was that meeting others with MS can have a detrimental impact on psychological wellbeing because it places illness in the foreground (Dennison et al., 2011). The identity threat perspective proposed by this synthesis is able to incorporate this model, one suggestion being that a reason people try to hold illness in the background is because it endangers the identity of a healthy, valued member of society that they are attempting to preserve.

In a realist synthesis, mechanisms rather than programmes are the main unit of analysis and the method recognises value in diverse sources with varied research designs. Accordingly, evidence from a variety of professionally guided interventions as well as peer-led support groups was drawn on to develop a picture of how the intervention in question might work (or not) and for whom. While this is a strength of the method, synthesising research from different intervention types also raises the question of generalisability. For instance, despite the comment of the participant in Salminen et al.'s (2014) study regarding the importance of support from peers in any form of rehabilitation, there is some speculation in the proposal that mechanisms found in the context

of peer groups can be transferred to a group CBT context. Uccelli et al.'s (2004) comment that there may be a ceiling effect to the benefit derived from peer support alone also deserves consideration. These authors suggest that one reason support groups are not always found to produce improvement is that, after a limited number of meetings, such groups have met participants' need for social support. From this point forward, the group fails to meet ongoing needs which, the authors suggest, may be derived from more specific coping skills training. One implication of this is that group psychological adjustment interventions may be of greater overall benefit to participants than generic peer support groups since they offer both cognitive behavioural content and, at least in contexts of lower identity threat, the benefits obtained from meeting others with the condition. Mohr et al. (2001) agreed with this suggestion, asserting that the benefits attained from peer support should not be confused with efficacy in treating mood disorders. Rigby et al. (2008) similarly speculated that benefits derived from group format are evident within the first few sessions, whereas development of the skills learnt during CBT intervention takes longer to acquire and show any clinically significant change. While these suggestions are in line with the proposals made in the synthesis, there remains some indication that there may also be an interaction effect between skills-based content and group format. This lies in the mechanisms of learning from others with the condition and, more indirectly, the value of meeting others with shared subjective experience. It may be that the opportunity to discuss strategies offered by cognitive behavioural approaches with other group members provides added benefit over talking about them with the therapist

alone. It could also be that the action of certain of the mechanisms may be augmented or reduced depending on the particular ethos of the group and how it is lead and structured (Gallagher et al., 2013; Wakefield et al., 2013b). For instance, Twomey and Robinson's (2010) study was designed with the intention of empowering participants, and apparently resulted in an increased sense of collective identity and group pride.

4.5.1 Clinical implications

This CMO configurations or mid-range theories proposed by this realist synthesis have a number of clinical implications. Firstly, they indicate that a group format can offer benefits distinct from intervention content and which would not be achieved through one-to-one delivery. Many of the mechanisms also appear to be specific to groups of people with MS and could not be provided by support networks where MS was not a common feature. Importantly, groups serve different purposes for different people, and the results provide a reminder that individuals' motivation to attend may differ from clinicians' assumptions regarding the perceived function of the group. Different individuals may derive benefit from differing underlying mechanisms, and further understanding of which aspects are most helpful to which individuals would be valuable.

The second implication is that identity threat needs to be considered when designing, targeting and delivering interventions. At the very least, results indicate that service providers should ensure that interventions are described

and delivered in ways that are sensitive and reach people with MS without emphasising illness identity (Fitzgerald & K. A. Paterson, 1995). Consideration of how best to frame interventions such that the participants' need to preserve valued sense of self is met may be key to engaging people (Dennison et al., 2011; Fitzgerald & K. A. Paterson, 1995).

With respect to identity threat, timing also appears to be important. While denial may be perceived as maladaptive, it is important to recognise that defensive denial is commonly related to maintaining positive self-perceptions (Wiebe & Korbel, 2003). Labelling or implicitly criticising patients' coping strategies as 'in denial' may damage self-esteem, and for many people, while the identity threat posed by MS remains high, resisting being categorised as a member of a disabled group may have a protective effect on self-concept and psychological wellbeing (Dennison et al., 2011, p. 485). Several researchers have highlighted the need for psychological support to be available soon after diagnosis when adjustment issues may be paramount (Dennison et al., 2011; Irvine et al., 2009). Firth (2014) concluded a review of MS psychological adjustment interventions with the suggestion that support groups may be a viable initial intervention for those with less complex or severe difficulties, with group intervention as an intermediate step and individual interventions a final step (p. 799). This proposal is echoed in current NICE guidelines for adults with depression and a chronic physical health problem, which recommends peer support groups as an initial option for those with milder depressive symptoms. Individual guided self-help programmes are suggested as another option, but

individual CBT with a therapist is recommended only for those who have an inadequate response to initial interventions, who have more severe depression or have declined group-based CBT or for whom this is not appropriate/available (NCCMH, 2010, p. 209-211). The results of the synthesis indicate that in addition to the severity of depressive symptoms, the identity threat posed by taking part in a group intervention needs consideration. The guidelines recommend that intervention choice take into account patient preference, likelihood of adherence to the treatment and potential adverse effects. Results here indicate that those most recently diagnosed may be more likely to perceive group interventions as highly threatening to their sense of self and may be more likely to drop out or find certain aspects of the group format have a detrimental impact of psychological wellbeing. Such individuals may be better served initially by one-to-one interventions. C. Dalton and Gottlieb (2003) discuss the concept of readiness for change, and suggests that it is enabled by clients perceiving they have adequate support to do so. Healthcare providers may offer the initial support necessary to enable this process (C. Dalton & Gottlieb, 2003). One-to-one interventions may also offer a safer environment in which to tackle where beliefs around disability identity and the unacceptability of illness.

An alternative strategy may be to attempt to reduce the identity threat posed by a group format. Designing interventions in such a way that the group element is maintained but identity threat is reduced may enable participants to derive the benefits from positive mechanisms, such as shared

understanding, while reducing the negative outcomes of mechanism related to increased identity threat. Grouping participants according to age or disease stage is one possibility. While the theory that that this would reduce social identity threat needs further testing, some support comes from the study by Visschedijk et al. (2004). This RCT only included participants with a recent diagnosis and reported relatively low attrition rates. It may be that, in addition to reducing identity threat, a sense of shared identity is found with group members better able to relate to each other. In another RCT, participants were divided into groups on the basis of age (Graziano et al., 2014). Favourable reports regarding the group aspect and the high attendance rates indicate the acceptability of a stratified group format. Nevertheless, in both these studies, specific investigation regarding whether this factor has a significant influence on attendance, attrition, identity threat or sense of shared identity is needed. Findings from survey by McCabe et al. (2015) offer further support, with more varieties of support group, including those comprised of younger peers identified as a need amongst respondents. The survey also provided some indication of the value of separating people into symptom severity groups (2015). One downside of such a stratified approach is that it may reduce the opportunity for certain, potentially beneficial, mechanisms, such as the opportunity to learn from positive role models who are coping well with a more advanced stage of the disease. Given the value found by some in helping others, it may be that this mechanism could be built in to programmes, for instance, by having guest speakers at some of the sessions, or, potentially as group leaders or assistants.

With respect to intervention design, the synthesis results indicate that developing programmes that affirm the identity of those with MS may be beneficial for some participants. As Quinn and Earnshaw (2011) suggest, intentionally developing more positive group identities that challenge and undermine the legitimacy of stigma, may help to reduce internalised stigma and its detrimental impact on psychological wellbeing. An example of this is the recently developed disability affirmative therapy, which incorporates the reframing of stigmatised traits and recognises that living with a disability can result in growth and become a source of meaning for the individual (Bogart, 2015; Olkin, 2016). CBT has no theoretical position on identity change, so does not generally address this aspect of adjustment. A notable exception in the context of MS is Graziano et al.'s (2014) CBT-based psychological adjustment intervention. This incorporated the topic of identity redefinition into the intervention content and initial results appear to be promising.

An important line for future research is to examine the mediating role of MS group identification and disability identity on the effectiveness of MS psychological adjustment interventions (Bogart, 2015). The study by Wakefield et al. (2013a) examining the impact of support group identification on mental health made an important start here. Investigating the association between group identification and intervention outcome, as well as examining how group identification may change over the course of the intervention would be valuable in testing some of the theories proposed by this synthesis.

4.5.2 Study limitations

One limitation of this synthesis is that decisions regarding what constituted low, medium and high identity threat were, to a certain extent, subjective. While dividing the continuum in this way provided a useful way of presenting the underlying processes and when they are realised, further work detailing what signifies threat at different levels would be valuable. There were, for instance indications that in the context categorised as medium identity threat, people had begun a process of identity revision, whereas in contexts of high identity threat, it was not yet possible for people to consider this prospect.

Another limitation of this synthesis is that in considering group psychological adjustment interventions for people with MS, only identity threat from MS was considered. Mental health is also a stigmatised condition, thus by attending MS groups with a focus on mental health, participants may risk opening themselves up to stigma from both labels. A further aspect not considered is that, with respect to mental health groups, group norms may not always be positive, which could have a negative effect on psychological wellbeing. Another factor that was beyond the scope of the synthesis was the difference made by the presence of a professional leading the group, as opposed to peer-only groups. This difference poses significant variation in delivery format and possible outcomes and needs further investigation. The influence of gender also merits further exploration. There were indications that women were both more willing than men to attend and engage with groups, and showed greater identification with support groups (McCabe et al., 2015; Wakefield et al.,

2013a). This is in line with the wider literature that men are typically less likely than women to seek psychological help (Addis & Mahalik, 2003; J. Berger, Levant, McMillan, Kelleher, & Sellers, 2005) or attend support groups that women (Kessler, Mickelson, & Zhao, 1997). Whether certain mechanisms are more applicable to women than men could be an interesting related line of inquiry.

One of the advantages of the realist synthesis is that it enables synthesis from across study design. The resulting diversity of included articles increases the range of respondents with respect to age, illness stage and method of recruitment, reducing potential biases. That said, the synthesis articles only included adults with MS and, although MS is rarely diagnosed in juveniles, findings cannot be generalised to a younger population. Another advantage of synthesising across a range of studies is that CMO configurations can be built up as findings of one study can suggest an explanation for results of another. While the strength of such evidence could come under criticism, it is important to remember that realist synthesis is an interpretive process, aiming to build plausible explanations. The end-point of is not a summary of the evidence supporting the proposed relationships between contexts, mechanism and outcomes, but 'beginning theories' (Leeman et al., 2010). These theories, then require specific testing and refinement in order to answer the research question more definitively. Beginning this testing and refinement was the aim of the studies constituting the remainder of the thesis.

Chapter 5. Investigation of Identity Threat and the Perceived Benefits and Drawbacks of Group Versus Individual MS Psychological Adjustment Interventions

5.1 Summary

Following the findings of the realist synthesis, the main aim of the study presented in this chapter was to investigate the factors influencing identity threat and how these may influence engagement with and perceptions of group and individual MS psychological adjustment interventions. The second aim was to explore the relative benefits and drawbacks of group and individual interventions with respect to identity threat and social identity processes.

Sixteen participants who had taken part in the feasibility RCT of group versus individual psychological adjustment interventions were interviewed. Seven had taken part in the group sessions and nine had taken part in the one-to-one condition. With respect to the first aim, results indicated that the identity threat posed by MS varies depending on social identity loss and continuity; incorporation of MS into identity; stigma; time, symptom progression and ageing; and people's illness narratives. Identity threat was found to influence perceptions of the intervention content and reduced intervention engagement. The threat was especially marked in the group delivery format. Intervention timing also emerged as a key variable with indications that identity threat is heightened soon after diagnosis. There were also indications that gender could be linked to identity threat and willingness to engage with the intervention, with men sometimes reported to be more reluctant to engage with a group intervention.

With respect to the second aim, this study begins to makes explicit the relative identity-related benefits and drawbacks of both individual and group interventions. The benefits of group delivery were in accord with those

identified in the realist synthesis, including the opportunity to meet others with similar experiences who could understand what it was like to live with MS, as well as the chance to socialise, share information, normalise illness, challenge negative stereotypes and compare oneself favourably to others. Drawbacks included confrontation with a feared identity, unhelpful group norms and participants putting on a mask. The primary advantage of the individual intervention was that, for some, it provided a safer place to confide personal problems.

The potential for people's illness narratives to influence identity threat, as suggested in this study, merits further investigation. Accordingly, a more in-depth narrative analysis of two of the transcripts was undertaken, as presented in the following chapter (chapter 6).

5.2 Introduction

The results of the realist synthesis in the previous chapter indicated that identity threat can influence engagement with and perceptions of group psychological adjustment interventions. Research is now needed to specifically investigate the factors that affect identity threat and how this may influence perceptions of attending either group or individual MS psychological adjustment interventions. There is also a need to explore the relative benefits and drawbacks of group and individual interventions with respect to identity threat and social identity processes. Research within clinical neuropsychology indicates that attending psychological adjustment groups based on cognitive behavioural principles can improve mood and reduce the impact of MS on people's lives (Lincoln et al., 2011). While such findings are promising, whether

it is the intervention content or the group context that is of primary importance has, thus far, been given limited consideration by researchers. The social identity approach offers a useful framework from which to explore the benefits and drawbacks of being part of a group intervention and how this may compare with the experience of one-to-one sessions.

Social isolation is often experienced by those living with MS (Kirchner & Lara, 2011; Robens et al., 2014) and a common assumption regarding MS group interventions is that the social interaction is inevitably beneficial (e.g. Thomas et al., 2006; Visschedijk et al., 2004). This assumption has rarely been examined in the MS literature and fails to take into consideration the anxiety that may be caused by alterations to the groups people are part of, even if such changes are positively perceived. As outlined in the introductory chapter (chapter 1), as relational creatures, our sense of self is constructed through our interactions with others (S. A. Haslam et al., 2009; Levine, 1999). Social groups provide a base where people can feel accepted and find significance, identity and purpose (Spencer & Pahl, 2006). Loss of social group memberships, as can occur in chronic illness, may constitute the removal of foundational identities, and result in mood disturbance (Lewin, 1948). This was supported by the results of the survey study (chapter 3). Importantly, new and unfamiliar social identities will not necessarily be welcomed. As evidenced in the realist synthesis (chapter 4), MS groups and the accompanying MS social identity are often negatively perceived and can pose a threat to an individual's pre-diagnosis identity. The effect this may have on engagement with MS interventions needs

investigation. Accordingly, the primary aim of the current study was to investigate the factors influencing identity threat and how these may influence engagement with and perceptions of group and individual MS psychological adjustment interventions. Within this, consideration was given to participants' illness narratives. Narratives – the story we see ourselves, our illness, others and our relationships with them as fitting into – are essential to the construction of our identity (Ricoeur, 1991). With respect to illness, self-narratives, and the societal narratives that influence them can either constrain or enable the individual who is attempting to make meaning of their situation (Sparkes & Smith, 2011). As Hughes and K. Patterson (1997, p. 355) realised, "impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning." Thus, an understanding of participants' illness narratives may shed light on the process of identity revision and the formation (or not) or new group memberships.

The second aim of the study was to identify perceived benefits and drawbacks of both group and individual psychological adjustment interventions for people with MS. The focus was on identity-related advantages and disadvantages of each delivery format as opposed to the more established logistical or practical factors.

Participants were recruited from those who had taken part in the feasibility randomised controlled trial examining the efficacy of group versus individual CBT-based psychological adjustment interventions for people with MS (das

Nair et al., 2015). Participants for the feasibility study were recruited in response to advertisements on the MS Society website and local branch newsletters, as well as from invitation by clinicians working in NHS Multiple Sclerosis Clinics in Nottingham. Inclusion criteria for the feasibility trial included a diagnosis of depression, as indicated by a score of and three or more on the General Health Questionnaire 12 (GHQ-12; Goldberg, 1992) or eight or more on the Hospital Anxiety and Depression Scale (HADS) depression or anxiety sub-scales (Zigmond & Snaith, 1983).

The intervention consisted of six hour-long sessions once a week, with participants having been randomly allocated to either a group or individual format. The sessions were delivered by a clinical psychologist or psychology assistant and the same manualised content was followed in both conditions. Topics covered in the sessions were problem solving, target setting, worry, gloom, relationships and the future.

5.3 Method

For the current study, people were interviewed following participation in either the group or individual condition. Ethical approval for the study was incorporated in the ethical approval for the wider feasibility trial. This was granted from the East Midlands, Nottingham 1 Research Ethics Committee (12/EM/0380), the University of Nottingham's Institute of Work, Health & Organisations Research Committee, and Nottingham University Hospitals NHS

Trust Research & Innovation Department. (See appendix 6 for ethical approval letters).

5.3.1 Participants

Sixteen participants agreed to be interviewed following the intervention, seven from the group condition and nine from the individual condition. Consent was obtained from the psychologist delivering the intervention. In the feasibility RCT, of the eleven people allocated to individual sessions, nine completed all six sessions. There were two group interventions, which ran in succession. Of the ten people allocated to the group intervention, seven were allocated to the first group and three to the second group. Two participants attended all six sessions, three attended five of the sessions and two came to three of the sessions. Three people did not attend any of the sessions, with reasons for non-attendance being a relapse, bereavement and not being offered their preferred delivery format (as described in das Nair et al., 2015). One participant was later found to have a diagnosis of neuromyelitis optica, but was retained in the study (as described in das Nair et al., 2015). Table 1 shows the demographic characteristics of the interviewees.

