THE UNIVERSITY OF HULL

The association between cognition, social functioning, physical

impairment, and relationship factors in individuals with multiple

sclerosis

being a Thesis submitted for the Degree of
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A: Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical report and appendices including a reflective statement.

Part one is a systematic literature review examining the different factors within a couples' relationship which may impact on the psychological and physical functioning of the individual diagnosed with multiple sclerosis (MS). A systematic search of five databases identified 11 papers meeting the inclusion and exclusion criteria. The findings are reported as well as a discussion of the clinical implications, quality assessments and limitations of the papers reviewed.

Additional factors, other than aspects of the patient's relationships, may also impact on the patient's well-being. In line with the biopsychosocial model, biological changes caused by the MS, such as cognitive deficits, may also influence the patient's well-being, specifically their ability to function socially.

Part two is an empirical paper, which investigates the impact of cognitive deficits on the individual with MS. More specifically the impact of memory and information processing deficits on social functioning are explored, when controlling for mood and physical disability. The study also investigated the relationship between memory and IPS using the BMIPB. Participants completed a number of questionnaires assessing their social functioning and completed the BMIPB. The results from these assessments are discussed alongside the clinical implications for the findings and areas for future research.

Part three comprises the appendices, which provide further information regarding the systematic literature review, empirical paper and also includes a reflective statement.

B: Table of Contents

C: List of Tables

D: Table of Figures

PART 1: Systematic Literature Review

This paper is written in the format ready for submission to the journal Clinical Psychology Review. Please see Appendix 2.1 for the "Guidelines for Authors".

Word count: 12,910 (excluding tables and references)

Relationship factors that impact individuals with multiple sclerosis: A systematic review

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Abstract

A vast amount of previous research has investigated, due to the severity and widespread impact of multiple sclerosis (MS), how this disease could hypothetically impact on a couple's relationship. More recently research has focused on this being a bidirectional association, in that aspects within the couple's relationship could have a detrimental effect on the patient's well-being. This systematic review aimed to identify and collate the factors within a couple's relationship which may impact on the physical and psychological well-being of the partner diagnosed with MS. A systematic search of five databases identified 11 papers meeting the inclusion and exclusion criteria. The findings highlight the importance of taking a biopsychosocial approach when assessing and working with MS patients. It may be beneficial to offer partners additional support or to involve them in the patient's therapeutic input, e.g. couple therapy. The review highlighted that more longitudinal and qualitative studies are required, in addition to emphasising the need for intervention studies to clarify the direction of the association between relationship factors and patient well-being. The review summarises the aspects within a couple's relationship which may impact on the patient, as well discussing the clinical implications, quality assessments and limitations of the papers reviewed.

Keywords: multiple sclerosis, couple, partner, functioning, relationship factors

Introduction

Multiple Sclerosis (MS) is disease of the central nervous system which affects the individual's brain and spinal cord. It is characterised by unpredictable and fluctuating symptoms including difficulty walking, visual impairments, fatigue, cognitive impairments, sensory disturbance, pain, limb weakness, and problems balancing (NICE, 2004). MS patients frequently experience social and financial strain subsequent to their diagnosis as their MS symptoms often affect their ability to work or socialise (Rao et al., 1991; Higginson, Arnett & Voss; 2000). Consequently the individual often becomes more dependent on the support of significant others. It has been reported that 60% of this support is provided by the individual's husband or wife (Carton, Loos, Pacolet, Versieck & Vlietinck, 2000).

It has been well documented that an individual's health difficulties can impact on their social and intimate relationships, yet this is a reciprocal relationship as social relationships have also been found to impact on an individual's health (Kiecolt-Glaser & Newton, 2001). A vast amount of previous research has investigated, due to the severity and widespread impact of the individual's MS symptoms, how this chronic disease could hypothetically impact on the couple's relationship (O'Conner, McCabe & Firth, 2008). However, a wave of research has developed which has investigated the notion that this association could be bidirectional, in that aspects within the couple's relationship could have a detrimental effect on the MS patient's physical and psychological well-being. It is important to investigate this interaction between aspects of a couple's relationship and patient functioning as it has implications for treatment plans for both patients and caregivers. There are now numerous studies exploring the various different aspects of the couple relationship in the MS population. Therefore this

review aims to explore and summarise which various factors within a couple's relationship may impact on the individual with MS, in addition to highlighting the common limitations and methodological issues in the research found. It is beyond the scope of the review to determine the causation of these associations.

The couple relationship is especially influential on the patient's well-being as it is the 'most important social context within which the psychological aspects of the chronic illness are managed' (Rodgers and Calder, 1990, p.25). When a significant other is diagnosed with an illness it disrupts the family dynamic, more specifically it may provoke an adjustment of the couple's roles within the family and could highlight their ability to cope as a unit in the face of adversity (Revenson, 1994). The effectiveness of the couple's ability to cope and the strengths of their relationship may then determine how well the patient functions, both physically and psychologically. The biopsychosocial model (Engel, 1977) encapsulates these complex interactions as it takes into account how the patient, the illness and wider systems such as the patient's relationships are interconnected. Subsequently the following section will briefly highlight some of the associations found between couple relationships, physical health and psychological functioning in studies of patients experiencing a range of health difficulties.

The Impact of Relationships on Physical and Psychological Functioning

The impact of social relationships have been found to be just as influential on a person's health when compared to other risk factors such as blood pressure, smoking and obesity (Campbell, 2003). Merely being in a supportive relationship has been associated to better health outcomes (Umberson & Williams, 1993), positive adjustment to chronic illness (Cutrona, 1996) and general well-being (Burman & Margolin, 1992).

Regrettably, not all individuals who are in a relationship are supported and unfortunately certain factors within these relationships may yield detrimental effects on the patient. Coyne and Bolger (1990) found that negative aspects of the relationship were believed to be more important than the beneficial effects of a supportive relationship on the impact to the patient's health. Additionally a previous review looked at 64 studies and concluded that physical health is indirectly impacted by the marital relationship (Kiecolt-Glaser & Newton, 2001). They indicated that there are numerous variables within the relationship that may moderate the impact of marital processes on the biological system, such as coping congruency and gender trait differences.

Additionally, it has been reported that married individuals engage in more positive health behaviours and have better physical and mental health than those who are single (Kiecolt-Glaser & Newton, 2001). Furthermore, poorer physical and mental health has been related to individuals who have divorced (Umberson & Williams, 1993). High marital satisfaction has also been shown to influence survival rates after heart failure (Coyne et al., 2001) and kidney disease (Kimmell et al., 2000). Lastly, Mancini and Bonanno (2006) found a link between physical health difficulties, relationships and psychological functioning. They found that marital closeness lessened the possibility of psychological distress, including depression, anxiety, lacking self-esteem, when suffering from high levels of physical disability.

Psychological difficulties such as depression, acceptance of the illness and level of adjustment may also impact on the biological and emotional well-being of the patient. It has been demonstrated in previous studies that depression can alter a person's cardiovascular, immune and endocrine functioning (Simonsick, Wallace, Blazer & Berkman, 1995; Glassman & Shapiro, 1998). Furthermore higher acceptance of

physical disability has been related to improved metabolic control and better coping strategies (Richardson, Adner & Nordstrom, 2001). A patient's level of acceptance has also been shown to be influenced by their partner's feedback about their illness and appearance. This then impacts on how the patient perceives their disability, as negative perceptions (either increased or decreased by their partner's perception) have been shown to lead to lower levels of acceptance (Taleporos & McCabe, 2002). Acceptance is a key feature of a person's adjustment to their health difficulty and together can influence how engaged they are with their therapy/treatment and thus may affect the outcome of their health problem (Keogh & Feehally, 1999; Telford, Kralik & Koch, 2006). Hence psychological functioning may be influenced by marital relationships which in turn could impact on the biological functioning of the patient.

Therefore, previous research using participants from the general population and other health groups highlights the interconnection between physical, psychological and social factors which may influence how an individual's illness impacts their psychological and physical well-being.

Specific to Individuals with MS

Individuals with MS often face losing their physical independence and ability to complete daily activities, as a consequence their social interactions become restricted and they depend more on their significant others (Carton et al., 2000). The severity and unpredictable nature of MS presents a number of considerable challenges to the patient. They are confronted with dealing with feelings such as vulnerability, loss, inequality, and in some cases shame (Rolland, 1994; Grytten & Maseide, 2006). Therefore support from their partner may be of paramount importance when considering the patient's psychological well-being.

As evidenced in previous research with patients diagnosed with different health conditions the support or lack of support from a relationship may not only affect an individual's psychological adjustment but it could also impact on their physical symptoms and recovery (Umberson & Williams., 1993; Coyne et al., 2001). Hence in patients with MS it is possible that relationship factors may impact on periods of disease activity or physical symptoms in addition to their psychological functioning. However, it could be argued that the partner is equally affected by the illness as they adopt the role of caregiver to their spouse which may be burdensome for the partners. Therefore both members of the relationship may become interdependent on one another for support and the effectiveness of this relationship/support may impact on both partners' adjustment to the illness. Hence as the biopsychosocial model suggests, social relationships may be interconnected to the physical and psychological functioning, specifically in MS patients and their partners.

Previous research in the general population and other health groups highlight the numerous aspects within a couple's relationship which may also affect the individual with MS. For example, coping styles employed by the partner and patient have been found to influence and shape each other's adjustment (Coyne & Smith, 1991). In addition to coping styles, the partner's acceptance and perception of the MS may also influence the patient's level of adjustment (Taleporos & McCabe, 2002). Negative interactions between the partner and patient could be a source of stress in itself as the patient, already dealing with a number of emotional challenges, may have few psychological resources available to manage such interactions..

Illness representations (Leventhal et al., 1997) have also been found to affect the patient's adaptation to the illness in a wide range of conditions (Orbell & Hagger,

2003). It is hoped that by processing information about their illness and developing a range of cognitive representations, that patients can make sense of their symptoms and develop effective coping strategies. Positive interpretation and seeking emotional support has been related to positive psychological outcomes (Moss-Morris, Petrie, & Weinman, 1996). However, it is not solely the patient's illness representations that may influence how they cope with their illness. It has been found in patients suffering from psoriasis that if patient and partner illness representations are dissimilar then this can lead to increased psychological distress for both (Richards et al., 2004). Illness representations, alongside perceived stress and emotion focused coping, have been shown to be important to the level of adjustment attained in MS patients (Dennison, Moss-Morris & Chalder, 2009). Therefore, illness representations may be another factor in the couple's relationship that could impact on the patient's level of adjustment.

Research has also shown that when faced with adversity such as a chronic illness some patients develop positive changes to the self and their philosophy of life; this has been termed as posttraumatic or adversarial growth (Tedeschi & Calhoun, 2004). Adversarial growth has been shown to occur and to be adaptive in MS patients; this in turn has been associated to effective coping strategies and positive adjustment (Mohr et al., 1999). However, the factors that influence the development of such an outlook on their illness are not well documented. Investigating factors, such as whether partner adversarial growth impacts the level of growth in the patients, are important as it could influence the patient's level of adjustment to their illness.

In summary, studies have found an association between relationship factors and the physical and psychological functioning in a wide range of health patients. In addition to this research, a number of different factors in a couple's relationship may impact on the

well-being of an individual with MS. It is important to examine these factors within the relationship as they ultimately offer guidance on which systemic factors should be considered during assessment and influence the appropriateness of interventions and for both the patient and their partner. Therefore it is of paramount importance to MS patients that aspects of the couple relationship are investigated. Possible aspects of the couple's relationship which may impact on the functioning and patient's well-being will be discussed in this review.

The rationale for the current review was based upon the conclusions of previous studies suggesting that aspects of the couple's relationship may impact on the patient. There are a number of individual studies that have investigated these specific factors in MS patients, and which consequently may influence the type of clinical interventions offered. Additionally there is a lack of any systematic review which collates and critiques the numerous different studies investigating the impact of factors within a couple's relationship. Therefore the objective of the current review was to undertake a systematic literature review of published research which specifically investigates the different aspects of the couple's relationship which may impact on the physical and psychological well-being of the partner diagnosed with MS. The research questions addressed in this review were;

1) Which aspects within a couple's relationship impact on the patient's psychological and physical functioning?

2) What are the clinical implications of these findings?

3) What are the common limitations and methodological issues of the research in this area?

Method

Search Strategy

An electronic search was carried out up to and including January 2012. Various databases which covered a range of disciplines that may conduct research on MS and relationships were searched for relevant articles. These included; PsycInfo (via Ebsco), Medline, Scopus, Cochrane Library and Web of Science. There was no start date cut-off employed in the search. A search for previous literature reviews in this area was conducted and none were identified.