Table 9. Demographic characteristics of interviewees

n=16		Mean (SD)	Range
Age (at randomisation) (years)		47.6 (11.6)	29-66
Time since diagnosis (at randomisation) (years)		8.3 (6.5)	1-23
Hospital Anxiety and Depression Scale (baseline)			
	Anxiety	10.3 (4.9)	2-21
	Depression	9.9 (2.9)	6-15
	Total	20.1 (6.7)	10-35
General Health Questionnaire-12 (likehart scoring) (baseline)		20.4 (6.4)	9-30
		n	%
Gender	Men	5	31.3
	Women	11	68.8
Diagnosis	Relapsing-Remitting	9	56.3
	Primary Progressive	0	0
	Secondary Progressive	2	12.5
	Benign	1	6.3
	Neuromyelitis Optica	1	6.3
	Missing	3	18
Ethnicity	White British	14	87.5
	White Malaysian	1	6.3
	Indian	1	6.3
Relationship Status	Married/ Partner	10	62.5
	Single	5	31.1
	Divorced	1	6.3

5.3.2 Data collection

Semi-structured interviews were conducted with the participants. Seven were carried out by the author, and nine by a research colleague. This colleague was carrying out an independent investigation into the impact of family identity on identity change and psychological adjustment in people with MS. The interviews lasted between 20 and 60 minutes and took place either at the university or at the participant's home at their request. In line with a semi-structured approach, the tone of the interviews was conversational with no fixed question order or wording (H. Rubin & I. Rubin, 2005). The same topic guide was used by both interviewers and covered the participants' experience of the intervention, their thoughts and feelings about the content and format, and their social relationships and group memberships before and after diagnosis (see appendix 7). Some participants had been randomised to the individual sessions and some to the group sessions, which enabled collection of data regarding both the experience of one delivery format and perceptions of the format not undertaken. Where it facilitated discussion, eco-mapping techniques were used to help build a picture of the participants' social networks (Ray & Street, 2005). This is an interviewing tool, originally developed in social work, but more recently applied to clinical settings whereby a graphical depiction (similar to a mind-map) of the relationships between individuals, their families and wider social and support networks is produced. The technique was carried out to help elicit information about an individual's previous and current social identities and to allow participants to reflect on any changes to social identities using a visual stimulus. Each interview was audio-

recorded and transcribed verbatim with pseudonyms used for purposes of anonymity.

5.3.3 Data analysis

Thematic analysis was used to identify and categorise emerging themes. NVivo 10 software (NVivo Version 10, 2012) was used to support this process. The analysis involved seven phases, drawing on guidance from Braun and Clarke (2006, p. 87):

Phase 1: Familiarisation with the data. The first transcript was read, re-read and initial thoughts noted.

Phase 2: Generating initial codes. The transcript was systematically worked through to identify semantic and latent content relevant to the research questions. Data extracts were then coded.

Phase 3: Search for themes. These codes were examined for patterns and collated into conceptually related themes. Potential hierarchical relationships between the themes were identified.

Phase 4: Reviewing themes. The overarching and sub-themes generated were reviewed and refined in an iterative process to ascertain coherence of data within the themes, distinct boundaries and relevance to the research questions.

Phase 5: Defining and naming themes. Themes were further refined and the overall story they told considered. Possible theme names were noted.

Phase 6: Themes reconsidered in light of other transcripts. The themes and concepts were used as a guide to code the transcript of another participant. Some concepts were altered or added to in order to incorporate both data sets. Refinement of themes continued in this way until all the transcripts had been analysed.

Phase 7: Producing the report. Quotes that demonstrated the essence of the themes were selected from across the participants for inclusion in the report.

Following this process helped ensure systematic and transparent analysis and interpretation of data. This is line with the recommendation that qualitative research be rigorous in conduct, one of the four central principles underpinning Spencer et al.'s (2003) framework for appraising the quality of qualitative research.

5.4 Results

With respect to the first aim, to explore the factors influencing identity threat and how these influenced intervention engagement, three overarching themes were constructed from the analysis of participants' comments. These were, firstly, that the identity threat posed by MS varied, secondly, that this threat reduced engagement with the intervention and thirdly, that identity threat

influenced people's perceptions of the intervention content. The themes and sub-themes are listed in table 10. With respect to the second study aim, a range of identity-related benefits and drawbacks of both individual and group interventions were identified, as outlined in table 11.

5.4.1 Factors influencing identity threat and how these influence engagement with, and perceptions of, group and individual interventions

Table 10. Factors influencing identity threat and how these influence engagement with and perceptions of group and individual interventions

Overarching themes	Sub-themes
1) Identity threat from MS varies	Social identity loss & continuity
	Incorporation of MS into identity
	Stigma
	Time, symptom progression and ageing
	Illness narrative
2) Identity threat reduces intervention engagement	Delivery format
	Timing
	Gender
3) Identity threat influences perception of intervention content	Focus on future
	Focus on past
	Narrative perspective

1) Identity threat from MS varies

Five sub-themes related to the experience of identity threat were identified. These were: social identity loss and continuity; incorporation of MS into identity; stigma; time, symptom progression and ageing; and illness narrative. The degree of identity threat experienced varied across participants and sub-themes.

1a) Social identity loss & continuity

Many participants described a loss of, or alterations to, their pre-diagnosis social group memberships. The degree of loss varied, but whether it threatened an individual's sense of self appeared to depend partly on the importance attached to the lost groups. For instance, a woman whose group of work colleagues had constituted a significant social identity experienced the loss of this group as a considerable threat to her sense of self:

> *So you are very close to your colleagues, because you rely upon them to watch your back for you, and to help you, because professionally you are working close together. But I haven't got that anymore, it's like half, the majority, about two thirds of my life has just disappeared* (Frances).

Whether or not other valued groups were simultaneously maintained also appeared to influence the degree of identity threat experienced. There were indications that such threat could be reduced when the lost groups were less central to sense of self, which was rooted instead in other valued and

continued relationships. For some, family identity was a particularly valuable base in this regard. One woman commented: "*If it wasn't for parents, fiancé and my [location] friends I don't know where I'd be*" (Sara).

Another woman, who did not have close family, appeared to experience MS, meeting other people with the disease, and the corresponding feeling of being categorised as someone with MS, as particularly threatening to her identity:

> *You want to mix with normality and feel you are just generally part of the human race, and not plucked out with a label around you [I: Yeah] And I think most people would agree. But it is different I think for people that have got a partner, [Interviewer (I): Mmm] you know, because they have still got, it is easier, obviously because the partner will assist, but I mean the friends that they have had together are more unlikely to walk out on both of them* (Rosie).

1b) Incorporation of MS into identity

The degree to which participants incorporated MS into their sense of self varied. Some found diagnosis overwhelming and appeared to try to prevent it from dominating their identity by compartmentalising or trying to ignore the disease: *"…always in a complete state of denial about any of this is happening. 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*" (Frances). Similarly, another woman reported changing the term

"*MS first aid kit*", used in the intervention manual, to "*emotional first aid kit*" because "*I don't like to say that I've got MS*" (Jessica).

Some participants accepted MS to a degree and knew people with MS, but did not necessarily view these as social groups to which they belonged, and did not want MS to define them. Sara, for instance, tended not to disclose the condition to others and explained that she approached attending MS groups as she would going for a medical appointment. The result was:

> *kind of like a, not like a Jekyll and Hyde but like having two different identities. Because it's like, when I do meet up with the MS people like you're mentioning it is like really, really helpful but then with like my gym friends, say like the people, like most people don't know I've got it at all* (Sara).

When drawing out her social networks in the eco-map, she was pleased to discover that those she knew with MS didn't feature: "*Oh, that's really cool that they're not actually on it, because it's like, for me I feel like my MS is like the focus of everything these days*" (Sara). Another lady commented on the importance of having social groups outside of an MS context, where she could talk about things other than illness and "*have a girly laugh or complain about your husbands*" (Alanah). She reflected: "*You don't want to get too wrapped up in your illness otherwise that is taking over again and you want to, sort of try and push it aside a little bit*" (Alanah).

At the other end of the spectrum, some people wanted the certainty a label provided and actively sought diagnosis: "*it's not that I needed the diagnosis to get drugs because I was, I was fine, I just needed a label*" (Kelly). Specific reference to an MS social identity was made by one man in the term, "*we MSers"*" (Christopher). Another participant described a clear "*old self*" and "*new self*" (Priya). She had experienced considerable loss of friendship groups and now sought out those whom she felt shared her values and newfound outlook on life. Amongst others, this included people with MS. She remarked: "*that was some I could socialise with, because they don't go out clubbing and bar-ing do they, and drinking? So it was great to kind of socialise with people with my new me*" (Priya). The extent to which she had incorporated MS into her identity was evident when describing how comfortable she felt attending an MS conference: "*I was just like, this is home*" (Priya).

1c) Stigma

Several participants reported experiencing stigma as a result of their condition. For instance, one woman said: "*as soon as they know the diagnosis, they don't know what to say, and I am sure some people now, don't avoid me on purpose. They just think god, [I: Yeah] what do I say?"* (Frances). When MS was perceived to be stigmatised, meeting others with the condition appeared to be particularly threatening to identity. Certain aspects of MS posed more of a threat than others, with wheelchairs often seen as a particularly stigmatised aspect of the condition: "*my boyfriend took me to [city] to this huge MS event,*

and then I walked in and there was absolutely loads of people in wheelchairs and I just burst into tears and I just wanted to get out" (Sara).

Another form of stigma came from feeling invalidated when people didn't believe there was anything wrong. For instance, one lady described how family and friends did not understand how she felt, because she looked well on the surface: "*Some people just don't get it. They just don't understand and they look at you and think, 'There's nothing wrong with you'*" (Dawn).

Several people described anticipating stigma. One lady went to considerable lengths to avoid anticipated stigma, admitting, for instance, that she avoided using mobility aids in order to hide the MS from others: "*I don't use the crutches I am supposed to, because you can't dismiss it as a sprained ankle, if you have got crutches, because even idiots don't believe that*" (Frances). Some people feared that they would no longer be able to retain membership of valued groups if they disclosed their condition. One result was identity performance in order to protect social identities perceived to be threatened: "*nobody at work knows*" (Beth). There was evidence that, for some people, when threatened identities were less central to sense of self, disclosure was less of a risk. For instance, one of the younger women, admitted:

> *It's like the older people, because I normally go during the daytime and you get like loads of OAPs and most of them know about it. [I: Yeah] But like people my age, [I: Yeah] like I don't like them knowing really* (Sara).

Disclosure was similarly safer when people felt sure that they would continue to be accepted as members of valued groups despite having MS. For instance, one man, who expressed an assurance that friends and family members would continue to value him despite MS, was able to disclose his illness and could even allow colleagues to make good-natured fun of symptoms:

> *Now they call me 'Wobbly' at work, err, which is nowt special because even my nephews call me Wobbly - Uncle Wobbly - err, in fact I went to [an event] a couple of weeks ago and err, I got a, the award for the best dancer* (Leonard).

1d) Time, symptom progression and ageing

There were indications that, for some people, time, symptom progression or ageing reduced the identity threat posed by MS. There was some overlap between these factors. Following diagnosis, several participants reported an initial denial of MS and fear of what the illness might mean for who they would become in the future. For instance, Sara recalled: "*because as soon as you're diagnosed with MS you think that's what I'm going to be like, I'm going to be like confined to like a wheelchair and stuff.*"

Several participants reflected that it took time to come to terms with the condition: "*I think I was able only to adapt to that change was because I had time*" (Priya). Some participants reported that over time, they were able to disclose their condition to others, but that initially they kept it hidden: "*I*

thought that to begin with 'Don't tell anybody, they don't need to know, I'll be ok' but, by telling people it's just so much easier" (Gerrard).

There were indications that, in addition to time, for some people, social identity threat decreased as symptoms progressed. Beth commented she had become more involved with MS organisations since her symptoms became worse: "*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*" (Beth). Interestingly, over time and as symptoms progressed, Beth came to see mobility aids, commonly viewed as stigmatising, as beneficial: "*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 hired one of those little motorised chairs. It was fantastic*."

Beth also found that MS posed less of a threat as she got older because symptoms could be attributed to either the disease or older age: *"But then sometimes you're not sure it's your age, sort of thing, because as you get older it happens to other people as well. It's not just MS".* Also significant here was that as people age, their friends without MS were also more likely to be dealing with ill health, thus equalising any comparison between MS groups and non-MS peer groups: *"I mean I think an age thing, we're always complaining about, oh, we're getting older, oh, my back hurts, my leg hurts and then you think, well, you know. So everybody has got things going on" (*Alanah).

1e) Illness narrative

The narrative people saw themselves as part of also appeared to influence the experience of identity threat. Two narrative categories that emerged were illness as quest and illness as endurance. Several of the participants appeared to approach illness as a quest. From this perspective, MS carried less stigma; instead individuals sought to overcome and grow through the experience. One participant even used a directly heroic analogy, explaining that, in contrast to "*your average Joe*", he tried to think as Napoleon did: *"Napoleon said don't bring me problems bring me solutions [I: yeah] and that's the way you tend to think, err, nothings a problem [I: yeah] because if there's a problem, you sort it out and find a solution"* (Leonard).

For another participant, a quest narrative helped free her from identity threat resulting from negative comparison with other people: *"friends often remind me, look where you have been in the past. You have made a great journey forward. [I: mmm] Just don't think about other people. Don't compare yourself"* (Priya).

By refusing to let MS determine their capabilities and, in this sense, to define them, some participants who viewed their condition within a quest narrative seemed more able to enjoy the present. For instance, a quest narrative appeared to enable Sara to see comparisons with others with MS as opportunities to be grateful for her current abilities as opposed to occasions for fearing what she might become: *"So it's not like I see them and I just get*

happy that I'm not like that, but then I don't see them and just think that's what is going to happen to me" (Sara).

The contrasting narrative was one of illness as endurance. Frances, who appeared to experience MS as a threat to identity, saw MS very much from this perspective, as the following quote illustrates:

> *I was brought up to believe that people never have flu, they just have bad colds. There is no such thing as migraine, it is just a bad headache. And people who are depressed are basically whinging bitches who can't cope with life* (Frances).

2) Identity threat reduces intervention engagement

When MS posed a significant identity threat, participants appeared to be more reluctant to engage with the intervention. There was evidence that this applied to both individual and group formats, although having to meet other people with MS in the group intervention posed an additional threat. Timing was also found to be a significant factor with regard to identity threat and willingness to engage with the intervention. There were some indications that gender could also affect perceptions of identity threat, particularly with respect to attending the group intervention.

2a) Delivery format

For some participants, identity threat appeared to be heightened in the group format. In the quote referenced previously, Rosie indicated that she felt attending the group would mark her out from healthy society: *"Personally I like normality. You want to mix with normality and feel you are just generally part of the human race, and not plucked out with a label around you"* (Rosie, individual intervention). She described avoiding MS groups in an attempt to avoid confrontation with a feared future identity. The prospect of meeting other people in wheelchairs was especially threatening: *"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*."

Another woman, Frances, who took part in the individual intervention, admitted that although "*it would have been nice to have that shared thing with people",* fears of confronting what might happen would have prevented her from attending the group intervention: "*And that was the worry with the group as well, that you see people, you think oh god this will be even more depressing than I am now, because this is what is going to happen"* (Frances). For Frances, the fear of MS becoming all-consuming appeared to be paramount and she was particularly reluctant to join groups where MS was the only thing she had in common with the other people. Groups where carers attended seemed to reduce the identity threat in this regard: *"The MS Society they do a coffee*

afternoon at one of the local garden centres. Cos I was going to go to that, because I think there are people, the carers are there as well" (Frances).

Frances and Rosie had both been randomised to the individual intervention so it is not possible to ascertain whether they would have attended the group sessions had they been allocated to them, or how they would have found the experience. Interestingly, though, another participant randomised to the group format, reported negative preconceptions of the MS groups and a prior preference for the individual sessions. To his surprise, after attending the group sessions, his perceptions were altered and he admitted finding it helpful to meet other people with MS in the context of the intervention:

> *…as it turns out I think the groups better 'cause like you say you can feed off other people's err, problems [I: yeah] err, and other people's solutions, you know what I mean err, if they come across solutions [I: yeah] err, I never thought of that you know what I mean? So I think the group is better* (Leonard).

A participant allocated to the individual condition appeared to be less threatened by the prospect of a group intervention because he saw other people in MS groups first and foremost as people. He identified with them on this level, as opposed to categorising them as MS patients:

> *I don't see it as a group of people with, it is a group of people with MS, but because I have been through every level that they are on or about to go through or have been through or whatever, it is just a group of people. It just so happens it is MS* (Nicholas).

2b) Timing

Timing appeared to be critical in terms of identity threat and intervention engagement. Several participants experienced identity threat as being particularly high just after diagnosis. For instance, Sara, a group participant, commented:

> *when I was first diagnosed for like the first, like probably, two years I didn't want anything to do with like the MS and I didn't want anything to do with other people that have MS [I: Yep] so I'd never have wanted, I would never have agreed to, like, the research project* (Sara).

Several people commented that they felt they had needed to come to terms with the MS to some degree in order to consider taking part in an intervention. Timing appeared to be especially important when contemplating the group format. For instance, Alanah, a group participant diagnosed more than two years prior to the intervention, commented: "*I think I was just about ready now to have some contact"* (Alanah). Another group participant said that initially she wouldn't have wanted to see how bad she could get. When asked what had helped her overcome this fear, she replied: "*Well, I've got worse myself I think,*

so it's happening and there's nothing you can do about it" (Beth, group intervention).

One group participant, Dawn, did comment that she wished she had done the intervention sooner after diagnosis. However, since this comment was made retrospectively it is not possible to determine how threatening the prospect of meeting others would have been at that time.

2c) Gender

Gender was another factor that some people appeared to associate with identity threat and willingness to engage with the intervention. For instance, Leonard reported gender as contributing to his reluctance to engage with a group intervention:

> *Interviewer:* *Why were you hesitant about it being a group?*
>
> *Leonard:* *Erm, well its just a man thing 'int it I suppose.*
>
> *Interviewer:* *Yeah*
>
> *Leonard:* *You know what I mean? Err group therapy? Bloody hell.*
>
> (Leonard, group intervention).

Another of the men similarly perceived gender as influencing willingness to attend MS support groups more generally, although his comments cannot necessarily be taken to extend to his perceptions of the group intervention: "*There is quite a bit of loneliness associated with MS I find, unless you go to the*

very WI-style meetings, which I do struggle with" (Christopher, group intervention).

While both these comments were gender-related, it may be that the perceived reluctance of men to take part in groups is due as much to a difference in coping and communication styles than to group intervention attendance constituting a threat to identity, as one woman suggested:

> *I know men with MS but, I don't have contact with them. I see them at the hypobaric oxygen but we don't really talk. [I: Yeah] It's just women, because women do talk. [I: yeah ok]. Men do, but men do it differently to women* (Jessica, individual intervention).

3) Identity threat influences perception of intervention content

In addition to affecting intervention engagement, identity threat appeared to influence people's perception of the intervention content. Focus on the future, focus on the past and narrative perspective were found to be particularly relevant factors.

3a) Focus on future

Some participants felt that the intervention content was unhelpful in forcing them to think about a feared future identity. Rosie, who took part in the individual sessions, described how she felt the content required her to consider an unwanted future, which she found largely unhelpful:

> *I have tried not to think of the future too much, because it is no good worrying about something that may or may not happen. And nobody knows, because it is so unpredictable. So erm, this seems to emphasise in a way the bad things in a way. 'What would you do if?' And I found that a bit hard* (Rosie, individual intervention).

She described how this affected her mood negatively:

> *But yesterday morning I went through this, and I was in good spirits beforehand, and I was in tears by the time I had finished, thinking, you know, certain things hit home that I hadn't been thinking about* (Rosie).

Similar comments were made by Frances, who appeared to experience MS as overwhelming and a considerable threat to identity: "*I found it quite, erm, the whole CBT thing quite depressing [I: mmm] because it was forcing the issue* (Frances, individual intervention). By contrast, there were indications that when MS posed less of a threat, some people perceived the strategies covered in the intervention more positively. For instance, Alanah commented:

> *it did make you think what was really going on and why we are letting things, sort of, take over your life rather than you sorting things out in a way, which was really quite helpful. I enjoyed it. Rather than just sort of, putting them all in the back of your head and thinking, oh, I can't deal with this and I can't deal with that* (Alanah, group intervention).

3b) Focus on past

The degree to which MS was incorporated into identity also appeared to affect some participants' perceptions of content that made them reflect on their earlier life. Priya, who had experienced considerable loss of pre-diagnosis social groups, had embraced MS as part of a new identity. She responded negatively to such reflection, and perceived it as focussing too much on the past:

> *I think it focussed far too much on the past as opposed to the future, and that question there made me stupidly angry because why on earth would I want to look at my old self, when my old self has died, and I have lost everything? Why would I?* (Priya, group intervention)

By contrast, another participant who described strong social identity continuity and appeared to experience MS as less of a threat to identity, found the reflective aspect helpful:

> *So what she did for me was made me sit back, look at my life, look at my MS, look at how it was affecting my life and then make the choices that I needed to make, which had made me much happier* (Dawn, individual intervention).

3c) Narrative perspective

Perception of the intervention content also appeared to be influenced by participants' illness narratives: the story they saw themselves as fitting into and through which they viewed illness. Some of the participants who saw illness according to a quest narrative approached illness as a journey and were keen to learn from the intervention content. For instance, Christopher saw CBT as an opportunity for growth and adjustment:

> *I think there's definitely room for CBT because of how it, I think it can speed up, I think it's taken me a long time to adjust to things, but there are new things all the time and I think CBT could be very, very useful.*
>
> (Christopher, group intervention)

A quest narrative appeared to enable some participants to have a more positive perspective of overcoming difficulties. For example, Sara commented how the psychologist had encouraged her "*to concentrate not on like the stuff that you can't do but the stuff that you can do".* William had a similar outlook:

> *its an eye opener to actually look inside a little bit more and to find erm, a solution to a problem that you weren't aware of [I: yeah] So once you know the solution, once you've got the solution and the problem, you can find the answer. I think knowledge is power.*
>
> (William, individual intervention)

In contrast, Frances, who acknowledged having a perspective whereby people with illness were perceived as weak, said she found the intervention content largely unhelpful. She explained: "*It opened massive cans of worms all over the place, and it was quite an eye opener in a way. So I think you ought to warn people* (Frances, individual intervention).

5.4.2 Perceived benefits and drawbacks of group and individual intervention formats

Table 11. Perceived identity-related benefits and drawbacks of group and individual intervention formats

Overarching themes	Sub-themes
1 a) Benefits of group format	Shared understanding
	Normalisation of illness
	Socialising
	Sharing information
	Negative stereotypes challenged
	Positive downward comparison
1 b) Drawbacks of group format	Confrontation with feared identity
	Unhelpful group norms
	Putting on a mask
2 a) Benefits of individual format	Easier to confide
2 b) Drawbacks of individual format	Do not meet others with shared experiences

1 a) Benefits of group format

Shared understanding

Shared understanding was highlighted by many of the participants as being an advantage of the group format. As one woman said, "*it was good to be in a room with other people that understand you"* (Sara, group intervention). Another woman described the value she found in "*talking through things that we all experience*" (Beth, group intervention). The potential benefit of meeting others with shared experiences was also acknowledged by people allocated to the individual intervention. One woman who had taken part in the individual sessions expressed a desire to meet others who shared the same specific symptoms as her, particularly given the wide variety of symptoms people with MS can experience: "*it would be nice to come across somebody else who actually gets the vertigo like this"* (Frances, individual intervention). The freedom to discuss more personal symptoms was also mentioned: "*and also with the bladder problems as well and then, you know, that's something you don't talk about to anybody else and then you talk about that"* (Alanah, group intervention). Shared understanding with other people with MS was often contrasted with the frustration of feeling misunderstood by family and friends:

> *I can't talk about that with my sisters cos they haven't got a clue what I go through, [I; Yeah] and just the simplest of things I was able to talk about, and someone just understood. I thought that, that's great. That's really good* (Priya, group intervention).

Dawn described a similar frustration at the lack of validation from members of her family: *it's frustrating when as much as you explain it they can't, just don't get it, they don't understand* (Dawn, individual intervention).

Interestingly, in the individual intervention, Kelly admitted to she had found it hard to tell her problems to, or find answers from, someone whom she didn't feel was in a position to fully understand: *"it just felt like she [the psychologist] was a normal everyday person off the street, so couldn't really [I: yeah] give me the answers or, maybe relates the wrong word?"* (Kelly, individual intervention).

The desire to meet other people who understood was further apparent in the suggestion that people might be able to identify with other group members more easily if participants were grouped according to socio-economic or life stage factors:

> *I suppose you could actually determine people who have children under a certain age because the effect on them would be different to somebody who have got children older and are self-caring. People who are married, and people who aren't married. People who live alone, people who don't live alone* (Frances, individual intervention).

Beth, a lady in her fifties, made the similar suggestion that younger people may find groups for younger people with MS more relevant. In line with this, Priya

reported valuing the opportunity the group had provided to meet other younger people with the disease:

> *That's my big thing is that people with MS are generally older. There are young people being diagnosed but not many young people that I am in touch with [I: Yeah] and I had touch with young people, which was good for me* (Priya, individual intervention).

That it may be easier for younger people to identify with other younger people with MS was also confirmed by Kelly. She reflected that, when diagnosed as a teenager, she hadn't been able to meet many people of a similar age with whom she could identify: *"there's a lot more people now [I: yeah] than there was when I was back when I was 16. But it's different age groups isn't it? I didn't really associate with older people"* (Kelly, individual intervention).

Finally, several participants mentioned how they valued the opportunity for laughter afforded by in-group understanding. For instance, Alanah explained an in-group joke about difficulties with everyday tasks: *"Oh, yeah, we did have a laugh, yeah. It was so funny. The light bulb thing took over the whole thing for five weeks"* (Alanah, group intervention).

Normalisation of illness

For some people, normalisation of illness was another perceived benefit of the group format. Several of the participants commented on the reassurance they

felt upon realising there were other people in the same boat. For instance, Alanah expressed the relief of finding that other people experienced similar difficulties to her: *"and it was sort of, oh, yeah, that's the same for me"* (Alanah, group intervention).

In some cases, even participants who reported reluctance towards taking part in the group intervention acknowledged that the group format could have benefits in terms of the comfort afforded by finding out you are not the only one:

> *also I suppose there is this whole support thing, so it is not just happening to me, it is happening to other people, [I: yeah] and you can take comfort from that. Because you sometimes think, oh is it just me.* (Frances, individual intervention)

Christopher came to a similar conclusion: "*I think it could help people, make them feel less alone*" (Christopher, group intervention).

Socialising

In addition to the comfort of knowing they were not the only ones living with the disease, some participants valued the opportunity the group format provided to socialise with other people: "*that has been a big thing for me just being able to socialise with people"* (Priya, group intervention). Alanah, similarly, found the social aspect important: "*groups and people to talk to, I think that's a good thing actually"* (Alanah, group intervention).

Beth commented that she *"enjoyed having the interaction really*", so much so that she suggested organising a reunion: "*it would be nice to organise something like that I was thinking, perhaps on the same day or something and just organise something so that we can see how people have got on and things"* (Beth, group intervention).

Sharing information

For some people, another important aspect of meeting others in the group was the opportunity this provided to share tips and advice. As Leonard realised: "*Yeah, it's silly things that become a, a, problem, and it's to hear how other people get round 'em"* (Leonard, group intervention). This extended to information beyond the remit of the intervention content as such. For instance, Alanah explained: "*Even just, sort of like getting forms and that sort of thing. Somebody always knows something that you don't know, and then you think, Oh! I didn't realise that. And it has been quite useful"* (Alanah, group intervention). Several people commented that this had enabled them to see things from a different perspective. For example, Alanah further elaborated: "*I suppose you swap ideas as well really, swap things that are going on and things all seem to, as you say, come into perspective of what's really going on"* (Alanah). Beth, similarly, saw this as a benefit of groups: "*you hear different perspectives on things"* (Beth). Some of the participants allocated to the individual condition could also see this as a potential benefit of the group format: "*It is good in a way to hear of other people's shared experiences, to*

share experiences and see how they have overcome things, if they have managed to" (Rosie, individual intervention).

There were indications that some participants found it easier to accept advice from people with shared experiences and understanding. For instance, when discussing the benefits of the group format, Sara mentioned sharing tips immediately alongside talking to people who understand you: "*Like I said with like sharing tips, that kind of thing. Speaking to other people who understand you*" (Sara, group intervention). In addition to obtaining information, several people commented that they liked being able to offer advice to others. When asked which aspects of the course she had particularly enjoyed, Evelyn replied: "*Really the discussion between the people, getting hints on how to do things that you might not have thought about. Or being able to give a bit of information that other people hadn't thought about"* (Evelyn, group intervention). She indicated that living with MS could make her feel "*unnecessary"* and that listening to others gave her some significance and purpose: *"So I actually quite like listening to people's problems because it takes my mind off my own. It's something I can do"* (Evelyn). That the group format offered the opportunity to feel helpful was commented on by another participant: *"I suppose it's a bit like the volunteering, like having a bit of use instead of you being the person that everyone is having to like look after and reassure and stuff"* (Sara, group intervention).

Some participants allocated to the individual condition expressed a similar

desire to feel useful. As Rosie pointed out: "*I think it is important to be helpful. You know, that is a basic need isn't it?"* (Rosie, individual intervention).

Negative stereotypes challenged

There were a few indications that negative perceptions of others with MS, and of MS groups, could be challenged during the course of the group intervention. Leonard, for example, was initially reluctant to attend an MS group which he perceived would be a group of people *"sitting around finding problems feeling sorry for themselves".* However, as outlined above, he later acknowledged that, having attended the group sessions, he now felt the group intervention format was actually more beneficial than an individual format.

A related finding was the indication that MS groups more generally could provide people with positive role models, particularly with respect to stereotypes of disease progression. Although she attended the individual intervention, when talking about another MS group she had been to, Rosie commented that she felt someone there who had recently been diagnosed had found meeting her helped allay his fears:

> *it was great, because the second time there was someone who has only just been diagnosed and scared to death. And I think it was good for him to see there was somebody there that could walk around unaided, sort of thing* (Rosie, individual intervention).

Positive downward comparison

Some people found that comparing themselves favourably with others with more severe symptoms made them appreciate their relatively reasonable state of health.

> *I enjoyed it. I thought it was quite an eye opener because I was with another gentleman actually. He'd had so many problems and it all, sort of, made mine seem a little bit, you know, oh, I've got nothing wrong with me really at the end of the day* (Alanah, group intervention)

This sentiment was echoed in the albeit slightly tongue-in-cheek comment from one of the individual intervention participants: "*The upside of a group is you think, well at least I am not that bad. [laughs]"* (Frances, individual intervention). In a similar way, Leonard appeared to find it helpful to meet other people who he felt he was coping better than. With respect to coping strategies and the group intervention he reflected:

> *'cause another one in the group, erm, everything was a problem [I: right] But it's not a problem, sort it out, you know what I mean? [I: yeah] Bring a solution, not a problem. [I: yeah] You know what I mean? Err, but that proved to me that what I'm doing is right, not [I: Right, ok] which I found really good actually* (Leonard, group intervention).

1 b) Drawbacks of group format

Confrontation with feared identity

While positive downward comparison was a potential benefit of the group format, a related potential drawback was negative downward comparison. Although none of the interviewees who took part in the group sessions highlighted this as a problem in actuality, several of the people allocated to the individual format expressed a fear of having to confront an unwanted future identity: "*I think it would be more depressing for somebody who has got relapsing remitting at an early stage [I: Yeah] to be with somebody who is more advanced"* (Rosie, individual intervention).

Meeting other people in wheelchairs appeared to be especially daunting for some:

> *I think the problem for me when I've done other things in groups where everyone's had MS, it's really difficult because you get people that don't look as though they're affected at all, all the way to people who are in wheelchairs and it's really hard not to look at people and think that'll be me in a couple of years' time*. (Rebecca, individual intervention)

Unhelpful group norms

Some people were wary of attending a group where a diagnosis of MS was the identifying characteristic. Frances, for instance, was disinclined to attend any MS groups "*if they always just want to sit around and talk about their MS.*" Her fear appeared to be related to MS becoming all-consuming:

Okay you are trying to avoid the isolation but, I have got enough going on in my brain about my MS without then having to talk about it on a social basis. Professional basis, fine. I don't mind doing that. Socially, no I don't want to do that, thank you very much. [I: mmm] And if that is your only point of - not point of contact that is not the word - the only thing you have got in common with each other, [I: common ground, hmm] that would dominate, I would imagine.

(Frances, individual intervention)

Kelly, also randomised to the individual intervention, expressed similar concerns regarding the group format: "*I've spoken to a friend that's doing something else, and she said the problem with group sessions, everybody's making their symptoms sound, it's competitive of who's got the worst symptoms*" (Kelly, individual intervention). That everyone attending the groups had a certain level of mood difficulties was an area of concern for Rosie, who suggested it may be beneficial to have mixed groups that included people who weren't classed as depressed to "*see how they have achieved things or how they react to certain situations"* (Rosie, individual intervention).

It is not possible to determine whether these participants would have found these concerns to be true had they attended the group sessions. The only group attendee who made a related comment was Leonard who, as outlined above, saw others' relatively poor coping or negative attitudes as reaffirming how well he was coping. Christopher, had a contrasting concern regarding

grouping everyone with MS under the same umbrella:

> *The problem with MS is, it's individual. It's different for every single person so how can you treat a group with? Okay, they've all got the same umbrella disorder, but how can you then treat them all the same?* (Christopher, group intervention).

Putting on a mask

Several participants commented that a drawback of the group format was that some people would contribute more than others, and stressed the challenges of group management. With respect to identity, the related potential downside was that of identity performance:

> *I think in a group, I personally probably wouldn't have contributed particularly. [I: Yeah] Um, and there is always, I always think, a danger in a group that you are, you're trying to project the person that you think everybody wants you to be.* (Frances, individual intervention)

Alanah also wondered whether identity performance came in to play, when reflecting on the behaviour of another group member:

> *I did sometimes think at the end of the day actually maybe sometimes people cover up things in that way, you know, I can do it. But probably*

because [other group member] actually agreed to attend the group, maybe [other group member] did actually need to get things out a little bit (Alanah, group intervention).

2a) Benefits of individual format

With respect to the individual intervention, several of the advantages participants reported were logistical: transportation arrangements were easier and there could be greater flexibility with regard to timing. Some participants also commented that in one-to-one setting the content could be tailored to the individual. With respect to identity-related advantages, the main benefit appeared to be that some people felt safer disclosing personal information in an individual setting.

Easier to confide

Several participants admitted to being concerned what other group members would think of them. Dawn, for instance, felt that this would have prevented her from sharing some of her thoughts:

I think in a group situation I wouldn't have got as much from it because there are things, perhaps, that I would say to [psychologist's name] on a one-to-one that I wouldn't say in a group. Because there are things that are personal to you that other people might think, 'Stupid woman.'

(Dawn, individual intervention)

Rebecca similarly explained that she finds it easier to confide in a one-to-one setting:

> *Although I find the group, it's nice to feel that you're not the only one in that position, ermm, I feel very reluctant to talk in those kind of circumstances, so it was much easier to confide in [psychologist's name], and talk to her. So that was a, that was a good element of it for me* (Rebecca, individual intervention).

Interestingly, Rebecca further commented that, although reluctant to share in a group setting, she preferred the face-to-face contact offered by the individual intervention compared to computerised CBT programs she had attempted, citing lack of motivation to complete homework as a drawback of the latter.

2b) Drawbacks of individual format

On a practical front, a drawback several participants commented on was that it was harder to think of ideas on your own: in the group format you could bounce ideas off each other and something someone else said would trigger a thought for you. This was noted as being particularly relevant for people with cognitive difficulties. With respect to identity-related processes, the primary perceived drawback of the individual intervention appeared to be that it did not provide the opportunity to meet other people with shared experiences.

Do not meet others with shared experiences

Alanah said that her initial preference had been for the group intervention because the individual intervention wouldn't have given her the chance to find out how other people were coping with living with MS: "*Well I think I did sort of want to find out how other people are coping and getting on with things"* (Alanah, group intervention).