In order to assess how much research in this area was available two initial terms were entered into the databases; multiple sclerosis AND relationship*. Further search terms were then selected by using the most common keywords from relevant articles. The final sets of search terms used were as follows; adjust* OR support* OR perceived support OR depression OR mental state OR anxi* OR emoi* OR stress OR satisfaction OR relationship quality AND relationship OR marital OR marriage OR spouse* OR partner* OR wife OR husband OR coupl* OR kin AND multiple sclerosis. Articles that featured these terms either in their title, abstract, subject or keywords were then identified. When it was unclear from the abstract whether the study would meet the selection criteria the full copy of the article was obtained so it could be fully reviewed against the inclusion/exclusion criteria. Also, search limits were applied (dependent on the database) when possible. These meant that studies were only included which were; from peer reviewed journals, in the English language, were not drug trials, and used human participants. In addition to the systematic search for research, reference lists were also hand searched from the relevant papers found via the electronic databases. This was to ensure that research which was not available in an electronic form or hadn't

been found otherwise was also reviewed, however only one research paper was found this way; Lehman and Hemphill (1990).

Study Selection Criteria

Studies were screened against a selection criterion which was developed and refined when reading abstracts from the initial searches. The rationale for the inclusion and exclusion criteria can be found in Appendix 4.1. Studies were only included in the review if the met all the inclusion and exclusion criteria.

Inclusion Criteria

- Participants must have a clinically definite diagnosis of MS as determined by the McDonald criteria (McDonald, Compston, & Edan, 2001) in either primary progressive, secondary progressive or relapsing-remitting MS.

- Studies were included if the majority of the sample were married or in a couple relationship.

- Participants must not have any other neurological disease or health difficulty other than MS.

- Studies published in peer-reviewed journals.

- Studies published in the English language.

Exclusion Criteria

- Studies that aimed to investigate the impact of MS on the caregiver or relationship, as opposed to the impact of relationship factors on the individual with MS or their partner.

- Studies that only focused on the well-being outcomes for the partner and not MS patient.

- Studies that did not include the relationship type of MS patient to significant other.

- Studies investigating the sexual relationship in MS.

- Studies investigating prevalence of marital relationships in MS patients.

- Studies investigating the reliability or validity of a new measure/questionnaire.

- Studies not involving human subjects.

- Studies investigating the effects of drug therapy in patients with MS.

- Case reports.

- Systematic literature reviews.

- Unpublished studies.

Data Extraction

Information was extracted from studies using a data extraction form which was specifically designed for recording data for this review (Appendix 4.2).

Data Synthesis

The studies reviewed used numerous different outcome measures and employed a diverse range of methodologies. For this reason statistical methods of data synthesis were not appropriate. Therefore subsequent to data being extracted it was collated and reported qualitatively within the review. The findings of the review are described using a narrative approach including a critical analysis of the studies included.

Study Quality Assessment

All articles included in the review underwent a quality assessment. The methodological quality of the articles was assessed using a checklist which consisted of questions which were adapted from three valid and reliable checklists (Downs & Black, 1998; STROBE, 2007; NICE, 2007). The quality of the studies used in this review could not be appropriately assessed by just one of these checklists due to the varying methodologies. Therefore the researcher developed a quality checklist using the most appropriate and relevant questions from the three checklists. The adapted checklist can be seen in Appendix 4.3 and the source of each item on the checklist can be found in Appendix 4.4. The adapted checklist consisted of 28 items which were considered relevant for assessing the quality of quantitative studies and qualitative studies used in this review. A point scoring system was employed to enable comparisons across both quantitative and qualitative studies, where a score of 20 was awarded to a study meeting all 20 criteria of the methodological quality checklist. No studies were excluded from the review due to low quality scores. To ensure reliability of the ratings an independent rater also assessed all 11 studies used in the review. The ratings and percentage of agreement between ratings can be found in Appendix 4.5. Overall, most items when rated produced a percentage agreement of between 81.8% and 100% which indicates a good level of reliability. Furthermore, inter-rater reliability was assessed using a Pearson correlation which also suggests a high level of reliability ($r(9) = .883$, p < .001).

Results

Details of Included and Excluded Studies

Figure 1 highlights the study selection methodology used in the current review. Using the search strategy a total of 3529 studies was produced. The article titles and abstracts were then searched for relevance and limits were applied, when possible, which included articles from peer reviewed journals, in the English language, were not drug trials, and used human participants. This left a total of 94 articles. Duplicate articles were removed leaving 69. The abstracts and titles of the remaining 69 articles were searched against the inclusion and exclusion criteria. A total of 55 articles were subsequently removed. The remaining 14 articles were obtained and full articles read.

The 4 articles excluded and the reasons for the removal of these articles can be found in Appendix 4.6. Pozzilli et al.'s (2004) study recruited a mixed sample of partners and other caregivers such as parents. After careful consideration it was decided that this study should be included in the review as the study implemented a longitudinal design and investigated the impact of caregiver depression on the patient, additionally the majority of the sample, 54%, was comprised of partners. This was considered a large enough proportion of the sample which would help clarify additional relationship factors, such as caregiver depression, which could influence the patient's well-being.

One article (Lehman & Hemphill, 1990) was selected from manual reference searches. Therefore a total of 11 articles were included in this review, a summary of these studies can be found in Table 1.