Priya similarly described how she would not have wanted to be allocated to the individual intervention because she wanted to meet other people with MS. She stressed that in the one-to-one sessions, the healthcare professional may not be able to understand in the same way that people with MS could:

> *…group exercise for me was the major thing of this whole exercise [I: Mmm hmm] because, I am glad, I am glad I didn't go to a single consultation, that was the other one wasn't it, the single one? [I:Yep] Because although [psychologist's name] is a great doctor, I think doctors can only sympathise, they can't empathise. And that was a big thing for me to be able to talk about experiences* (Priya, group intervention).

Interestingly, even one of the women who reported a tendency to avoid meeting other people with MS, nevertheless expressed the same desire to meet people to whom she could relate: "*So sometimes, yes, with the group it*

would, it would have been nice to have that shared thing with people" (Frances, individual intervention).

5.5 Discussion

A person's experience of wellbeing is not solely dependent on physical condition. A broader process of identity change takes place in chronic illness and 'who am I?' is a central question that illness can expose (Brookes, 1994, as cited in Frank, 1997). While previous literature in the field of MS has focussed on acceptance of and adjustment to illness, there has been less consideration of the ways identity threat may influence these processes or how they may affect engagement with psychological adjustment interventions. This analysis revealed that social affiliations and the groups people consider themselves part of – their social identity – can be significantly affected by MS. It further indicated that whether or not people were willing to engage with the intervention, particularly in a group format, depended on how participants saw themselves and others with MS, and whether they consequently perceived MS, and meeting others with the disease, as a threat to their identity.

The degree of identity threat from MS appeared to depend, in part, on the importance attached to lost groups and whether or not membership of other valued group were maintained so as to provide a continued foundation. As Klein, Spears and Reicher (2007) asserted, it is not possible to sustain social identities that can no longer be expressed in practice or that are no longer validated by others. Thus, coming to terms with MS may involve identity

reconstruction, particularly where there are significant changes to social group memberships. The impact of identity threat in the current study was evident in participants' identity performance and attempts to conceal symptoms. This is consistent with Jones, Jetten, S. A. Haslam and William's (2012) suggestion that non-disclosure reflects a desire to present oneself as relatively unchanged. Stigma was also found to influence the identity threat posed by MS. In contemporary western culture, health is viewed as an entitlement, and restitution stories, where the normal condition of health is restored, are the preferred cultural narrative (Frank, 1995). The societal expectation for individuals to recover from illness is highlighted in work drawing on Parson's classic concept of the sick role (Parsons, 1991; see also Varul, 2010). Thus, when people are chronically ill and unable to return to full health, they are no-longer fully accepted members of society, and are only allowed to exist in the world of healthy people on visa status (Sontag, 2001). This can leave those living with chronic illness feeling discredited, and, as such, chronic illness becomes a stigmatised identity. In line with this, several participants appeared to feel devalued by medical and societal discourse and of less worth in the eyes of others who were seemingly less interested in them if they were ill. This finding parallels the findings of research into stigma-related identity threat in chronic illness (including MS), particularly around concerns of acceptance in the workplace (McGonagle & Barnes-Farrell, 2013). It also consistent with research by Coyle (1999), which found threats to identity, including perceptions of being devalued, dehumanised and stereotyped, to be the primary factor accounting for public dissatisfaction with health care.

Importantly, as suggested by the realist synthesis, identity threat emerged as a key determinant of willingness to engage with the intervention. If individuals did not want to see MS, or society's construction of MS and those with it, as part of who they were, being part of an MS group could constitute an identity threat. The degree of incorporation of MS into the individual's sense of self differed accordingly. Some respondents didn't want anything to do with MS or people with it. Others appeared to be able to acknowledge symptoms without letting MS become their defining social identity. Still others came to see MS as integral to their new sense of self. Identity threat was particularly pertinent in relation to meeting others with MS in the group context. Nevertheless, taking part in the one-to-one one intervention appeared to constitute a similar threat since for some, doing so, constituted acknowledgment that they are a person who has MS with the perceived norms and behaviours of this group (Tajfel, 1982). Interestingly, a similar pattern has been found in people with Parkinson's disease, another chronic illness. Charlton and Barrow (2002) found that members of self-help groups for people with Parkinson's disease accepted and incorporated the disease and its consequences into their everyday life. Non-members, conversely, were those who strove to maintain normal life and deny the disease. As Tajfel (1982, p. 16) astutely observed, when determining group belongingness the first question is not one regarding feelings towards others – "do I like these people?" - but one of self-definition – "who am I?".

Timing also emerged as an influential factor in willingness to take part in the intervention. The indication was that people needed to come to terms with the

MS to some degree before they were ready to take part. This appeared to be the case for either format but, again, meeting others with MS, particularly those in wheelchairs, was an added threat in the group format. For some, personal symptom progression was the pertinent factor in alleviating this fear. Ageing also appeared relevant in reducing the alienation felt as a result of having MS, primarily because more people in peer-comparison groups were also experiencing illness. This finding is in line with insights from social comparison theory (Festinger, 1954, as cited in DiLorenzo et al., 2008) and results of the realist synthesis. Gender emerged as a further relevant factor with respect to engaging with the group intervention, with some people perceiving men to be more reluctant to take part in MS groups. This is consistent with broader research on traditional masculine ideology and men's reluctance to seek psychological help (Sullivan, Camic, & Brown, 2015). It is also in line with findings from the J. M. Holmes et al. (2012) study (where non-attendance at psychological MS groups was more common amongst men than women) and merits further specific investigation in the context of MS groups.

An identity threat perspective helped explain not only willingness to engage with MS interventions, but also perceptions of intervention content and format. In relation to content, the most striking finding was that some people who experienced MS as highly threatening to identity, responded negatively to the CBT approach. The primary reason given was that it forced people to think about the MS and what might happen in the future, when the preferred coping strategy was one of avoidance. With respect to intervention format, several

people who took part in the one-to-one intervention held negative preconceptions of the group format and were fearful of meeting others with worse symptoms. Interestingly, several of the participants who actually attended the group intervention appeared able to use this very experience to reflect on their relatively good fortune and make positive comparisons. However, without having interviewed the participants beforehand it is not possible to determine whether the perceptions of the group participants differed from those in the one-to-one condition originally.

Identity threat and perceptions of the intervention were further found to be influenced by the illness narratives held by participants. According to Ricoeur (1991) people make sense of the experience of illness in terms of its place in the perceived plot of their life story. Those who approached illness in light of a quest narrative often appeared more able to place themselves in an overcoming role. Seeing illness as a journey and an occasion for growth appeared to help limit unhelpful ruminations about the future and enabled participants to find encouragement rather than fear in comparing themselves to others with more severe symptoms. It enabled some participants to see the intervention as an opportunity to learn more about the condition and themselves. This is in line with Frank's (1995) work on illness narratives, where seeing illness as a quest enabled the biographical disruption caused by chronic illness to be reframed as a challenge. According to Frank, although people with chronic illness are unable to fit into the preferred cultural narrative of restitution, by placing themselves in a quest narrative, individuals were able to

meet the societal pressure to be successfully ill (Frank, 1995, 1997). The current results indicate that for some of the participants, a driving force in the reconstruction of social identity was the desire to find purpose and grow from the experience of illness. As discussed above, some people appeared to manage this whilst keeping MS separate from their identity. Others integrated MS into their new sense of self and welcomed the opportunity to belong to new social groups in line with how they now saw themselves, their values and approach to life. When illness was seen according to a contrasting endurance narrative, there were indications that stigma was internalised, and MS seen as more threatening. For some participants, when this narrative dominated, illness called for self-reliance and was seen as the individual's problem. The accompanying coping strategy tended to be to ignore the MS and avoid facing the associated fears and feelings. Moreover, beliefs that to be ill was shameful, a burden on others or not to be talked about but endured without complaint appeared to leave people less predisposed to meet others with MS or engage with the intervention content.

Finally, in addition to highlighting the importance for clinicians and researchers to consider the effect of identity threat on intervention efficacy, this study makes an important contribution to the literature by making explicit the relative advantages and disadvantages of group and individual MS interventions. Cruwys, S. A. Haslam, Dingle, C. Haslam, et al.'s (2014) fundamental assertion that it is shared identification that is the crucial ingredient in gleaning benefits from groups is strongly supported in this study.

The opportunity to meet other people who understood, who were in the same boat and who had shared experiences was highly valued by many of the group participants. It was also acknowledged as a potential benefit by several people in the individual condition. Jones et al. (2012) recognised, talking to others who understand provides validation of one's experiences but is not always possible with those who are not in the same position. Moreover, when identity is recognised as relational and coming in part from where we belong in relationship to others, the desire to be known and understood can be seen as being underscored by social identity processes. The study findings also provide support for Cruwys, S. A. Haslam, Dingle, C. Haslam, et al.'s (2014) model of social identity as a psychological resource. In line with the model, there was evidence that being part of a group could have beneficial effects via a sense of belonging, the receipt and provision of social support and the sense of purpose this could provide. There was also support for the existence of the fourth element, the adoption of normative group behaviours and attitudes, although the caveat here was that these norms were not necessarily perceived as positive. As discussed, MS being the identifying group feature was met with mixed responses, and, in the case of psychological adjustment interventions, the norm of a diagnosis of depression was deemed unhelpful by some. The research finds interesting parallels in a study exploring attitudes to peer support groups for people with motor neurone disease (MND) (Locock & Brown, 2010). This study described two similar overarching themes: valuing camaraderie and comparison, and choosing isolation. The researcher found that in line with social comparison theory, people value the support and

camaraderie provided by MND support groups, as well as the opportunity for positive comparison, either from the hope afforded by seeing others coping well with the disease or from feeling better about their situation when meeting others who are worse off. However, in accord with the present findings, the paper also reported some people were saddened and shocked by seeing others with MND and that isolation was a defensive strategy chosen to protect oneself from encountering a possible future. Interestingly, the authors further commented on the identity tension that could occur when membership of an MND group started to define an individual as 'a person with MND', as opposed to a person who also happens to have MND (Locock & Brown, 2010).

5.5.1 Limitations

One limitation of this study is that the retrospective nature of the interviews limits insight into how people's perceptions of the intervention may have changed as a result of taking part. Although some participants reflected on how, upon completion, their views of the group differed from their preconceptions, such comments were still made with hindsight. In the same vein, while it was valuable to uncover people's perceptions of the alternative format, it is not possible to ascertain how closely these would have matched their experience of it. It would also have been interesting to have been able to interview people who decided not to attend the intervention, especially where reasons for this were not being allocated their preferred treatment format. With respect to the sample demographics, a limitation was that there were a greater number of female respondents. Although significantly more females

than males are diagnosed with MS, given the indications that men may be more reluctant to engage with group interventions, having a larger number of male participants may have provided greater insight into this issue. Another limitation was that the size of the intervention groups was relatively small. Several people commented that a larger group would have been preferable and participants may well have had a different experience in a larger group. Further research determining optimal group size would be useful here.

There were also several limitations regarding the sampling in the original feasibility study. In particular, included participants had high levels of depression or anxiety, as indicated by scores on the HADS and GHQ-12. People with lower levels of mood disorder may show a different pattern of results. The participants had also given consent to be in an RCT, so participants who did not want to be allocated to either the group or individual treatment arm would have been excluded from the study.

As a methodology, thematic analysis also has several limitations. In particular, it fragments biographic accounts into categories across cases. Searching for typical themes is clearly useful in the context of rehabilitation, but comes at the cost of loss of context. This was rectified to a certain extent in exploration of participants' self-narratives and their impact on intervention engagement, but additional insight may have been gleaned from interpreting interviews as a whole and honouring individual agency (Riessman, 2008). Adopting thematic analysis also meant that the focus was on interrogating content. As such,

certain sources of information, including broader linguistic features, were not incorporated in the analysis. Neither was there much reflection on the role of the interviewer and ways in which the text is co-constructed; accounts are presented as having emerged in full from the participant rather than in a dialogical process. Given the topic, the influence of identity presentation needs to be acknowledged, since the participants' perceptions of themselves and the interviewer may have had bearing on how they presented themselves (Wengraf, 2001). For instance, what was disclosed may well have been affected by the interviewer's position as a clinical researcher. The interviewers' gender may have been another relevant factor, although having both a female and a male interviewer accounted for this to some degree.

5.5.2 Implications for therapeutic interventions

Interpreting the interviews from a social identity perspective provided an interesting example of the value of integrating insights from social psychology with clinical neuropsychology. CBT has no theoretical position on identity change so does not typically address this aspect of adjustment. However, this study builds on the findings of the realist synthesis in highlighting the necessity of considering identity-related factors when designing and delivering interventions, and contributes to the case for an approach to neuropsychology that is intrinsically relational. Recognition that identity is relational and that social identity processes influence perceptions of interventions requires a change from the predominantly individualistic approach to neuropsychological rehabilitation (Walsh et al., 2012). For instance, an awareness of the

importance of relationships in providing validation and enabling growth and identity revision means that in addition to seeing increased social contact as a desired functional outcome of an intervention, it may also need to be considered as an intervention input. Moreover, recognising identity as fluid and actively generated in social interaction (Levine, 1999) necessitates as shift in perspective in rehabilitation from acceptance of permanent change, a "clinical dead end" (Yeates, Gracey, & McGrath, 2008, p. 568), to a process of adaptation and identity (re)construction.

Some researchers have begun to consider the importance of identity processes in neurorehabilitation. In the context of brain injury, Nochi (2000) emphasised that identity is developed and realised in interaction with others. Accordingly, he recommended the use of support groups with others with similar conditions. However, it is clear from the current study that, for people with MS, the picture is more complex. Simply being part of a support group will not necessarily provide a positive sense of identity or be the best solution to the social isolation so commonly experienced. A crucial difference between brain injury and MS is that the latter is degenerative in nature. This appears to heighten the level of threat posed by meeting others with the condition. Such identity threat needs to be recognised by clinicians delivering MS group interventions. Practically, greater consideration could be given to how participants are grouped. One suggestion was that grouping people of a similar age or at a similar stage of the disease may reduce identity threat as well as increasing the likelihood of shared experiences and feelings of identification.

Some studies have attempted such grouping. Graziano et al. (2014), for instance grouped people according to age in their RCT of group-based CBT for people with MS. Visschedijk and colleagues (2004) made the decision not to include people confined to wheelchairs in an intervention for people recently diagnosed with MS. While this may reduce identity threat and level of distress for some attendees, excluding people from groups because of their wheelchair status, or putting them in a separate group risks further discrimination and stigmatisation. It also denies people at an earlier stage the opportunity of meeting others with feared symptoms who are, nevertheless, coping well. A more acceptable strategy may be to offer an individual intervention to people who have recently been diagnosed and who find the prospect of meeting people with more severe symptoms overwhelming. Research into the relative benefits and drawback of computerised as opposed to face-to-face CBT programs with respect to identity threat may also be of value.

With respect to the challenge of the normative group attribute being a diagnosis of depression, one suggestion was to have more heterogeneous groups to allow people to learn from those who are coping well. An interesting possibility may be to include people with MS who are coping well as guest speakers or intervention assistants, to provide positive role models. Such an approach is an integral part of some neurorehabilitation programmes. For instance, communication groups for people with aphasia following a stroke are often co-facilitated by peers alongside trained healthcare professionals (Rotherham, Howe, & Tillard, 2015). In the context of MS, research

investigating whether such an approach generates benefits in practice, or whether it improves intervention uptake for people who may be put off by negative preconceptions regarding such group norms would be valuable. In a related vein, several respondents appeared to find it empowering to be able to offer other group members tips and advice, an element which could be intentionally built into the programme structure.

Despite the complexities, the overarching message of this analysis is that identity processes are highly significant to both the experience of MS and to engagement with psychological interventions, particularly when delivered in a group format. While the negative implications of identity threat need to be carefully considered, the potential benefits of meeting others with similar illness experiences were clearly evident. The impact of people's illness narratives emerged as another influential factor with respect to identity threat and intervention engagement, but has been given only limited recognition in neurorehabilitation to date. A narrative analysis would enable deeper insight into the ways participants' illness narratives influence their perceptions of the group and individual interventions. It would also complement the cross-sectional nature of this thematic analysis. Accordingly, in the next chapter a narrative analysis of the transcripts of two of the participants is presented.

Chapter 6. Narrative Analysis

6.1 Summary

Narratives – the story we see ourselves, our illness, others and our relationships with them as fitting into – are essential to the construction of our identity. With respect to illness, narratives can either constrain or enable individuals who are attempting to make meaning out of their situation. Thus, an understanding of participants' illness narratives may shed light on the process of identity revision and how this relates to taking part in a group intervention. The thematic analysis presented in the previous chapter highlighted the importance of illness narratives with respect to identity threat and engagement with the psychological adjustment intervention. Two narrative perspectives emerged as especially prominent: illness as endurance and illness as quest. Accordingly, a more in-depth analysis was undertaken to further illuminate how these illness narratives may influence identity threat and perceptions of the group and individual intervention.

Two transcripts were analysed, one from a group participant and one from a participant who had been allocated to the individual condition. Results highlight the power of narrative perspective to influence how people respond to and live with MS and offer an explanation for the differing responses to the prospect of group or individual interventions. The findings suggest the value of clinicians being aware of patients' illness narratives. They also indicate the therapeutic value of narrative and suggest the potential benefit of including a narrative element with psychological adjustment interventions.

6.2 Introduction

"a man is always a teller of tales, he lives surrounded by his stories and the stories of others, he sees everything that happens to him through them; and he tries to live his life as if he were recounting it." (Sartre, 1963, p. 61)

Humans are storytellers by nature. Stories are a fundamental means of expressing ourselves. Stories appear in all cultures and preserve memories and cultural identity. Stories have narrators and audiences, genres and plots, characters and relationships. Most fundamentally, perhaps, stories carry meaning and telling each other our stories helps us make sense of who we are and our place in the world. As such, stories, or narratives, are a critical aspect of self-understanding and essential to our identity (Ricoeur, 1991) and the process of identity change.

Western healthcare has largely ignored the significance of narrative and tends to locate problems squarely within individuals (Davis, 1986). We exist in relationship to others, however, and narrative study acknowledges that we make sense of the experience of illness in terms of its place in the perceived plot of our lives, the stories we tell about ourselves and the stories others tell about us (Neimeyer, 2004). The cornerstone of narrative psychology is the belief that our identities are both discovered and created as we work out what story we fit into. In the words of literary theorist and philosopher Paul Ricoeur, we are constantly in the process of "applying to ourselves the plots that we have received from our culture and of trying on the different roles assumed by

the favourite characters of the stories most dear to us" (Ricoeur, 1991, p. 33). When serious illness is not compatible with our existing life narrative, our identity is threatened and we must consider afresh where we fit in the plot and in relationship to others (Fife, 2005) in family life, work, leisure and society at large. Illness narratives have grown in prominence as narrative study has come into its own over the past three decades. Several types of illness narratives have been proposed, most notably, perhaps, Frank's (1995) seminal typologies of restitution, chaos and quest. Riessman (2003) suggests that the growing interest in illness narratives has developed partly in reaction to the narrow biomedical focus on disease and tendency to disregard the patient's experience of illness and how they perceive and respond to it. Another reason for the increasing interest in narrative studies is the contemporary preoccupation with identity (Riessman, 2008) and, in contrast to essentialist thinking, a growing understanding of identity as fluid, something that is constructed and performed (Holstein & Gubrium, 2000; Riessman, 2008). According to Ricoeur (1991), although we have a core personality that remains the same, there is another aspect of our identity that changes over time and in relationship to others. This ties in with the concept of social identities and how this aspect of our sense of self is subject to change. With respect to illness, Charmaz (1983) observes that loss of self is one of the major losses in chronic diseases. Bury (1982) classically describes chronic illness as biographical disruption, whereby the sufferer's identity and self-narrative is shaken by this seismic life event (Neimeyer, 2004). The disturbance includes changes to social relationships: "disruptions in biography are, at one and the same time, disruptions of social

relationships" (Bury, 1982, p. 180). When self-narratives are shaken by serious illness in this way, one response is to undergo a process of identity revision and reconstruction (Mishler, 2006; Neimeyer, 2004). Where possible, this involves recasting events into coherent stories (Crossley, 2000), such that the narrative configuration imbues them with meaning, restoring purpose to lives disrupted by disease (Ricoeur, 1991). Studying illness narratives allows exploration of the re-visioning of identity and plot that can occur in chronic illness (Besley, 2002; Brown, Nolan, Crawford, & Lewis, 1996; Bruner, 1990; Green, Todd, & Pevalin, 2007; Neimeyer, 2004). In the current context, it may shed light on why people have differing perceptions of interventions for chronic illness, why group contexts may pose more of an identity threat for some and how this could be taken into account when recommending or delivering psychological adjustment interventions for people with MS.

There is some literature on biographical disruption in MS (e.g. Green et al., 2007), but to the best of the author's knowledge, no studies have taken an explicitly narrative approach or investigated social identity change through this lens. The thematic analysis presented in the previous chapter highlighted the importance of illness narratives with respect to perceptions of identity threat and engagement with the psychological adjustment intervention. Two narrative perspectives were particularly prominent: illness as endurance and illness as quest. To further illuminate how these illness narratives may influence identity threat and perceptions of and engagement with the

intervention, a more in-depth thematic narrative analysis of two of the transcripts of was undertaken, as presented in this chapter.

6.3 Method

A narrative analysis was conducted on two of the transcripts from the interviews described in the previous chapter. Transcripts were chosen according to three inclusion criteria. The first criteria was that one of the participants had taken part in the group intervention and the other had attended the individual sessions in order to provide an exemplar from each delivery format. Similarly, the second criteria was that the transcripts offered exemplars of both the quest and endurance illness narratives, as identified in the thematic analysis in the previous chapter. The third criteria was that both participants had been interviewed by the thesis author.

Since there is no single method of narrative analysis, it is necessary to decide what aspects of narrative to focus on as the basis for interpretation (Riessman, 1993). For the present purposes a thematic narrative analysis was undertaken, as outlined by Riessman (2008). In thematic narrative analysis, the content is interrogated with an emphasis on what is said, as opposed to structure and linguistics or 'how' and 'why' stories are constructed. General concepts are generated, but, in contrast to the more common form of thematic analysis guided by grounded theory principles, biographic accounts are not fractured into categories across cases. Instead they are interpreted as a whole and placed within the context of each participant's narrative of life. The analysis recognises

people are limited to imagining and representing their lives in terms of existing cultural narratives, and the overarching narratives drawn on will be considered with particular reference to Frank's (1995) typologies of illness narratives.

6.3.1 Participants

Frances was a woman in her mid-fifties with relapsing-remitting MS. She was diagnosed with MS one year prior to randomisation to the individual arm of the feasibility RCT. She is married with two children. As a result of living with MS she has stopped working and, consequently, has lost what to her was a highly significant social identity. She feels socially isolated, having previously socialised predominantly with work colleagues whom she no longer sees in person. MS poses a considerable identity threat and she goes to some length to conceal her symptoms. She tries to cope by ignoring the MS, which is not even talked about with friends, and she is wary of being seen as burdening others. She is very reluctant to join MS social groups, which she perceives as highly depressing, and particularly dislikes encountering other people in wheelchairs. Her prevailing narrative of illness is one where illness, and depression, are something to be endured with an attitude of forbearance.

Sara was a woman in her early thirties, also with relapsing-remitting MS. She received her diagnosis five years prior to randomisation in the feasibility RCT and was allocated to the group condition. She has also lost work colleagues as a result of living with MS, but has maintained strong, supportive relationships with certain other friends as well as with her parents, fiancée and wider family.

She strives to maintain her previous fast-paced lifestyle and prefers not to disclose the condition to others, particularly people her age. She does not like to be seen as weak or in need of looking after, but seems to have accepted MS to some degree, and is involved with several MS organisations. She appears to position herself predominantly within a quest narrative, attempting to overcome the challenges of living with the disease and grow through the experience.

6.4 Results and Discussion

6.4.1 Identity threat

As discussed in the previous chapter, when living with chronic illness, an individual's experience of wellbeing is not dependent solely on physical condition. A deeper process of identity change may occur, exposing questions of identity. In the context of brain injury, there is evidence that wellbeing can be sustained by a sense of self-continuity in spite of illness (Jones et al., 2012). Here, in relation to MS, Sara's comments indicate a comparable desire to present herself as relatively unchanged and, thus, maintain her pre-MS identity: "*I'd rather just like carry on like forgetting about it and just carrying on and [I: yeah] because people can't tell that you're like this."* Frances adopts a similar coping strategy: *"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."*

From a narrative perspective, both Sara's and Frances' life stories have been interrupted by illness: Bury's (1982) 'biographical disruption'. Nevertheless,

where possible, both women's preferred response is to attempt to ignore the MS and strive to maintain a sense of self-continuity. This becomes harder when valued social group memberships are lost as a result of the illness. As illustrated in the previous chapter, Frances experienced considerable social identity loss:

> *"So you are very close to your colleagues, because you rely upon them to watch your back for you, and to help you, because professionally you are working close together. But I haven't got that anymore, it's like half, the majority, about two thirds of my life has just disappeared".*

That this aspect of self can change means that chronic illness can pose a threat to a person's former identity, as is apparent in Frances' comments. Sara also describes loss of colleagues, but for her, this appears to be a less significant loss. Her most valued relationships, including her fiancée, family and close friends, are maintained and appear to provide a firm and continued foundation. Consequently, changes to social groups outside of these appear to pose less of a challenge to her sense of self: "*at the moment, I'm living with my parents again and I've got everything that's, like all the support network that I need really."*

In addition, these core relationships seem to supersede any identity Sara found in work, as the following extract indicates:

So when my grandma was like really ill I just thought, 'Stuff that. Life's too short', so I just went to my employees and said 'I want to go for like redundancy'. [I: yep] So I did that and the day that, um, I did that and had that meeting and everything my grandma actually died, so it was just like okay [laughs] [I: Wow] But I don't regret it whatsoever because I needed to be there for like my mum.

Despite her openness amongst family, Sara generally prefers not to disclose her condition to others. This may be motivated partly by a desire to avoid discrimination and enable continuation of group memberships, supporting her wellbeing by enabling the maintenance of a coherent narrative of self. However, while on the one hand a coping strategy of non-disclosure may help sustain a sense of personal integrity and continuity (Jones et al., 2012), Sara identifies the concurrent cost as a feeling of disintegration through having to present "*two different identities*". Another motivation for Sara's non-disclosure appears to be related to how she feels others will perceive her if they learn about her illness. She admits she does not like to be seen as someone in need of being looked after and is especially reluctant to disclose her condition to peers:

Sara: *It's like the older people, because I normally go [to the gym] during the day-time and you get like loads of OAPs and most of them know about it. [I: Yeah] But like people my age, [I: Yeah] like I don't like them knowing really.*

Interviewer: Is that partly because - what are the reasons for that?

Sara: I don't know. I feel kind of embarrassed about it.

She uses the word '*embarrassed'* on several occasions indicating that she wants to continue to be seen as strong, fit and capable, particularly amongst peers. She appears to see illness and her symptoms as a sign of weakness and this stands in marked contrast to her former work-hard, play-hard, fast-paced lifestyle:

> *like the old me, I would wake up at 4 o'clock in the morning, I would go to the gym, go to work, go to the gym on my lunch break and then I'd go out for like drinks with like my friends after work and it would just constantly be like that.*

Frances, too, perceives illness as weakness, and describes how she has grown up with this narrative:

> *I was brought up to believe that people never have flu, they just have bad colds. There is no such thing as migraine, it is just a bad headache. And people who are depressed are basically whinging bitches who can't cope with life. (Frances)*

Like Sara, Frances also tends to hide her symptoms. As observed in the previous chapter, she expects others to avoid her should she disclose her condition and, at best, does not expect people to want to know about it: *"I wouldn't dream*

of telling people, erm, because I don't think people are that interested to be perfectly frank."

Common to both Sara and Frances' decisions not to disclose lies a perception of chronic illness as weakness; a condition largely stigmatised by society. This is in line with Frank's (1995) assertion that people use the overarching narratives their culture makes available when telling their own stories: personal narratives are influenced by the dominant societal narratives. As he observes, contemporary western culture views health as an entitlement, the normal condition that people ought to have restored, and there is a cultural preference for restitution narratives (Frank, 1995). Against this backdrop, chronic illness can become stigmatised (Radley, 1995) and people living with chronic illness can feel devalued for not living up to the societal expectation for recovery. Much has been written on Parson's (1991/1951) seminal work on the sick role and the moral obligation to recover (Frank, 1997; Radley, 1995). Since people with chronic illness have not played this sick role properly, they are only allowed to exist in the world of healthy people on visa status (Sontag, 2001). The story they now fit in tells them they are of less worth as a person. This plotline seems to be reflected in Sara's comments: "*every month I would like go to the doctor's, another sick note, another sick note. So my manager was like, 'Why don't you agree to, like, a career break?'"*

The repetition of *"another sick note"* highlights her frustration at being unable to perform to her previous ability, and having to stop working appears to

contribute to her fear of being seen as useless. This is exacerbated by the language used in medical discourse which tends to depersonalise: *"The worst thing for me is like going to the doctor's and all those kinds of places and they say, just being referred to as disabled".* Frances expresses a similar sentiment:

> *I was trying to explain to her I don't feel disabled [I: yeah] Because I don't. I am supposed to have crutches, I don't use them [I: okay]. I have really bad vertigo, so I don't look disabled, particularly.*

6.4.2 Identity threat and meeting others with MS

Seeing illness as stigmatised in this way also appears to affect how both Sara and Frances feel about meeting other people with MS. Doing so challenges how they see themselves, and, perhaps more importantly, how they perceive others will see them, both now and in the future (Brockmeier, 2000; Pavawalla, Salazar, Cimino, Belanger, & Vanderploeg, 2013). For Frances, the prospect of meeting other people in wheelchairs proves especially threatening: "*because we go to the hospital, they are all in wheelchairs, which is incredibly depressing, I hate going to hospital."*

Meeting other people with MS also appeared to pose an identity threat for Sara, at least initially. She describes a similar experience of being taken to an MS event relatively soon after receiving her diagnosis: "*I walked in and there was absolutely loads of people in wheelchairs and I just burst into tears and I just wanted to get out."* At this stage, meeting others constituted a threat to

her identity and initially she "*didn't want anything to do with like the MS and I didn't want anything to do with other people that have MS".*

When discussing her thoughts on taking part in MS groups, Frances saw having MS as the only common ground as a negative, explaining her concern that it would dominate. This appeared to relate to a fear of her identity being overwhelmed by MS, and had the result that while she was prepared to talk to professionals about the disease when necessary, she did not want to take part in MS social groups:

> *Okay you are trying to avoid the isolation but, I have got enough going on in my brain about my MS without then having to talk about it on a social basis. Professional basis, fine. I don't mind doing that. Socially, no I don't want to do that, thank you very much.*

Interestingly, Sara draws a similar professional-social distinction. When asked whether she sees MS groups she attends as separate to or part of her identity she replied: "*Um, separate because that's more like going to see, like having a neurologist appointment or a psychologist appointment, that kind of thing."*

Both women are, thus, wary of MS coming to dominate their identity and are aware of stigma surrounding the illness. Both appear to be influenced to some degree by a cultural preference for restitution narrative and, having been diagnosed with a chronic illness, they are faced with the impossibility of

conforming to this expectation. Interestingly, they adopt two contrasting narratives in response. Sara's approach to living with MS is in accord with Frank's (1995) narrative typology of illness as quest. By contrast, Frances assumes the role of a stoical figure, attempting to bear her symptoms without burdening others, with an overarching narrative more akin to illness as something to be endured. This narrative dichotomy parallels Radley's (1995) observation (in research into MS and quality of life), that people with disability report feeling judged as "less of a person" if they do not either battle towards a cure on the one hand or stoically bear their impairment on the other (Radley, 1995, p. 109; see also Reynolds & Prior, 2003). The implications of seeing and living out illness according to these two narrative perspectives is considered below.

6.4.3 The endurance narrative

According to Frank, when it is not possible to fit into the societally preferred restitution narrative, there remains a cultural pressure to be "successfully ill" (Frank, 1997, p. 131). In a narrative of endurance, this appears to be achieved by the protagonist becoming a stoical figure, shouldering their lot without complaint or undue reliance on others. In line with this, Frances strives to hide her symptoms, preferring, for example, not to use mobility aids. With reference to socialising with her husband's group of friends, Frances again chooses not to disclose her condition: "*certainly I wouldn't dream of foisting my ailments into their conversations about how [football team] has done."* She appears acutely aware of the burden of illness and does not want to impose, or been seen as

imposing on others: "*I wouldn't want to put myself in a position where people felt obliged to see how I am, and make sure I am okay. You know."* This applies not only to friends and colleagues, but extends to healthcare professionals: "*It's like I don't phone the MS nurses, like when I am supposed to and they get angry, you know."* She goes on to explain the reason lies in her fears of how others will perceive her:

> *the anxious patient can be a nightmare, and I don't want to be that. Or the woman in the pub who is always telling everybody about her this that and the other. [I: Mmmm] And I don't want to be that.*

One result of refusing support appears to be that the MS becomes all-consuming. Here, there are elements of Frank's chaos narrative, which presupposes a lack of control and a feeling of being "sucked into the undertow of illness and the disasters that attend it" (Frank, 1995, p. 34). In a chaos narrative, though, reflective distance is not possible, there is only immediacy, which precludes storytelling. Here, Frances is able to reflect on her experiences and, further, attempts to take control of the threat of MS dominating her life by avoiding meeting other people with the disease. Indeed, she reports having had a prior preference for the one-to-one as opposed to the group intervention format, with the prospect of having to confront patients with feared symptoms posing a considerable identity threat: "*And that was the worry with the group as well, that you see people, you think oh god this will be even more depressing than I am now, because this is what is going to happen."* She describes having

such a negative response to attending a yoga group for people with MS: "*Because it was just phenomenally depressing, for me. [I: yeah] Because it was in a, always in a complete state of denial about any of this is happening."* Another reason for her preference for the individual intervention lies in fears of how others, even others with MS, will perceive her. She was, for instance, concerned about bumping into other group members outside of the intervention setting. She also admitted she would most likely engage in identity performance in a group context:

> *I think in a group, I personally probably wouldn't have contributed particularly. [I: Yeah] Um, and there is always, I always think, a danger in a group that you are, you're trying to project the person that you think everybody wants you to be.*

Despite her reluctance to meet others with MS, Frances did indicate a desire to be understood and meet others with shared experiences: "*you know, that's sort of, to try and explain it to somebody who has never had it, is a nightmare. But, erm, so in a group, if you have got somebody else that shared, the shared experience."* However, this desire was overshadowed by the demands imposed on her by her narrative perspective and the threat of MS coming to dominate her identity. The identity threat presented by a diagnosis of chronic illness and the corresponding risk of illness becoming overwhelming, is discussed by Besley (2002) with respect to the narrative turn in therapy. She refers to relevant observations by Gergen, that when diagnostic labels are perceived as

part of a person's essential identity this can result in pathology becoming all-consuming (Gergen, 1991, as cited in Besley, 2002). This fear of MS dominating identity is also apparent to a certain degree in Sara's comments: "*For me I feel like my MS is like the focus of everything these days".* However, it is noteworthy that she resists the cultural pressure to define herself purely in medical terms and is determined to show: "*there's more to my life than MS".* Why and how she holds on to a broader picture of who she is may to be partly due to the meta-narrative she places herself in, namely the quest narrative (Frank, 1995).

6.4.4 The quest narrative

In the quest narrative the metaphor is one of a journey. Although there are overtones of stoicism, where trials are endured but not minimised (Frank, 1995), the emphasis is on what can be learnt as a result of persevering. It is the role of the hero to rise to the occasion; losses may be mourned but the focus is on growth and character change. The protagonist must overcome obstacles, gain wisdom and find meaning and insight into one's sense of self in the midst of and out of their suffering. In quest stories, biographical interruption is reframed as a challenge (Frank, 1995). Although tidy ends may be desired, where this is not possible a different kind of end, a different purpose, needs to be discovered (Frank, 1995). Disease may disrupt life, but part of the role of narrative is to restore an order whilst holding to this truth.