Figure 1. Flow chart demonstrating an overview of systematic review process.
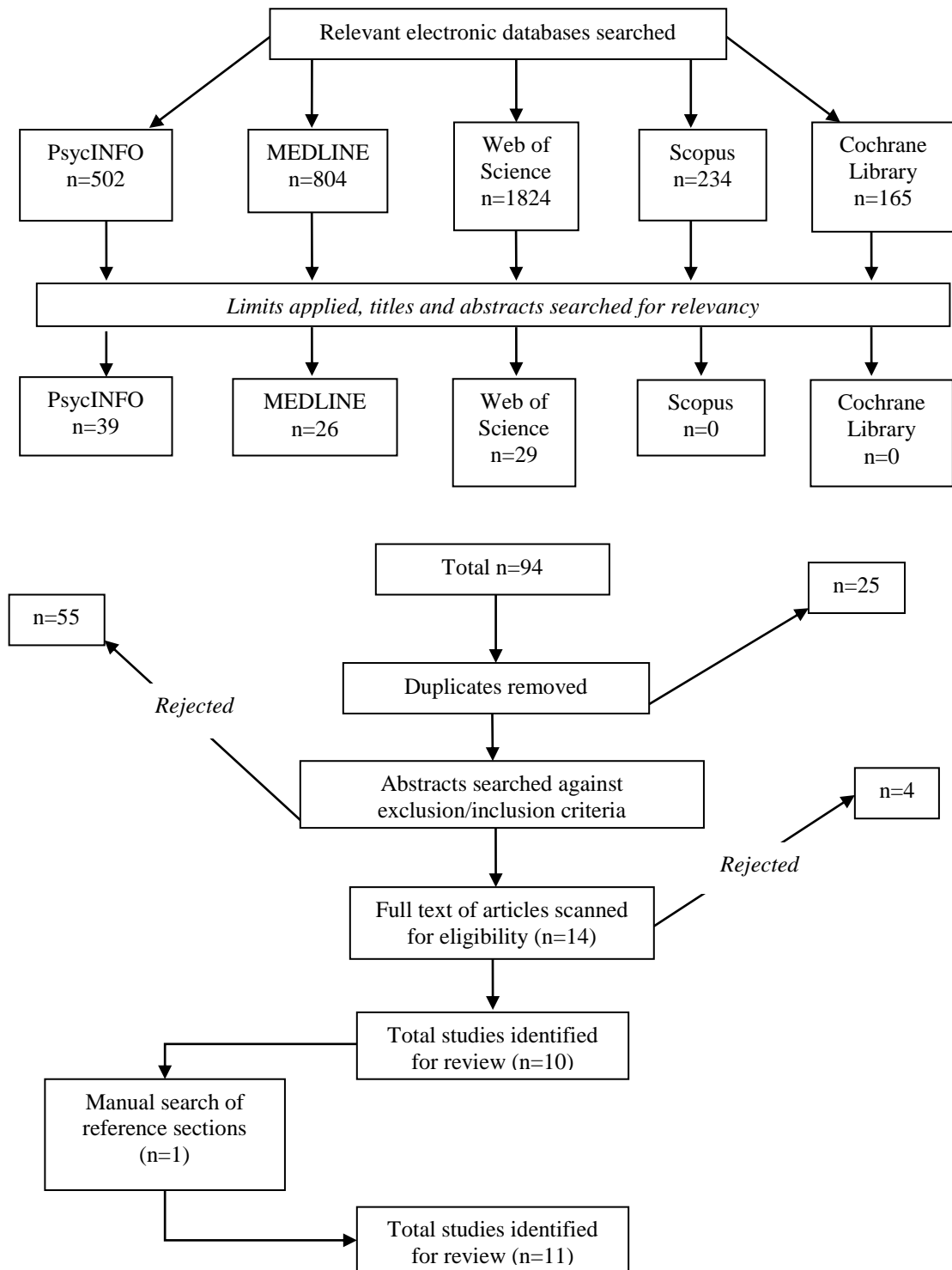
Table 1. Overview of Included Studies.

Study	Aim	Design	Participants		Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures			
Woollett & Edelmann (1988)	To investigate the relationship between marital satisfaction, disability, social support and life satisfaction.	Cross-sectional Questionnaire 20 dyads Marital satisfaction, disability, social support and life satisfaction	g: NR (NR), r.d: $\bar{X}$=24 years r.t: all married	g: 30 male, 42 female ($\bar{X}$=47.5), d.t: 48%=SP, 52%=RR d.d: 10.3 years ISS: $\bar{X}$=23 (SD, 12.3 (0-64 higher scores=more disability)	• LSI (MS P) • ISS (MS P)	• GRIMS (couple) • SNL (couple)	Yes	• No relationship was found between disability, life satisfaction and marital satisfaction • Partners were found to be less martially satisfied than MS partner. • As life satisfaction and social network density increased, marital satisfaction also increased. • GRIMS score was lower for partner but did not reach 'dissatisfied' cut off.	14
Kleiboer, Kuijer, Hox, Jongen, Frequin, & Bensing (2007)	To investigate the impact of negative responses received from partner on end-of-day mood for both MS patient and their partner.	Diary method over 14 days 61 dyads Negative responses, end-of-day mood, and buffered emotional support.	g: 14% female ($\bar{X}$=49.3), r.d: $\bar{X}$=22.6 years r.t: 'couples cohabiting'	g: 87% female ($\bar{X}$=46.8), d.t: RR=57%, SP+PP=43% d.d: 8.3 years EDSS self-report: $\bar{X}$=14 (0-64 higher scores=more disability)	• End of day mood: PANAS (couple) • Kurtzke (1981) self-report scale (MS P) • MS Symptoms experienced 10-point scale (MS P)	• Negative response 4-point scale (couple) • Emotional support 4-point scale (couple) • Daily Hassles 22 item scale (couple)	Yes	• Supported domain specific model • Patients and partners who reported receiving negative responses had higher end-of-day negative mood but was not related to end-of-day positive mood. • The adverse effect of received negative responses on end of day mood was moderated by receiving emotional support on the same day for both patients and partners.	18

Study	Aim	Design	Participants		Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures			
Kleiboer, Kuijer, Hox, Schreurs & Bensing (2006)	To examine the relationship between reciprocity of provision and receipt of emotional and instrumental support, daily mood, and self-esteem among patients and partners.	Diary method over 14 days 61 dyads Provided and received support, instrumental and emotional support, reciprocity of support, disability, self-esteem and end-of-day mood.	g: NR ($\bar{X}$=49), r.d: $\bar{X}$=23 r.t: 92% married, 8% cohabiting 77% had children	g: 87% female ($\bar{X}$=47), d.t: RR=57%, SP+PP=43% d.d: 8 years EDSS: NR	• End of day mood: PANAS (couple) • Self-esteem 7-point scale (1 item) (couple) • MS Symptoms experienced 10-point scale (MS P)	• Scale for emotional (3 items) and instrumental (1 item) support received and provided each day (couple) • Daily Hassles 22 item scale (couple)	Yes	• When instrumental support was reciprocated self-esteem significantly increased for both patients and partners. • No other significant relationships were found between reciprocation of received and provided support in dyads. • Patients' end of day mood was related to providing emotional and instrumental support, whereas partners' end of day mood was related to receiving emotional support from patients.	19
Pakenham (1998)	To examine the relationship between coping congruency, average level of coping, adjustment and psychological distress in patients and partners	Longitudinal: T1 and T2 (12 months) Questionnaire 45 dyads Coping congruency, average level of coping, coping style, adjustment and psychological well-being.	g: 29 male, 16 female ($\bar{X}$=50.55), r.d: $\bar{X}$=24 r.t: 82% married, 7% immediate family member, 11% close friend	g: 12 male, 33 female ($\bar{X}$=50.04), d.t: 50%=PP+SP, 50%=RR d.d: 7.64 years EDSS: $\bar{X}$=5.36 (SD, 1.99, 0-10 higher scores=more disability)	• BSI (couple) • BDI (couple) • EDSS (MS P)	• CRA (partner) • PAIS-SR (MS P) • WCC (couple)	Yes	• Coping congruence and average level of coping are related to collective and individual adjustment. • No support that similarity in (avoidant) emotional coping style is more adaptive. Found higher emotional coping scores were related to greater collective distress and poorer adjustment scores. • Greater differences in problem-solving coping style between partners was related to lower levels of collective depression and better adjustment at individual level. Therefore dissimilar problem-solving coping style is more adaptive.	17