The quest narrative is woven throughout the text. Sara is aware of the stigma surrounding illness, but is hopeful and determined to continue to contribute to

the world and those around her. This is evident in her positive attitude: "*apparently I'm like really, really positive and everything and loads of people have always said that I've, um, I was really like uplifted and everything. I didn't sit there and cry about my MS or anything."* According to Frank (2012), quest narratives tend to contain elements of manifesto and this starts to come across in Sara's anger at those who focus on the negatives:

> *he hasn't got MS himself, but his wife has and she was, like, in a wheelchair [I: okay] and he thought it would be nice for him to tell me, erm, that, erm, 70 or 80% of people with relapsing-remitting end up wheelchair-bound, so it was just like, oh cheers! [I:Yeah] So if you have people with those kind of attitudes it's not helpful at all.*

Also within the plot of the quest narrative is the desire to learn from the experience, which may form part of Sara's reason for wanting to be part of a research project in the first place. This may also account for her highly positive perceptions of the group intervention, repeatedly described as "*really useful*". The opportunity to gain self-understanding was gratefully received:

> *there was this anger diary that was really like, woah, kind of thing because you didn't, I never thought of myself as like an angry person, and then I was filling it in and it was just like, 'Gosh. I get wound up so often'.*

It is, however, important to bear in mind the interview context. It could well be that, consciously or not, Sara is keen to show that she is being 'successfully ill' and making the most of opportunities provided. Given the medical discourse discussed above, she may be particularly determined to prove her worth to clinicians and researchers. In accord with this, she repeatedly challenges the prevalent view that being ill renders her useless, appreciating, for instance, the value of sharing tips and ideas amongst the MS group: "*I suppose it's a bit like the volunteering, like having a bit of use instead of you being the person that everyone is having to like look after and reassure and stuff."*

We draw our identity, in part, from the impact we have on others; we need to know that we matter and make a difference in others' lives (Curtis & Eldredge, 1997). This theme is identified in the wider literature on mental health, most recently with the recovery movement's recognition of relationships and finding meaning (Bonney & Stickley, 2008; Repper & Perkins, 2003). Since her diagnosis, Sara has started volunteering in a range of settings that she considers worthwhile and meaningful. She comments this "*looks quite good on your CV"* demonstrating she has not given up on returning to work. Volunteering has been a lifeline in terms of being able to maintain this aspect of herself:

> *this kind of stuff keeps me sane because you feel really stupid and useless and kind of like worthless as well. [I: Yeah] So doing this kind of thing, it, that really picks you up, [I: Yeah] massively.*

Frank's quest hero echoes this aspiration to be productive and reach out to others, and this appears to have been a desire in Sara even before she became ill. She describes how she chose to work for human rights charities in "*meaningful and like challenging"* roles. For her, perhaps, the quest continues in spite of, not because of, illness. That she has been able to continue to contribute meaningfully in a work context protects her against the acknowledgment that there has been some change – that there is a difference between her "old self" and her current self – providing a crucial thread of self-continuity. At the same time, it appears that being able to see MS as separate to her identity has supported Sara's wellbeing. This may be due to the way her primary identity and ontological security come from and remain rooted in close family relationships. In light of this, it is interesting to note Frank's (1995) insistence that part of the quest story is achieving the incorporation of illness into the teller's life. While the prevailing medical narrative around illness may insist that suffering is without meaning, according to Frank (1995) within the quest narrative lies a moral responsibility to find purpose and gain self-understanding. Frank writes that there will inevitably be resistance and wrestling before the boon of the suffering become clear. He likens this aspect of quest stories to Jacob wrestling with God in the Bible. Though Jacob emerges with a limp, he receives the blessing demanded and it is through the process of resistance that he is given a new name and identity, Israel; the self is found. Applying this to Sara's story, it could be that, despite her attempts to assure others of her acceptance of MS, there is still resistance. There are hints of this in the way she tries to hang on to her previous lifestyle:

And then it's like really annoying because it's like, if I have like, I don't know like applications and I stay up til I don't know 3 o'clock just doing them and doing them and everything, and then a few days after I'm just whacked for like the next two weeks. And he's always just like, 'Why do you do it? You're supposed to be like pacing yourself and things like that', and that just like annoys me.

She acknowledges being "*really stubborn*" and admits "*I just kind of like try to put, like, my MS aside and just carry on like how I used to".* She also uses fighting language: "*if I gave in to my MS".* Thus, it may be that she is wrestling less with the disease as to hold on to a previous identity. Although her foundations and deep sense of self were not uprooted by the illness, perhaps some degree of identity reconstruction and grieving of loss is still needed in order to fulfil the quest.

In terms of taking part in the MS intervention, the quest narrative allows Sara to engage with, and make every effort to learn from, the content. It also allows her to recognise her journey is unique, which renders occasions of meeting others with worse symptoms less threatening to how she sees herself:

I mean there's that lady - I've forgotten her name – with the stick and then the lady in the wheelchair [I: yep] and you can look at them and just think, 'My god, that's like going to happen to me', but then it's like

nobody can predict the future and nobody knows like [I: yeah] if I will end up confined to a wheelchair or anything.

In comparison to Frances, Sara comments she is able to be grateful for her current abilities when meeting others in worse situations, rather than personalising their symptoms. Here, in addition to the quest narrative, faith appears to provide a meta-narrative that plays a part in enabling her to be thankful for what she has today rather than focussing on fears of what might be.

Sara: *Like I went to the gym early today and I was like on my bicycle and it was just like, I am like religious and I do, I pray and I thank God and like every day you're like, when I'm like on my bike and I'm just like thankful for like all my physical and mental like capabilities and stuff.*

Interviewer: *Yeah. Do you think that has played a significant part in your attitude and how you've coped?*

Sara: *I think so. Yes. Definitely.*

This attitude of 'the self better than others', in Sara's words *" there are so many million times worse, worser like illnesses and diseases than like MS"*, is similarly identified by Nochi (2000, p. 1797) as a common reconstructed narrative amongst those with brain injury who are now relatively at ease with their lives. For Sara, this attitude leaves her free to engage with others in the MS group and discover "*it is actually really, really useful to speak to other people that*

have it". The benefit derived from meeting other people with shared experiences points to another aspect of narrative worth consideration. This is the value of telling our stories to others, and, in particular, telling our stories to others who can understand.

6.4.5 Therapeutic value of narrative

A considerable body of literature describes the potential narrative holds for restoring coherence and integrity to lives disrupted by traumatic events (Joseph, 2011; Zang, N. Hunt, & Cox, 2013). This analysis additionally indicates that telling others who can understand can be an important, and potentially therapeutic, element. Despite other reservations, both Sara and Frances expressed a desire to meet other people who understood what it was like to live with MS. As Sara put it: "*it was good to be in a room with other people that understand you".* Indeed, she commented on this several times, indicating, perhaps, the fundamentality of the desire to be known and understood. For her, this stood in contrast even to well-meaning others:

> *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.*

Meeting others with shared experiences was identified in earlier chapters as one of the benefits of group interventions. Applying a narrative perspective to

the text here suggests an underlying reason lies in the need for validation. In the context of brain injury, Jones et al. (2012) recognise that recounting one's experiences to someone who understands provides a validation not always possible with those who are not in the same position. When the importance of self-narratives and their relationship to identity is understood, telling others who understand validates not only experiences of living with MS, but validates the self. It is apparent from the analysis of both Sara and Frances' transcripts that such validation becomes particularly relevant in light of the stigma and discreditation of self that can come from cultural narratives of illness.

6.5 General Discussion and Clinical Implications

This analysis demonstrates the power of illness narratives to influence individuals' experiences of MS. In particular, it highlights ways whereby cultural and self-narratives can affect the level of identity threat posed by MS. It also offers explanations for differing perceptions of psychological adjustment interventions, and differing responses to the prospect of undertaking group or individual delivery formats.

On the face of it, Sara and Frances have reacted very differently to living with the disease. Sara has an attitude of overcoming, welcomes the opportunity for growth afforded by the intervention and finds benefit in meeting others with MS. Frances, by contrast, adopts an attitude of forbearance, attempting to ignore the condition where possible, and shying away from contact with other people with MS. Although Sara has been diagnosed for longer, and, as such,

has had longer to adjust, the narrative analysis suggests an underlying reason for the women's differing responses is the different stories in which they see themselves. Interestingly, though, both their narratives can be seen as attempts not only to maintain a sense of personal integrity but also to minimise discreditation: both women are wary of the societal stigma associated with MS. Moreover, the analysis reveals that both women themselves perceive illness as weakness, providing support for Radley's (1995) assertion that those with chronic illness are subject to and influenced by cultural narratives and the corresponding expectations. While it is beyond the remit of this thesis to suggest ways in which societal stigma surrounding illness may be tackled, these findings do have several clinical implications.

First, the analysis highlights the importance for clinicians to be aware of how people's perceptions of and willingness to engage with psychological adjustment interventions may be influenced by their self and illness narratives. Both women feared MS coming to dominate their identity (a concern echoed in the wider MS literature (Boeije et al., 2002)). However, while for Frances this threat, and consequently the prospect of meeting others with MS was overwhelming, Sara was able to take part in the MS group and find benefit from meeting others in the group condition. For Sara, this threat appeared to be lessened by the strong sense of continued identity she finds in her relationships with her family. In addition, the quest narrative offered her a different perspective on taking part in the group intervention, which similarly reduced the identity threat. Greater awareness of the ways illness narratives may

influence perceptions of group interventions may enable better targeting of interventions, and provide insight into who may derive greatest benefit from group or individual delivery formats.

The second clinical implication of this analysis lies in the potential benefit of incorporating a narrative element in psychological adjustment interventions. One aspect of this may be in allowing people to tell their stories. Recounting traumatic life narratives solicits validation of one's experiences and can aid post-traumatic growth. A growing body of research is demonstrating the importance of narrative in integrating and overcoming challenging life experiences (Lyons, 2008; Neimeyer, 2004; Zang et al., 2013). As we have seen, this process can be facilitated or hindered at an interpersonal level according to the validation received (Neimeyer, 2004). The indication is that other people with similar experiences are best positioned to be able to be able offer the understanding sought. Further research could investigate whether exploration of narrative perspective is aided or hindered by group or individual intervention contexts, particularly when it is helpful to share and reflect on illness narratives together with others with MS and when, and for whom, the safety and privacy of one-to-one sessions is preferred.

Another aspect may be for interventions to include some reflection on how people see illness from a narrative perspective, and how this may be affecting their feelings and behaviours. Given the power of narrative to influence how people respond to and live with chronic illness there may also be therapeutic

value in identifying and, where appropriate, resisting dominant cultural narratives (as identified by Neimeyer, 2004). This is interesting to consider in light of the findings presented in the previous chapter, where some participants found meeting other people with MS helpful in challenging stereotypes of MS and what living with the disease looked like. The potential for incorporating a narrative element in psychological adjustment groups for people with MS and mental health difficulties is in line with Mattingley's (1994) assertion that narrative has a crucial role in clinical work, both as a retrospective account and as a structure that patients and clinicians seek to impress on clinical time. J. Holmes (2000) similarly claims that good practice necessitates a blend of narrative and evidenced-based approaches and calls for greater integration the two. Instances of the integration of CBT and narrative therapy are beginning to appear in the literature (Martín-Vázquez, 2014; Prasko et al., 2010; Robjant & Fazel, 2010) in what has been termed a narrative turn in psychiatry (Brown et al., 1996).

A final interesting possibility raised by this study lies in the value of integrating narrative insights with research looking at coping strategies and adjustment in MS. For instance Dennison, Moss-Morris and Chalder (2009) identified cognitive appraisal of MS as an important adjustment-related factor. In a literature review investigating psychological correlates of adjustment in MS, evaluation of the disease as threatening was found to be associated with poorer adjustment outcomes. Coping strategies such as positive reappraisal were found to be related to better adjustment while avoidance and wishful

thinking were predictors of poorer adjustment (Dennison et al., 2009). Viewing such findings through a narrative lens may offer a way to address unhelpful appraisals of illness and encourage more beneficial coping strategies.

6.5.1 Critique of narrative analysis

A critique often levelled at clinical research is that it fails to give much consideration to participants as contextualised in a world outside of the clinical setting (see Brown et al., 1996). A strength of narrative analysis is that it enables wider contextualisation, along with exploration of the meanings, feelings and implicit assumptions that organise the narrator's life (Wengraf, 2001). These assumptions often come from societal discourse and, though the typologies of illness narratives touched on here are by no means definitive, it is evident that such cultural narratives are drawn on in identity construction. Certainly narrative analysis gives researchers insight into people's illness experiences apart from the conceptions of illness formulated by bio-medicine. Importantly for the purposes of this investigation, narratives allow room for exploration of the impact of illness on sense of self and re-visioning of the relationship between the individual and their social world. Individuals and groups construct identities through narratives, thus engaging research participants in storytelling has the potential to achieve insight into the impact of MS on social identity that non-narrative methods do not (Riessman, 2008). One limitation of the current study is that it represents only a snapshot in time. It would be interesting and valuable to undertake a longitudinal study to gain

insight into how narratives develop as people live with MS for longer or as their symptoms become worse and more visible.

In adopting thematic narrative analysis and thus choosing primarily to interrogate content, certain aspects of narrative have, inevitably, been omitted here. Structural coherence, for instance, can reflect degree of personal integrity, but was not considered in the above analysis. There was limited recognition that the process of transcription is already an interpretative practice and information carried in features of speech, such as whispers, intonation and non-lexical utterances, was neglected here (Riessman, 1993). A crucial part of narrative is that the stories are told to another. Storytelling is a dialogue of imaginations (Frank, 2012) and in interviews, meaning is contested and interactionally accomplished (Mathieson & Stam, 1995). Some consideration was given to narrative as a co-constructed, dialogical process (Frank, 2012) in the above analysis. The participants' perceptions of me and my role as interviewer would have had bearing on what they presented of themselves. For instance, given Sara's embarrassment at disclosing her condition to peers, it is noteworthy that I could be considered amongst this group as someone of a similar age and educational background. At the same time, what she disclosed may well have been influenced by my perceived position as part of the clinical profession, and the corresponding assumptions of my beliefs surrounding illness experiences. Interviewees may see themselves as being 'at risk' and, therefore strive to represent themselves in a particular way to the interviewer (Wengraf, 2001). Questions of circulation

could also be guiding self-presentation; the interviewees may be aware that their story could have a wider audience than the interviewer alone and more may be at stake than how I see them (Frank, 2012).

A critique commonly directed at narrative analysis is whether truth can be established. It is certainly important to remain aware of the complex relationship between narrative, memory and time, since we revise and reframe the remembered past in order to square it with our present identities (Riessman, 2008). The debate around truth becomes all the more pertinent in the context of interviews, where narratives are co-authored and the teller can chose what to present of themselves. That said, it is also argued that the human propensity to cast life in narrative form renders it peculiarly hard for narrators to completely control or manipulate, consciously or unconsciously (Wengraf, 2001). As outlined in the methodology chapter, I tend towards a critical realist approach to truth (Archer, Bhaskar, Collier, Lawson, & Norrie, 1998) acknowledging a layered ontology of social reality and, thus, appreciating that interviews may present only a partial picture. As Stivers (1993) argues, the point is increased understanding and insight rather than certitude. This answers another critique of the current analysis regarding the generalisability of findings. Every person and every story is different, and, at this stage, it is not possible to extrapolate beyond the two individual lives considered here. Nevertheless, as discussed above, the analysis offers valuable insights into living with MS and responses to interventions, and suggests the value of considering narrative in a clinical setting. It also suggests possible categories of

illness narrative in MS, which could be investigated further in future research. It is also worth bearing in mind J. Holme's (2000) remarks regarding the need to tailor scientific knowledge with the biography and circumstances of each individual patient.

Finally, there is a moral dimension within the critical realist framework, as in the quest narrative. As we have seen, identity is, in part, bestowed upon us by others - the stories they tell us about ourselves and where we fit in relationship to others (Cloute, Mitchell, & Yates, 2008; Curtis & Eldredge, 1997; C. Haslam et al., 2008). However, humans also create stories and social structures, thus our behaviours need not necessarily be determined by existing ones (Giddens, 1979). Perhaps, then, the primary importance of such narrative research is to engage readers in illness stories, inviting them to see things from the narrator's perspective and to provide alternative narratives in which people can situate and understand themselves and others.

Chapter 7. General Discussion

7.1 Summary

In this final chapter the overall findings of the thesis are summarised. Limitations of the research programme are considered and a range of clinical implications and recommendations are discussed. Finally, several avenues for further research are proposed.

7.2 Overall Findings

Emerging literature is beginning to uncover the profound impact that social identities can have on mental health and wellbeing. This research programme is amongst the first to apply a social identity approach to the field of clinical neuropsychology and explore whether this is equally true in the context of MS. In particular, the thesis aimed to explore the widely held assumption that group delivery of psychological adjustment interventions is beneficial due to the opportunity afforded for social interaction.

Results from the survey study (chapter 3) confirmed the importance of social identity processes to the mental health of people with MS. In particular, the finding that both disruptions to social identity and anticipated stigma are associated with increased psychological distress offers an explanation for the high prevalence of mood disorders experienced by people with MS. Social identity processes were further found to be relevant to engagement with group psychological adjustment interventions. The finding that identity threat may influence perceptions of interventions and reduce intervention engagement

offers an explanation for why some people report finding group interventions helpful, while others are reluctant to meet other people with MS or avoid MS groups entirely. It may also go some way towards explaining the mixed findings in the literature regarding the value of MS support groups.

Results from the realist synthesis (chapter 4) and thematic analysis (chapter 5) also make a valuable contribution to the literature in making explicit those aspects of group intervention format that confer benefit. The identity-related benefits also provide support for Cruwys, Haslam, Dingle, Haslam, et al.'s (2014) model of social identity as a psychological resource, and its proposition that being part of a group can have beneficial effects via a sense of belonging, a sense of purpose and the receipt and provision of social support. The second, equally important, contribution to the literature lies in identifying the identity-related drawbacks of group format. Particularly noteworthy is the proposal that identity threat influences the degree to which such social identity resources may be gleaned without having an opposing, negative effect on wellbeing.