Study	Aim	Design	Participants			Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures				
Ackroyd, Fortune, Price, Howell, Sharrack, & Isaac (2011)	To investigate factors that inhibit or increase the possibility of adversarial growth in patients and partners.	Cross-sectional Questionnaire 72 dyads Distress, adversarial growth, illness representation, and disability.	g: 44 male, 28 female ($\bar{X}$=48.6), r.d: NR r.t: 93% married	g: 30 male, 42 female ($\bar{X}$=47.5), d.t: 48%=SP, 52%=RR d.d: 10.3 years EDSS: $\bar{X}$=5.17 (SD, 1.55)	• CMDI (couple) • EDSS-S (MS P) • MASQ (couple)	• PTGI (couple) • IPQ-R (couple)	Yes	• Patients and partners showed adversarial growth, patients had significantly higher adversarial growth scores than partners. • Partner growth significantly predicted patient adversarial growth, and vice versa. • Dissimilar scores between patients and partners on illness representations – consequences of MS subtest, patient mood, and patient growth, significantly predicted partner growth. • No significant relationship between distress and adversarial growth. However, as patient distress increased, partner growth also increased. Furthermore, they found that greater impairment on patient illness representation and cognition was associated to greater partner growth. • 'Communal search for meaning' supported.	18
Wineman, O'Brien, Nealon, & Kaskel (1993)	Investigated if the degree of congruence in illness uncertainty explained mood and family satisfaction of patient and partner.	Cross-sectional Questionnaire 61 dyads Congruence in illness uncertainty, marital satisfaction, and psychological functioning.	g: 27 male, 34 female; ($\bar{X}$=55), r.d: $\bar{X}$=30 years r.t: all spouses	g: 27 male, 34 female ($\bar{X}$=54), d.t: 18%=SP, 45.9%=PP, 1.6%=RR, 34.4%=unknown; d.d: 17.3 years ISS: $\bar{X}$=NR	• POMS (couple) • ISS (MS P)	• MUIS (couple) • Family Satisfaction Scale (couple)	Yes	• Individual and congruent perceived uncertainty between spouses had negative effects on marital partners. • For both, those who reported higher levels of uncertainty were more likely to have lower moods and feel dissatisfied with family life. • Main predictor of patients' family satisfaction was their own perception of illness uncertainty. For partners' family satisfaction was predicted most by congruence between each partner's perception of illness uncertainty.	15

Study	Aim	Design	Participants		Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures			
McPheters & Sandberg (2010)	To investigate the relationship between couple relationship, depression, and physical functioning of the patient with MS.	Cross-sectional Questionnaire 54 dyads Relationship quality, physical functioning and depression.	g: 80% male ($\bar{X}$=54), r.d: $\bar{X}$=28.7 years r.t: 94% married	g: 80% female ($\bar{X}$=53), d.t: 22%=SP, 11%=PP, 56%=RR d.d: 18 years ADL-MS: $\bar{X}$=50.02 (SD, 16.50, 0-70, higher scores=better physical functioning)	• CES-D (couple) • ADL-MS (couple)	• DAS (couple)	Yes	• Couple relationship quality positively correlated to MS patient physical functioning and depression negatively related to MS patient physical functioning. • MS patient and partner couple relationship quality negatively correlated to depression scores in partners. • MS patient couple relationship quality negatively correlated to MS patient depression scores, partner relationship quality was not significantly related. • Depression and relationship quality were associated with MS physical functioning. • Couples with higher relationship quality better able to cope with stresses of MS?	17
Pozzilli, Palmisano, Mainero, Tomassini, Marinelli, Ristori, Gasperini, Fabiani, & Battaglia (2004)	To investigate the relationship between caregiver depression and health status of MS patient.	Cross-sectional and longitudinal: Baseline and one year follow-up Questionnaire 133 dyads Emotional distress in partner, and physical health status of MS P.	g: 67% female ($\bar{X}$=53), r.d: NR r.t: 54% married, 21% parents, 11% children, 5% sibling, 9% friends	g: 30 male, 42 female ($\bar{X}$=47.5), d.t: 27=PP, 80=SP, 26=RR d.d: 58 = 20+ years, EDSS: $\bar{X}$=6 (4-7)	• POMS (partner) • STAI (MS P) • CDQ (MS P) • MMSE (MS P) • FIM (MS P) • FSS (MS P) • SF-36 (MS P) • EDSS (MS P)		Yes (one)	• Depression in caregivers was related to physical, emotional and health status of the patients at baseline and 12-month follow-up. • Changes in caregiver depression scores were associated with changes in disability and health status of patients. • Depression in carers associated to longer disease and increased severity of MS symptoms.	18

Study	Aim	Design	Participants		Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures			
Schwartz & Kraft (1999)	Investigated the impact of spouse responses, patient disability, and family environment predicted psychological functioning in patient with MS.	Cross-sectional Questionnaire 44 dyads Family environment, spouse responses, disability, relationship quality, emotional distress.	g: 70% male, ($\bar{X}$=NR), r.d: NR r.t: married or partner	g: 70% female ($\bar{X}$=44), d.t: 48%=SP, 52%=RR d.d: 9.33 years EDSS: $\bar{X}$=5.6 (SD, 1.63)	• CES-D (MS P) • SIP (MS P) • SF-36 (MS P) • EDSS (MS P)	• FES (MS P) • DAS (MS P) • SRI (MS P) • SPS (MS P)	No	• Solicitous spouse responses to patient disability were related to greater MS physical disability. • Relationship was stronger for those who were depressed. • Spouse negative responses to physical disability were associated to poorer mental health, whereas spouses who encouraged patient well behaviours were associated with lower emotional distress. • Poor psychological functioning was found in higher conflict and/or controlling family environments. • Higher levels of independence in families were associated with better patient psychological and physical functioning.	15
Harrison, Stuifbergen, Adachi & Becker (2004)	To investigate the relationship between marital status, marital concern, perceived impairment, health-promoting behaviours and acceptance of disability in MS patients.	Cross-sectional and longitudinal: 5 time points over 6 year period 454 MS P Gender, marital status and change, acceptance of disability, and perceived level of impairment.	g: NR r.d: NR r.t: NR	g: majority female ($\bar{X}$=48.5), d.t: NR d.d: NR ISS: NR 66% women, 72% men married consistently, 34% women, 28% other marital status over 6 year period	• Acceptance of Illness Scale (MS P) • HPLP II (MS P) • ISS (MS P)	• Marital Concern Scale (MS P)	No	• For both men and women acceptance of disability and perceived impairment increased significantly over time. • Being consistently married is associated with higher level of acceptance of disability and less perceived impairment over time • Men gained mental and physical benefits from remaining married compared to men who weren't consistently married. • Acceptance increased over time for women but this was not related to marital status	16