7.3 Limitations of the Research Programme

One of the main limitations of this research programme was that participants were primarily recruited from the Midlands area of the UK. This was extended to some degree by recruiting people for the online survey from the MS Society's national website, but the majority of participants came from the Nottinghamshire or Leicestershire area, limiting the generalisability of findings.

That said, there was considerable agreement between findings of the thematic analysis and the realist synthesis, and the latter included studies from a range of countries. It is also important to note that the results are drawn from people who have agreed to take part. The thesis findings offer suggestions as to why some people may choose not to attend psychological adjustment interventions. Ideally, these would be compared with reasons for non-attendance from those who chose not to take part. The same limitation also applies to the survey study. Ideally, the information from non-responders would be compared to responders to identify potential sources of bias (e.g. were those with high levels of psychological distress less likely to respond). However, this is a general limitation of this type of research and, while it would be informative, it is not practical or ethical to obtain data from non-responders.

The studies were all limited by a cross-sectional design. In the survey study this restricted the conclusions that could be drawn with respect to causality. In the studies using interview data, it meant that results were reliant to a certain degree on retrospective accounts. This is particularly pertinent with regard to the suggestion that timing is an important factor influencing identity threat.

Several other factors were given only limited consideration. For instance, the influence of MS type was not examined in great detail and the majority of the studies relied on self-reported diagnosis. Given that the degenerative and unpredictable nature of the disease may contribute to the threat posed by MS, in further research it would be worth exploring the pattern of effects with the

different types of MS, including progressive forms. Group size is another variable whose influence was not explicitly investigated in any of the studies.

7.4 Implications for Clinical Practice

In the wider research on neuropsychological rehabilitation, consideration of social identity processes suggests that increased social connection should not only be a desired outcome, but also an important input of psychological interventions. The findings of the current research programme support this suggestion in the context of MS and begin to establish a theoretical basis for decisions regarding whether to deliver group or individual psychological adjustment interventions.

Results indicate that a sense of shared identity can be a valuable aspect of group programmes. In particular, meeting others with whom one can identify offers the desired understanding, rarely obtainable even from well-meaning significant others who have not experienced what it is like to live with the disease. Importantly, detailing in this thesis the specific routes, contexts and mechanisms by which psychological benefits may be derived from group settings allows clinicians to shape interventions to best enable certain outcomes. For instance, results from the realist synthesis suggest that in order to generate feelings of empowerment and improve the self-efficacy of participants, clinicians could consider way to encourage a positive sense of collective identity. Equally important is an awareness of the drawbacks of the group format and the contributory mechanisms and contexts. Given this

awareness, it may be possible to challenge some of the mechanisms with negative psychological outcomes by making them explicit in the intervention content. For instance, where being part of an MS group may confer a social identity perceived by participants to be stigmatised, explicit recognition of this process could enable negative stereotypes and internalised stigma to be challenged within the context of the intervention. This is particularly important given the positive association found between stigma and psychological distress. The use of narrative may be helpful here. For instance, it may be beneficial for interventions to incorporate an element of reflection on illness narratives and how this influences perceptions of MS into the intervention content. Incorporating a narrative perspective may also support the process of adjustment and identity revision. Findings from the survey study indicated that disruptions to social identity are associated with increased psychological distress and reflecting on this disruption from a narrative perspective may aid the task of identity reconstruction.

Another clinical implication of this research is the challenge to frame, design and deliver group interventions in such a way as to reduce potential identity threat. There was some indication in the results of the thematic analysis that an emphasis on the professional as opposed to social aspect of the group may reduce the threat for some people. Timing was another factor related to identity threat. Researchers have highlighted the need for psychological support to be available soon after diagnosis (Dennison et al., 2011). In his review of psychologically focussed MS group interventions, Firth (2014)

suggested that support groups may be viable interventions for people with less severe or complex difficulties, followed by group interventions as an intermediate step and finally individual interventions. This stepped care pattern is echoed in the current national guidelines for adults with depression and a chronic physical health problem (NCCMH, 2010). Results from this research programme indicate that in addition to the severity of psychological symptoms, the identity threat posed by meeting others in a group condition needs to be taken into account when determining the suitability of group or individual interventions. The findings of both the realist synthesis and the thematic analysis suggest that people who have been diagnosed more recently may be more likely to perceive a group intervention as threatening and either avoid participation or be subject to potentially detrimental identity-related processes when confronted with a prospect of what they might become in the future. Accordingly, an individual intervention may be more appropriate at this stage and provide the support necessary to consider the process of adjustment and identity revision. For some, it may also provide a safer place to confide fears and begin to tackle beliefs around disability identity. Group composition may also be relevant to reducing identity threat with one possibility being to group participants according to age or disease stage. For instance, where identity threat is heightened for people recently diagnosed, grouping them together with others with early stage MS may reduce the threat and enable participants to access the benefits afforded by the group context. Such grouping may also increase the sense of social identity and shared

understanding since other people at a similar stage of the disease may be more likely to be experiencing similar difficulties.

A final clinical implication relates to group norms. Cruwys, Haslam, Dingle, Haslam, et al. (2014) proposed that normative behaviours are an aspect of social identity as a psychological resource that can protect against depression. However, such norms are not always positive, and with respect to MS groups, and specifically MS psychological adjustment groups where people are experiencing symptoms of depression or anxiety, normative behaviours may be unhelpful. This may be one explanation for the findings of a study in the realist synthesis that MS groups had a detrimental impact on those with better baseline mental health (Uccelli et al., 2004). As discussed in chapters 4 and 5, to avoid detrimental norms of depression or poor coping, one possibility may be to include guest speakers or intervention assistants with MS who are coping well and can provide positive role models. Furthermore, findings presented in the realist synthesis suggest that the assistants themselves may derive benefit from the sense of purpose and value this offers.

Perhaps the most important clinical consideration when deciding whether to offer group or individual interventions is for clinicians to know their patients. While the patterns identified above are useful for general recommendations, degree of identity threat is influenced by a variety of factors and will vary from person to person. Similarly, groups serve different purposes for different people and accordingly, individuals may derive benefit from differing

underlying mechanisms. The results highlight the importance for healthcare professionals delivering such interventions to be aware of the underlying identity-related processes and suggest ways they could try to ensure they are supportive rather than threatening to people with MS.

7.5 Implications for Further Research

The findings presented in this thesis suggest several avenues for further research. Firstly, a number of identity-related mechanisms that may influence perceptions of both group and individual psychological adjustment interventions are identified in the thesis. An important next step is to start to investigate in quantitative research whether such processes impact intervention efficacy. In the proposed multi-site RCT of group versus individual MS psychological adjustment interventions it would be valuable to incorporate the MS group identification scale as a baseline and outcome measure. This would enable investigation of the effect of group identification on intervention efficacy as well as the degree to which identification with the group changes during the course of the intervention. Although problems were encountered with the MS group identification scale used in the survey study, given that the measure would, in this instance, refer directly to the MS intervention group, it would be a suitable measure to use.

Identity threat would also be worth measuring in the RCT, but, to the best of the author's knowledge, no relevant scales currently exist. Development of such a scale is another important area for further research in itself. Meanwhile,

given the overlap between stigma and identity threat, incorporating a stigma scale would still offer useful insight into the impact perceived stigma has on attendance, attrition and intervention efficacy. It would also be interesting to explore whether stigmatised perceptions of MS are altered during the course of the intervention. The CIASS was found to be problematic with respect to the section on anticipated stigma at work. Accordingly, it may be that measures of internalised stigma (Molina et al., 2013), sensitivity to stigma (Major & O'Brien, 2005) or stigma resistance (Crabtree et al., 2010) are more appropriate. Factors that may reduce identity threat also need to be investigated. There were indications that social identity continuity helped reduce the identity threat posed by MS and it would be worthwhile investigating whether the maintenance of valued social groups influenced attendance and engagement with group interventions.

The focus of the thesis was on the delivery format of the intervention, as opposed to intervention content. As such, only limited consideration was given to the cognitive behavioural content and how this may interact with intervention format. There were indications that some people were more amenable to learning from peers with whom they could identify than from a professional who doesn't have experience of living with MS. This is an avenue that merits exploration. In addition, the thesis findings highlight the impact of social identity disruption on mental health in MS, and one implication is that incorporating the topic of identity redefinition into the intervention content may be beneficial. CBT has no theoretical position on identity change so does

not tend to address this aspect of adjustment, but given the overlap between narrative and identity, narrative techniques may, again, be useful here. This is in line with the 'narrative turn' that has been observed in psychiatry in recent years (Brown et al., 1996; J. Holmes, 2000) and instances of integrating CBT with narrative therapy that are beginning to emerge (Martín-Vázquez, 2014; Robjant & Fazel, 2010).

As noted in the limitations section, the current research programme is also restricted by its cross-sectional nature and reliant to a certain degree on retrospective accounts. Accordingly, it would be valuable to undertake a longitudinal study to investigate how identity threat from MS changes over time and as symptoms progress.

Finally, while this research programme began to test the mid-range theories or context-mechanism-outcome pathways identified in the realist synthesis, further refinement of the proposed pathways is needed in future research. The relationships between the purported intermediate outcomes and their impact on psychological wellbeing also need testing. Age and disease stage were identified in the realist synthesis as potential variables influencing identity threat and one avenue for further research would be to investigate the impact of group composition on intervention efficacy. For instance, as discussed in the previous section, studies grouping younger participants or those with early stage MS together would enable exploration of whether this does, indeed, reduce identity threat and how it impacts outcome measures of psychological

distress. Studies would not necessarily need to be limited to psychological adjustment interventions, and the findings of this research could be usefully applied to other MS group interventions or MS support groups more generally.

Finally, similar investigations with people with other neurological and degenerative conditions would be worthwhile. Encountering people with worse symptoms and having to confront what one might become in the future was identified as one of the main drawbacks of MS group interventions. Meeting others with MS is rendered especially threatening to identity due to the degenerative nature of the condition. This is likely to be true of a number of other progressive disease conditions and, in this way, the findings of this research programme may well apply beyond MS.

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Appendices

Appendix 1. Ethical Approval Letters for Study Entitled 'Investigation of Social Identity and Mood in People with Multiple Sclerosis'

Appendix 1a. Ethical Approval Letter from NRES Proportionate Review Sub-Committee London-Bromley

NHS
Health Research Authority

NRES Committee London - Bromley
Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT
Telephone: 01173 421383

17 April 2014

Professor Nadina B Lincoln
Professor of Clinical Psychology
University of Nottingham
Division of Rehabilitation and Ageing
Medical School, Queen's Medical Centre
University of Nottingham,Nottingham
NG7 2UH

Dear Professor Lincoln

Study title:	**Investigation of social identity and mood in people with multiple sclerosis**
REC reference:	**14/LO/0703**
Protocol number:	**14031**
IRAS project ID:	**145195**

The Proportionate Review Sub-Committee of the NRES Committee London - Bromley reviewed the above application on 16 April 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Lauren Allen, at nrescommittee.london-bromley@nhs.net.

Ethical opinion

On behalf of the Committee, the Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please ensure that the Invitation Letter makes reference to the Participant Information Sheet.

2. In the Participant information Sheet under the heading 'What are the possible disadvantages and risks of taking part?' please add in a sentence letting participants know who they can contact should they feel upset after completing the questionnaires, and provide contact details.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list

of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Advertisement	MS Society Website Advert v1.0	10 April 2014
Evidence of insurance or indemnity		31 July 2013
Investigator CV	Professor Nadine B Lincon	10 April 2014
Letter from Sponsor		08 April 2014
Letter of invitation to participant	1.0	10 April 2014
Other: Summary CV for Supervisor	Dr Roshan Das Nair	
Other: CV	Mr Alex Barker	
Other: CV	Miss Kathryn Smale	
Other: CV	Dr Nigel Hunt	
Other: CV	Dr Esmaeil Nikfekr	
Participant Consent Form	1.0	10 April 2014
Participant Information Sheet	1.0	10 April 2014
Protocol	1.0	10 April 2014
Questionnaire: Questionnaire Booklet	1.0	10 April 2014
Questionnaire: Demographic Information Sheet	1.0	10 April 2014
REC application		10 April 2014

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

NHS
Health Research Authority

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
information is available at National Research Ethics Service website > After Review

14/LO/0703 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

PP

Ms Carol Jones
Chair

Email: nrescommittee.london-bromley@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers"

Copy to: *Mr Paul Cartledge*
Carolyn Maloney, University Hospitals Leicester NHS Trust

A Research Ethics Committee established by the Health Research Authority

NHS
Health Research Authority

NRES Committee London - Bromley

Attendance at PRS Sub-Committee of the REC meeting on 16 April 2014

Committee Members:

Name	*Profession*	*Present*
Mrs Susan Beer	Retired Project Manager	Yes
Ms Carol Jones	Management Consultant	Yes
Dr Angela Orunta	Consultant Anaesthetist	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Miss Lauren Allen	REC Manager

Appendix 1b. Research and Development Approval Letter from the University Hospitals of Leicester NHS Trust Research & Development

University Hospitals of Leicester NHS
NHS Trust

DIRECTORATE OF RESEARCH & DEVELOPMENT

Research & Development Office
Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Director: **Professor Nigel Brunskill**
Assistant Director: **Dr David Hetmanski**
Head of Research Operations: **Carolyn Maloney**

Direct Dial: (0116) 258 8351
Fax No: (0116) 258 4226

12/02/2015

Dr Esmaeil Nikfekr
University Hospitals of Leicester
Department of Neurology
Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Dear Dr Esmaeil Nikfekr

Ref: **UHL 11366**
Title: **Investigation of social identity and mood in people with multiple sclerosis**
Project Status: **Project Approved**
End Date: **31/03/2015**

Date of Valid Application: 12/02/2015
Days remaining to recruit first patient: 70 Days

I am pleased to confirm that with effect from the date of this letter, the above study has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust. The research must be conducted in line with the Protocol and fulfil any contractual obligations agreed between UHL & the Sponsor. If you identify any issues during the course of your research that are likely to affect these obligations you must contact the R&D Office.

In order for the UHL Trust to comply with targets set by the Department of Health through the 'Plan for Growth', there is an expectation that the first patient will be recruited within 70 days of receipt of a Valid Application. The date that a Valid application was received is detailed above, along with the days remaining to recruit your first patient. **It is essential that you notify the UHL Data Management Team as soon as you have recruited your first patient to the study either by email to RDData@uhl-tr.nhs.uk or by phone 0116 258 4573.**

If we have not heard from you within the specified time period we will contact you not only to collect the data, but also to record any issues that may have arisen to prevent you from achieving this target. It is essential that you get in touch with us if there is likely to be a problem in achieving this target so that we can discuss potential solutions. The Trust is contractually obliged to meet the 70 day target and if an adequate reason acceptable to the NIHR has not

been submitted to explain the issues preventing the recruitment of your first participant, the Trust will be financially penalised.

In addition, we are required to publish the Title, REC Reference number, local target recruitment and actual recruitment as well as 70 days data for this study on a quarterly basis on the UHL public accessed website.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Document Name	Version	Date
REC Approval Letter	Study Approval	17/04/2014
Letter of Invitation to Participant	V1.0	10/04/2014
Participant Information Sheet	V1.0	10/04/2014
Protocol	V1.0	10/04/2014
Questionnaire Booklet	V1.0	10/04/2014
Demographic Information Sheet	V1.0	10/04/2014

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

Data collection for this study had commenced and completed prior to receiving University Hospitals of Leicester R&D approval. Due to the low risk nature of the study and the anonymous data collected Carolyn Maloney Head of Research Operations has agreed to authorise the use of the data.

Undertaking research in the NHS comes with a range of regulatory responsibilities. Please ensure that you and your research team are familiar with, and understand the roles and responsibilities both collectively and individually.

Documents listing the roles and responsibilities for all individuals involved in research can be found on the R&D pages of the Public Website. It is important that you familiarise yourself with the Standard Operating Procedures, Policies and all other relevant documents which can be located by visiting www.leicestershospitals.nhs.uk/aboutus/education-and-research

The R&D Office is keen to support and facilitate research where ever possible. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office. Our contact details are provided on the attached sheet.

We wish you every success with your research.

Yours sincerely

Carolyn Maloney

Carolyn Maloney
Head of Research Operations

Encs: .R&D Office Contact Information

CONTACT THE RESEARCH & DEVELOPMENT OFFICE

The **R&D Office** for UHL is located at Leicester General Hospital; you are welcome to contact us for telephone advice, or to arrange an appointment. All staff contact details can be found below:

David Hetmanski	Assistant Director of R&D	0116 258 4199
Carolyn Maloney	Head of Research Operations	0116 258 4109
Rita Patel	Contracts & Commercial Manager	0116 258 8241
Julie James	Clinical Trials Monitor/Trainer	0116 258 4686
Anne Moore	Asst. Clinical Trials Monitor/Trainer	0116 258 4686
Aldona Kirkham	Asst. Clinical Trials Monitor/Trainer	0116 258 4686
Lisa Wann	Team Leader/ Snr. R&D Facilitator	0116 258 8239
Tara Sadler	Research Support Officer	0116 258 8246
Zaynab Khan	Research Support Officer	0116 258 8243
Sharon Turner	UHL R&D Administrator	0116 258 8351
Thowani Lungu	UHL R&D Administrator	0116 258 4761
Wendy Gamble	Uni Research Governance Manager	0116 258 4099
Yasmin Godhania	Uni Governance Officer	0116 258 4867
Jacquelene Tsiga	Uni Governance Officer	0116 258 4867
Martin Maynes	R&D Finance Lead	0116 258 8242
Rachael Davies	UHL Research Accountant	0116 258 8183
Mandy Hartshorne	UHL R&D Assistant Accountant	0116 258 4556
Sadeq Rahman	UHL R&D Assistant Accountant	0116 258 4747
Dawn Wakeling	UHL Research Feasibility Officer	0116 258 4017
Khurram Memon	UHL R&D Information Manager	0116 258 4573
Kajal Solanki	UHL Research Data Manager	0116 258 4573
Jennifer Durrant	Research Communications Manager	07961 804431

Further contact details are available on the UHL Public Website
www.leicestershospitals.nhs.uk/aboutus/education-and-research/

Version 14. 31.05.2014

Appendix 2. Participant Invitation Letter and Information Sheet for Survey Study

[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.

If you would like to contribute to this research please complete the enclosed questionnaires and return 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 Nikfekr Esmaeil

Multiple Sclerosis Society

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

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:

ProfessorNadina Lincoln
ChiefInvestigator and Professor of ClinicalPsychology
Division of Rehabilitation and Ageing, MedicalSchool
Queen'sMedical Centre
University of Nottingham
Nottingham
NG7 2UH
Email: nadina.lincoln@nottingham.ac.uk
Tel: 0115 823 0230

Thank you very much for your time and consideration

Appendix 3. Questionnaire Pack and Demographic Information Sheet

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

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 '2' if you *Strongly Disagree*
Circle the '3' if you *Mildly Disagree*
Circle the '4' if you are *Neutral*
Circle the '5' if you *Mildly Agree*
Circle the '6' if you *Strongly Agree*
Circle the '7' if you *Very Strongly 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).

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

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

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

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"*.

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

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.

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

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

Hospital Anxiety and Depression Scale

[Hospital Anxiety and Depression Scale not reproduced here due to copyright reasons]

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: ProfessorNadina 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	☐	5-10 years	☐
1-3 years	☐	10-15 years	☐
3-5 years	☐	More than 15 years	☐

Type of multiple sclerosis: Please tick ☑ the corresponding box

Relapsing remitting	☐	Primary progressive	☐
Secondary progressive	☐	Benign	☐

Marital status: Please tick ☑ the corresponding box

Married/with partner	☐	Single	☐
Divorced/separated/widowed	☐		☐

Living arrangements: Please tick ☑ the corresponding box

Living with partner	☐	Living with family	☐
Living alone	☐	Living with friends	☐
Other	☐		

please describe: _____

Nationality: _____

Ethnic Origin: Please tick ☑ the corresponding box:

White		**Black**	
British	☐	Black British	☐
Irish	☐	African Caribbean	☐
Any other white background	☐	Any other black background	☐
Mixed		**Asian or Asian British**	
White and Asian	☐	Bangladeshi	☐
White and Black African	☐	Indian	☐
White and Black Caribbean	☐	Pakistani	☐
Any other mixed background	☐	Arab	☐
		Chinese	☐
		Any other Asian background	☐

Other ☐

Any otherethnic background: _____

Appendix 4. Hierarchical Regression Results including Recruitment Method as an Additional Factor

n = 196	Predictor variable	Outcome variable: psychological distress (HADS)						
		b (SE)	Beta	p	95% CI		R2 change	Total R2
Step 1	**Age**	-0.141 (0.056)	-0.192*	0.012	-0.252	-0.031	0.12**	0.12
	Time since diagnosis	-0.210 (0.396)	-0.040	0.597	-0.990	0.571		
	Gender	2.774 (1.262)	0.152*	0.029	0.285	5.263		
	Recruitment method (postal / online)	-2.615 (1.152)	-0.160*	0.024	-4.886	-0.343		

Step 2	**Age**	-0.095 (0.047)	-0.129*	0.044	-0.187	-0.002	0.290**	0.410
	Time since diagnosis	-0.134 (0.327)	-0.026	0.682	-0.779	0.511		
	Gender	1.799 (1.052)	0.098	0.089	-0.277	3.874		
	Recruitment Method	0.443 (1.071)	0.027	0.680	-1.670	2.556		
	Maintained group memberships	-0.292 (0.062)	-0.295**	<0.001	-0.415	-0.168		
	Anticipated stigma	0.328 (0.053)	0.393**	<0.001	0.223	0.433		
	MS group identity	-0.121 (0.055)	-0.127*	0.031	-0.230	-0.011		

*p<0.05 **p<0.01

Appendix 5. Search Strategies for Realist Synthesis

Search 1: CBT & MS

- Ovid (MEDLINE) (R) (Searched 1946-May Week 4, 2015)
  PsycINFO (Searched 1806 – May Week 3, 2015)
  Embase (Searched 1974 – 2015 May 27)

Date of searches: (last updated on 28 May 2015)

1. exp cognitive behavioural therapy/
2. exp cognitive behavioural therapy/
3. "cognitive behavio*".ab,hw,kw,ti,tw.
4. 1 or 2 or 3
5. multiple sclerosis.ab,hw,kw,ti,tw.
6. 4 and 5
7. Limit to english language

- CINAHL (no imposed date limits)

Date of search: (last updated on 28 May 2015)

1. AB multiple sclerosis AND TX cognitive behavio*
   Limiters: English Language

- ASSIA (no imposed date limits)

Date of search: (last updated on 29 May 2015)

1. ab(multiple sclerosis) AND (cognitive behavio*)

Search 2: MS & Social Identity

- Ovid (MEDLINE) (R) (Searched 1946-May Week 4, 2015)
  PsycINFO (Searched 1806 – May Week 3, 2015)
  Embase (Searched 1974 – 2015 May 27)

Date of searches: (last updated on 28 May 2015)

1. multiple sclerosis.ab,hw,kw,ti,tw.
2. exp identity
3. identity change.mp.
4. self-categori?ation.mp.
5. social identity.mp.
6. 2 or 3 or 4 or 5
7. 1 and 6

8. limit 7 to english language
9. remove duplicates from 8

- CINAHL

Date of search: (last updated on 28 May 2015)

1. AB identity
2. AB social identity
3. AB identity change
4. AB self-categorization
5. AB self-categorisation
6. 1 or 2 or 3 or 4 or 5
7. AB multiple sclerosis
8. 6 AND 7

- ASSIA

Date of search: (last updated on 28 May 2015)

1. ab(multiple sclerosis) AND (ab(identity OR OR social identity OR identity change OR self-categorisation OR self-categorisation)

Search 3: MS & support group or peer or stigma

- Ovid (MEDLINE) (R) (Searched 1946-May Week 4, 2015)
  PsycINFO (Searched 1806 – May Week 3, 2015)
  Embase (Searched 1974 – 2015 May 27)

Date of searches: (last updated on 28 May 2015)

1. multiple sclerosis.ab,hw,kw,ti,tw.
2. exp stigma/
3. stigma*.mp.
4. peer.ab.ti.tw.
5. "peers*".ab.ti.tw
6. support group.ab.ti
7. 2 or 3 or 4 or 5 or 6
8. 1 and 7
9. limit 8 to english language
10. remove duplicates from 9

- CINAHL

Date of search: (last updated on 28 May 2015)

1. AB peer OR AB peers
2. AB stigma*

3. AB support group
4. 1 OR 2 OR 3
5. AB multiple sclerosis
6. 4 AND 5

- ASSIA

Date of search: (last updated on 28 May 2015)

2. ab(multiple sclerosis) AND ab((peer OR peers OR support group OR stigma*))

Appendix 6. Ethical Approval Letters for Study Entitled 'Comparing Individual and Group Psychological Interventions for People with Multiple Sclerosis: A Pilot Randomised Control Trial'

Appendix 6a. Ethical Approval Letter from NRES Committee East Midlands – Nottingham 1.

NHS
Health Research Authority

NRES Committee East Midlands - Nottingham 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 883 9390

12 December 2012

Dr Roshan das Nair
Department of Clinical Psychology and Neuropsychology
Queen's Medical Centre,
Derby Road
Nottingham
NG7 2UH

Dear Dr das Nair,

Study title: **Comparing individual and group psychological interventions for people with multiple sclerosis: a pilot randomised control trial.**
REC reference: **12/EM/0380**
Protocol number: **12CP010**
IRAS project ID: **113059**

Thank you for your letter of 10th December 2012. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 November 2012

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering Letter		10 December 2012
Participant Consent Form	3.0	04 December 2012
Participant Information Sheet	3.0	04 December 2012

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Advertisement	1	21 September 2012
Covering Letter		10 December 2012
Evidence of insurance or indemnity		27 September 2012
Interview Schedules/Topic Guides	1.0	21 September 2012
Investigator CV	CV for Roshan das	27 September 2012

	Nair	
Other: Letter for Poster	2.0	03 October 2012
Other: Letter to Services	2.0	03 October 2012
Other: Information sheet reply slip	1.0	21 September 2012
Participant Consent Form	2.0	03 October 2012
Participant Consent Form	3.0	04 December 2012
Participant Information Sheet	2.0	03 October 2012
Participant Information Sheet	3.0	04 December 2012
Protocol	1.0	21 September 2012
Questionnaire: General Health Questionnaire 12		
Questionnaire: Hospital Anxiety and Depression Scale		
Questionnaire: Multiple Sclerosis Impact Scale (MSIS-29)		
Questionnaire: MS Self-Efficacy Scale (MSSS)		
Questionnaire: Beck Depression Inventory-II		
REC application	113059/367627/1/953	27 September 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/EM/0380 **Please quote this number on all correspondence**

Yours sincerely,



Rebecca Morledge
Assistant Committee Co-ordinator

E-mail: NRESCommittee.EastMidlands-Nottingham1@nhs.net

Copy to: *Dr Maria Koufali, Nottingham University Hospitals NHS Trust R&D department*
Ms Charlotte Davies, Nottingham University Hospitals NHS Trust R&D Office

Appendix 6b. Approval Letter from the University of Nottingham's Institute of Work, Health & Organisations Research Committee



Nottingham University Hospitals NHS
NHS Trust

Research & Innovation
Nottingham Integrated Clinical Research Centre
C Floor, South Block
Queen's Medical Centre Campus
Derby Road, Nottingham NG7 2UH

Tel: 0115 9249924 ext 70659
www.nuhrise.org

Mr Roshan Das Nair
IWHO International House
Room B13 Jubilee Campus
Wollaton Road
Nottingham

NG8 1BB

05 FEB 2013

Dear Mr Roshan Das Nair

Re: 12CP010

12/EM/0380
Comparing individual and group psychological interventions.

The R&I Department have reviewed the following documents and NHS permission for the above research has been granted on the basis described in the application form, protocol, and supporting documentation. The documents reviewed were:

NHS R&D form version 3.4
Guys neurological Disability Scale
Data Collection form version 1 dated 20/11/12
Participant consent form version 3.0 dated 04/12/12
Participant information sheet version 3,0 dated 04/12/12
Advertisement version 1 dated 21/09/12
Interview Schedules/Topic Guides version 1.0 dated 21/09/12
Other letter for poster version 2.0 dated 03/10/12
Letter to services version 2.0 dated 03/10/12
Information sheet reply slip version 1.0 dated 21/09/12
Protocol version 1.0 dated 21/09/12
Questionnaire: General Health Questionnaire 12
Questionnaire: Hospital Anxiety and Depression Scale
Questionnaire: Multiple Sclerosis impact Scale (MSIS-29)
Questionnaire: MS Self-Efficacy Scale (MSSS)
Questionnaire: Beck Depression Inventory-II



Your study now has NHS permission , on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

The Principal Investigator is responsible for

1. Compliance with all relevant laws, regulations and codes of practice applicable to the trial including but not limited to, the UK Clinical Trials Regulations, Medicines for Human Use (Clinical Trial) Regulations 2004, principles of Good Clinical Practice, the World Medical Association Declaration of Helsinki entitled 'Ethical Principles for Medical Research Involving Human Subjects' (1996 version), the Human Rights Act 1998, the Data Protection Act 1998 the Medicines Act 1968, the NHS Research Governance Framework for Health and Social Care (version 2 April 2005). Should any of these be revised and reissued this will apply. Copies of the up-to-date regulations are available from the R&I Office or via the R&I website http://nuhrise.org

2. Submission of study amendments to the Ethics committee and MHRA in accordance with the IRAS guidelines. Amendments and information with regards to changes in study status must be sent to R&I, (this includes changes to the local study team). Within 35 days from the receipt of a valid amendment submission, NUH will inform you if may not locally implement the amendment. If no objections are raised NHS permission is valid and the amendment may be implemented.

   When submitting documents for studies adopted into the NIHR portfolio please send the information to NUHNT.TRENTCLRN@nhs.net
   When submitting documents for all other studies please use the email address rdamend@nuh.nhs.uk

3. Ensuring all study personnel, not employed by the Nottingham University Hospitals NHS Trust hold either honorary contracts/letters of access with this Trust, before they have access to any patients or staff, their data, tissue or organs or any NUH facilities.

4. In accordance with the Department of Health's Plan for Growth, for initialising and delivering research within the NHS the 'first patient, first visit should occur 70 days from receipt of a valid submission in R&I. Therefore for all research where:

   - The sponsor is a commercial partner
   - NUH holds a funding contract with the National Institute for Health Research (NIHR)
   - The research is classed as a "clinical trial "on the IRAS filter page.

The research team is expected to collaborate with the department of R&I in reporting recruitment data to

rdmon@nuh.nhs.uk.

5. For GTAC-approved studies, the NHS permission should be forwarded to GTAC via the sponsor. GTAC should then issue a site authorisation letter which must be received by each site prior to recruitment commencing. A copy of this letter must be forwarded to R&I.
6. Comply with requests from NUH R&I to allow monitoring of research to comply with the Research Governance framework.
7. Record *all* types of adverse events (including Suspected Unexpected Serious Adverse Drug Reaction - SUSARS) in the patient medical records and study documentation and report to the sponsor as required by the protocol. Further guidance can be found in R&I SOP 11 - "Adverse Event Monitoring, Recording and Reporting for investigators".
8. Report any Serious Breach of the UK Clinical Trial regulations in connection with the trial or Serious Breach of the protocol, immediately after becoming aware of the breach to the study sponsor.

For NUH sponsored studies only, the Chief Investigator is responsible for:

i. All duties as detailed in the "Clinical Trial Delegation of Sponsorship responsibilities to Chief Investigator" agreement.
ii. Contacting the sponsor for review of all amendment documentation prior to submission to NRES and MHRA. Please note that according to NRES and MHRA regulations, all submissions of amendments need to be signed by the authorised sponsor's representative. All relevant documentation should be emailed to **rdappl@nuh.nhs.**
iii. Send copies of the completed Annual Safety, Progress reports and End of Study reports required by the Ethics Committee and the MHRA (if appropriate) to the Quality Assurance manager at NUH R&I.
iv. Notify NUH R&I of all SAEs by completing and sending the *"Serious Adverse Event reporting form"* to R&I **(only via fax, e-mail or by hand)**, within 24hrs of becoming aware of the event. If the event is defined as a SUSAR then a follow up report must also be submitted to R&I, via the above channels-**no longer than 7 days after the original report was submitted**
v. Reporting any Serious Breach of the UK Clinical Trial regulations in connection with the trial or Serious Breach of the protocol, immediately after becoming aware of the breach to NUH R&I as sponsor. Further guidance can be found in R&I SOP 12 "Protocol Violation and Serious Breach Reporting"

This approval letter constitutes a favourable Site Specific Assessment (SSA) for this site.

Please note that the R&I department maintains a database containing study related information, and personal information about individual investigators e.g. name, address, contact details etc. This information will be managed according to the principles established in the Data Protection Act.

Nottingham University Hospitals NHS
NHS Trust

Yours sincerely,

Dr Brian Thomson / Dr Maria Koufali
Director of Research and Innovation / Deputy Director Research and Innovation

cc Nottingham Research Ethics Committee

We are here for you

Institute of Work, Health & Organisations
http://www.nottingham.ac.uk/iwho

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Nadina Lincoln

Faculty of Medicine & Health Sciences
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The University of Nottingham
International House
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NG8 1BB
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f: +44 (0)115 846 6625

19/09/2012

Dear Nadina

I-WHO Ethics Committee Review

Thank you for submitting your proposal on "Comparing individual vs. group psychological adjustment interventions for people with multiple sclerosis: A pilot randomised controlled trial". This proposal has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

I am happy to tell you that the Committee has found no problems with your proposal. If there are any significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

You should also take note of issues relating to safety. Some information can be found in the Safety Office pages of the University web site. Particularly relevant may be:

The *Safety Handbook*, which deal with working away from the University.
http://www.nottingham.ac.uk/safety/
Safety circulars: Fieldwork P5/99A on http://www.nottingham.ac.uk/safety/fieldwork.htm
Overseas travel/work P4/97A on http://www.nottingham.ac.uk/safety/overseas.htm
Risk assessment on http://www.nottingham.ac.uk/safety/risk-assessment.htm

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

We would remind all researchers of their responsibilities:

- to provide feedback to participants and participant organisations whenever appropriate, and
- to publish research for which ethical approval is given in appropriate academic and professional journals.

Yours sincerely

IWHO Ethics Committee

Institute of Work, Health & Organisations
http://www.nottingham.ac.uk/iwho

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Nadina Lincoln
Eirini Kontou

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14/03/2013

Dear Nadina and Eirini

I-WHO Ethics Committee Review

Thank you for submitting your amendment to your study entitled "Comparing individual vs. group psychological adjustment interventions for people with multiple sclerosis: A pilot randomised controlled trial". This amendment has now been reviewed by I-WHO's Ethics Committee to the extent that it is described in your submission.

The Committee has accepted your proposed changes. If there are any further significant changes or developments in the methods, treatment of data or debriefing of participants, then you are obliged to seek further ethical approval for these changes.

We would remind all researchers of their ethical responsibilities to research participants. The Codes of Practice setting out these responsibilities have been published by the British Psychological Society. If you have any concerns whatsoever during the conduct of your research then you should consult those Codes of Practice and contact the Ethics Committee.

Responsibility for compliance with the University Data Protection Policy and Guidance lies with all researchers.

Ethics Committee approval does not alter, replace or remove those responsibilities, nor does it certify that they have been met.

Yours sincerely

Professor Nadina Lincoln
Chair IWHO Ethics Committee

Appendix 7. Interview Topic Guide

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**