Study	Aim	Design	Participants			Measures		Dyad data?	Findings	Quality Rating (0-20)
		Number of dyads/MS P, main variables investigated	Partner (gender, age relationship duration)	Person with MS (gender, age, type of MS, disease duration)	Psychological well-being, coping outcomes Physical disability measures	Relationship satisfaction/ adjustment /quality measures Social network measures				
Lehman & Hemphill (1990)	To explore support attempts from partners that MS patients found helpful and unhelpful.	Qualitative Cross-sectional Questionnaire 151 MS P Perception and attributions of support attempts from partner	g: NR r.d: NR r.t: NR	g: 75% female ($\bar{X}$=46), d.t: NR d.d: 6 years EDSS: mild to severe 70% married		3 open-ended qus: • Helpful • Unhelpful • Attribution of support attempts that failed (no analysis named, category codes for questions were analysed)		No	• Expressions of love, concern, and understanding were regarded as most helpful. • Most unhelpful were two categories: - Minimisation (challenging seriousness or existence of disease) - Maximisation (catastrophising or being overly protective) • Suggested that partners assess disease state based on physical appearance. • MS P made benign attributions to harsh and unsettling actions from partner. Possibly due to patients feeling vulnerable and so do not want to be rejected or loose partner by criticising their unhelpful support attempt.	**14**

Notes: Average age of participants in each group is reported in brackets. Measurement name is followed by who completed the measurement in brackets. $\bar{X}$ = average; d.t =disease type; RR = Relapsing-Remitting MS; PP = Primary Progressive MS; SP = Secondary Progressive MS; d.d = disease duration; r.t = relationship type; r.d = relationship duration; g = gender; NR = not reported in article; MS P = Person with MS completed measure.

LSI = Life Satisfaction Index B (Neugarten, Havinghurst & Tobin, 1961); SNL = Social Network List (Hirsch, 1980); ISS = Incapacity Status Scale (Kurtzke, 1955, 1984); GRIMS = Golombok Rush Inventory of Marital State (Rust, Bennun, Crowe & Golombok, 1986); PANAS = Positive and Negative Affect Schedule (Watson, Clark & Tellegen, 1988); WCC = Ways of Coping Checklist-Revised (Vitaliano, Russo, Carr, Maiuro & Becker, 1985); BSI = Brief Symptom Inventory (Derogatis & Spencer, 1982); BDI = Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961); CRA = Caregiver Reaction Assessment (Given et al., 1992); EDSS = Expanded Disability Status Scale (Kurtzke, 1983) PAIS-SR = Psychosocial Adjustment to Illness Scare-Self Report (Derogatis & Lopez, 1983); CMDI = Chicago Multi-Scale Depression Inventory (Nyenhuis et al., 1998); EDSS-S = Self-report Expanded Disability Status Scale (Bowen, Gibbons, Gianas & Kraft, 2001); MASQ = Multiple Ability Self Report Questionnaire (Seidenberg, Haltiner, Taylor, Hermann & Wyler, 1994); PTGI = Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996); IPQ-R = Illness Perception Questionnaire-Revised (Moss-Morris et al., 2002); POMS = Profile of Mood States (McNair, Lorr & Doppleman, 1981); MUIS = Mishel Uncertainty in Illness Scale (Mishel & Epstein, 1990); Family Satisfaction Scale (Olson et al.,1985); DAS = Dyadic Adjustment Scale (Spanier, 1976); CES-D = Center for Epidemiological Studies Depression Scale (Radloff, 1977); ADL-MS = Activities of Daily Living Self-Care for Persons with MS (Gulick, 1988); SF-36 = Short-form Health Survey (Ware & Sherbourne, 1992); MMSE = Mini Mental State Examination (Folstein, Folstein & McHugh, 1975); STAI = State-Trait Anxiety Inventory (Spielberger, Vagg & Barker, 1980); CDQ = Clinical Depression Questionnaire (Krugg, Scheier & Cattell, 1976); FIM = Functional Independence Measure (Kidd et al., 1995); FSS = Fatigue Severity Scale (Krupp, La Rocca, Muir-Nash & Steinberg, 1989); SIP = Sickness Impact Profile (Bergner, Bobbitt, Carter & Gilson, 1981); FES = Family Environment Scale (Moos & Moos, 1986); SRI = Spouse Response Inventory (Schwartz, Jensen & Romano, 1995); SPS = Social Provisions Scale (Cutrona & Russell, 1987); Acceptance of Illness Scale (Stuifbergen, Seraphine & Roberts, 2000); HPLP II = Health Promoting Lifestyle Profile II (Walker, Sechrist & Pender, 1995); Marital Concern Scale (Haberman, Woods & Packard, 1990).

Overview of Methodological Quality

The results of the quality assessment from both raters can be found in Appendix 4.5. The quality scores for studies ranged from 14 (Lehman & Hemphill, 1990; Woollett & Edelmann, 1988) to 19 (Kleiboer et al., 2006). Percentage agreement ranged from 81.8% to 100% between raters suggesting good reliability. The lowest agreement was on item 10 (81.8% agreement) which assessed whether the inclusion and exclusion criteria were stated in studies. The raters disagreed on the level of detail needed in the selection criteria which would indicate the criterion was 'clearly described'. Therefore item 10 could have been made clearer. The other items used either produced total agreement or a difference in one score.

Overall the studies reviewed had coherent background theory, good rationale and explicitly stated their research aims. The majority of the studies used reliable and valid measures and stated a detailed procedure. Sample sizes varied and the majority of participants were recruited from MS Society branches which may indicate a possible selection bias as a number of the studies stated their sample consisted of mainly well-adjusted couples. No studies commented on a power calculation however some studies did reflect on the limitations of their findings in relation to low power and small sample size. The majority of studies included a detailed account of their inclusion and exclusion criteria however some studies did not fully describe their participant selection criteria or characteristics of their sample. Consequently, it is difficult to fully compare these studies' findings to other studies; also the generalisability of their findings is questionable (Pozzilli et al., 2004; Harrison et al., 2004; Schwartz & Kraft, 1999; Lehman & Hemphill, 1990; Ackroyd et al; 2011). Only three studies (Harrison et al., 2004; Schwartz & Kraft, 1999; Lehman & Hemphill, 1990) did not include data from

both the MS patient and their partner therefore suggesting most studies took into account the partner's perspective making their findings more reliable and valid. Most studies outlined a clear and appropriate statistical analysis although exact *p* values were rarely reported. Studies tended to highlight the clinical implications of their findings in relation to previous studies and their own methodological limitations. The methodological quality will now be reviewed in more detail.

Study Design

Only one study used a qualitative design. When assessed this study gained a relatively low methodological quality score of 14, mainly due to the qualitative data analysis not being rigorous enough or based on a well-recognised qualitative analysis (Lehman & Hemphill, 1990). The rest of the 10 studies employed a quantitative design. Of these 10 studies 5 were cross-sectional studies using questionnaires or scales. Two studies (Kleiboer et al., 2006; 2007) used a diary method which required participants to record data every day for 14 days. The remaining 3 studies used a longitudinal design; two studies collected data at baseline and at one year follow-up (Pozzilli et al., 2004; Pakenham, 1998) and Harrison et al., (2004), collected data at five time points over a 6 year period. All studies collected data from both the MS patient and their partner with the exception of three studies (Lehman & Hemphill, 1990; Schwartz & Kraft, 1999; Harrison et al., 2004).

Participants

The sample sizes varied greatly between studies from 20 dyads (Woollett & Edelman, 1998) to 133 dyads (Pozzilli et al., 2004), or 454 MS patients (Harrison et al., 2004). Participant characteristics were similar across all studies. The majority of studies

recruited patients with a range of MS disease type although on the whole patients with relapsing-remitting MS made up most of the studies' samples with the exception of Wineman et al., (1993) who had a majority of primary-progressive MS patients and Pozzilli et al., (2004) whose sample mainly consisted of secondary progressive MS patients. The majority of participants were over the age of 40 years old and had been in their relationship for at least 20+ years. Additionally, the MS patients recruited in the studies reviewed had been diagnosed for at least 8-10 years and had low to moderate physical disability, with the exception of Lehman and Hemphill (1990) whose sample consisted of mild to severely disabled MS patients who had been diagnosed for on average 6 years. Therefore, on the whole the results from this review can be generalised to the different disease types in MS, however the studies lacked MS patients who were diagnosed for less than 10 years, younger, and had moderate to severe physical disabilities. Also MS patients who had been in a relationship for less than 20 years were not represented in the studies reviewed. Lastly, the majority of samples reviewed had a majority of female MS patients; however this is reflective of the MS population (Orton et al., 2006).

Measures Used

The studies reviewed assessed a number of different aspects of the couple relationship which may impact on the MS patient's physical and psychological functioning. These various aspects will be discussed in detail in the next section. Due to the wide range of aspects investigated the measures used in each study also varied. Some studies focused solely on the psychological impact on the MS patient and fewer studies investigated both the physical and psychological impact (Woollett & Edelmann, 1988; Pozzilli et al., 2004; McPheters & Sandberg, 2010; Schwartz & Kraft, 1999). The most commonly

used measures (used in two studies) included the Dyadic Adjustment Scale (DAS), Short-Form Health Survey (SF-36), Center for Epidemiological Studies Depression Scale (CES-D), Incapacity Status Scale (ISS) and Expanded Disability Status Scale (EDSS). The other measures used were specific to the aspect being investigated such as the Illness Perception Questionnaire–revised (IPQ-R) in Ackroyd et al., (2011), or used an alternative measure, such as the Golombok Rush Inventory of Marital State, as opposed to the DAS. All measures used had reportedly good reliability and validity and were well-known questionnaires with standardised instructions. However in the Kleiboer et al. studies (2006; 2007) they used scales and questionnaires which were developed by the study (e.g. emotional support and negative responses scales) and therefore the measures used are less reliable and valid.

Main Aspects of the Couple Relationship found in the Studies Reviewed

A number of similar aspects within the couples' relationship (e.g. type and level of support or coping congruency) were investigated in a number of studies. Therefore the review has collated the findings of studies into five different sections, dependent on the aspect of the couple relationship investigated. The various aspects and how they impact on the MS patient's psychological and physical functioning will be discussed and a critical analysis of the studies' methodologies will also be considered.

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Marital satisfaction/relationship quality

In line with the biopsychosocial model, a number of studies have specifically investigated the relationship between physical functioning, psychological distress and relationship satisfaction/quality in MS patients. McPheters and Sandberg (2010) found that couple relationship quality strongly related to MS patient physical functioning,

furthermore relationship quality scores negatively correlated to MS patient depression scores. The researchers suggest that relationship functioning and depression significantly predicted patient physical functioning, as increased conflict in a relationship may lead to greater depression in the patient which then impacts on their physical functioning. Although there was a strong association found between physical functioning and relationship quality it is not possible to ascertain a causal link due to their cross-sectional design (McPheters & Sandberg, 2010).

Previous research remains inconsistent when investigating the relationship between the biopsychosocial factors in MS. Pozzilli et al. (2004) support the findings from McPheters and Sandberg (2010) as they found that depression in caregivers was related to the physical, emotional and health status of patients, at baseline and a 12 month follow up. A change in caregiver depression was associated to changes in the patient's disabilities and overall health. Furthermore, greater depression in carers was associated to longer disease duration and increased severity of MS symptoms. These results strengthen the findings that there is a strong association between partner functioning and the patient's well-being, however again a causal link was not determined. In contrast to these findings Woollett and Edelmann (1988) found no relationship between physical disability, life satisfaction and marital satisfaction. However, this study did not take into consideration caregiver or patient depression and had the smallest sample of 20 dyads compared to 54 dyads (McPheters & Sandberg, 2010) and 133 dyads (Pozzilli et al., 2004). Also, the measures used in Woollett and Edelmann's (1988) study were not as up-to-date or widely used as the measures used in the other two studies, e.g. ADL-MS and EDSS. Additionally, Woollett and Edelmann (1988) obtained 14 on the quality assessment compared to 17 (McPheters and Sandberg, 2010) and 18 (Pozzilli et al., 2004). Woollett and Edelmann scored lower due to their statistical analysis and

selection criteria not being as clearly stated and when interpreting their results they did not consider confounding variables, such as depression, or the limitations of the study.

Despite the casual link not being determined an association between relationship quality, patient depression and physical functioning was found and is supported by Pozzilli et al.'s (2004) findings. It therefore seems sensible that clinicians should involve partners in therapy to facilitate improved communication around difficult topics such as the patient's' physical disabilities and how their relationship may be impacting on their day-to-day physical and psychological functioning. The clinician should focus on the positive aspects of the couple; their strengths, future expectations and hopes, and resiliency, and try to work collaboratively to decrease helplessness and increase acceptance of the illness for both the patient and partner.

The studies reviewed also highlighted the differences between men and women in relation to their dependence on the couple relationship for support when diagnosed with MS. McPheters and Sandberg (2010) found that women tended to seek other forms of social support when depressed, whereas the men in their study depended more on the support from the relationship. Harrison et al. (2004), also supports this notion as they found that men gained mental and physical health benefits from remaining married whereas no such relationship was found for women in their study. Therefore male MS patients may need more support if they are in an unsupportive relationship or perceive their relationship quality to be poor when compared to their partner's perspective.

The studies reviewed had similar limitations which should be considered when developing future research in this area of MS. All the studies struggled to recruit an equal number of men and women, therefore the differences between sexes should be

interpreted cautiously. Furthermore, the participants were mostly recruited from the MS Society and lacked severe physical disabilities which automatically made them less withdrawn and distressed couples as they were already accessing some form of support and needed less 1-1 care. Similarly, the length of relationship (20+ years) and disease duration (10-18 years) was relatively long and therefore couples were more stable and were more likely to have adjusted more effectively to the MS. Hence, couples who were distressed or MS patients who were more severely physically disabled were under-represented in these samples. Lastly, the differences in measures used made comparing findings from the different studies difficult, specifically relationship quality measures as each study used a different measure; Golombok Rush Inventory of Marital State (GRIMS), Marital Concern Scale (MCS), Dyadic Adjustment Scale (DAS). Future research should attempt to use a relationship adjustment scale (DAS) and a relationship quality scale such as the GRIMS or MCS. The studies reviewed also suggested that future research should focus on the effectiveness of interventions in order to clarify the causal direction of the association between relationship quality and patient physical functioning. In addition, research should include, as well as physical disability, relationship quality and depression, other possible risk factors that may impact on the patients' well-being such as partner responses and type of support offered.

Type of support offered

Two studies (Kleiboer et al., 2006; Lehman & Hemphill, 1990) have investigated the impact of the type and level of support offered on the patient and partner's well-being. Firstly, Kleiboer et al., (2006) highlighted the importance of distinguishing between two types of support; instrumental (the practical help required when one partner is ill) and emotional support. For both partners and patients receiving instrumental help was

associated to lower levels of self-esteem, possibly as this reminded the patient of their increased dependence and for the partner receiving instrumental help may have threatened their competence as a caregiver.

Reciprocating instrumental and emotional support was not found to be important to the patient's and partner's mood however the effects of the received or provided emotional support were related to the partners' role. Patients reported better end-of-day mood when they provided emotional support and partners reported better end-of-day mood when they received emotional support. Additionally, when patients provided instrumental help this associated to better end-of-day mood, regardless of whether it was reciprocated. Therefore these findings indicate that immediate reciprocation of support was not beneficial to either partner's end-of-day mood.

This research suggests that partners receiving emotional support and patients providing emotional support are a key way to communicate love and appreciation to one another. Clinicians should therefore consider that patients' well-being is not only related to receiving instrumental and emotional support but that patients should also be encouraged to provide emotional support to the healthy partner due to the benefits to their own mood and self-esteem. Likewise, more attention and reassurance should be given to the partner to welcome emotional support from the patient. Furthermore, patients may benefit from discussing how receiving instrumental support makes them feel and how the partner may be better able to approach this in the future to avoid the patient feeling less independent.

Lehman and Hemphill (1990) found that the most helpful form of support from partners was expressions of love, concern and understanding. Patients found it least helpful

when partners used two types of support attempts; minimisation (questioning the severity or existence of the illness/help requested is made to seem unimportant or minor) or maximisation (catastrophising the MS symptoms or its consequences/being overly protective). The researchers stated the type of support attempt was dependent on the patient's physical appearance, for example, the more physically disabled a patient was the more likely the partner was to catastrophise. This may be due to people's stereotypes of how people should function based on the patient's appearance.

In addition to these findings, it was also reported that the patient found it difficult to confront or even suggest that their partner was using unhelpful or upsetting support attempts. The patient often attributed an unhelpful support attempt to the partner's lack of knowledge about MS. The researchers suggest that MS patients may fear isolation or rejection from their partner as they do not want to lose their main caregiver and support, they may also feel guilty for needing their partner to care for them and so they 'should not complain'. Therefore some MS patients find it difficult to criticise or even consider that their partners might not be offering or giving the appropriate support. These findings indicate that MS patients, if a problem arises, may need extra support in order to elicit more effective support attempts from their partners.

Kleiboer et al.'s (2006) study obtained a quality score of 19 and was deemed to have a strong methodology. The study took into account the confounding variables of daily hassles, patient symptoms and previous end-of-day mood on the partners and patients scores each day. However, there were a number of limitations to the studies reviewed. Lehman and Hemphill (1990) obtained a score of 14 as its data analysis was less rigorous and although a rich and detailed amount of information was collected, the qualitative analysis for gaining the themes was not well-known and raised issues about

the generalisability of their findings. Also, Lehman and Hemphill (1990) did not obtain the partner's perspective on their own support attempts and this was highlighted as an area for future research.

Kleiboer et al. (2006) employed a diary method which could have led to participant scores being affected by their overall end-of-day mood (e.g. better patient mood meant they scored more helpful support) and so not all confounding variables could be controlled for. Also, the findings from the studies reviewed did not investigate the effects of being severely physically disabled on the costs and benefits of receiving and providing support as their samples only included patients who had low to moderate physical disability. The studies reviewed also had a biased sample as the couples recruited had on average been together a long period of time and many had been accessing support through the MS Society therefore implying they were relatively content couples. Hence the samples may have under-represented distressed couples. Additionally, the studies could not reliably analyse gender differences due to sample size and design, and so could not conclude if the meaning attached to certain types or level of support was dependent on type of gender.

Overall the studies reviewed indicate that certain partner support attempts are more helpful than others and both patients and partners may benefit from education from clinicians around different types of helpful and unhelpful support attempts. Clinicians need to be mindful that partners are under a lot of stress themselves and so to work collaboratively and in a non-blaming manner, in order to help their support attempts become more effective. Clinicians could also encourage patients to offer emotional support to their partners and for partners to welcome or take note of this support.

Further research should focus on the effects of type and level of support on gender and more longitudinal studies in this area would help clarify if certain types of cumulative support impacts on the patient's mood. Future research should also try and recruit participants from more than one centre or hospital and include a range of patients with varied physical ability. Also, specific research is needed to investigate whether an increase in emotional support could compensate for less instrumental support being provided and vice versa.

Coping styles

Pakenham (1998) used a longitudinal design to investigate the impact of coping styles in relationships on level of adjustment to the illness. They found that coping congruence and average level of coping was related to collective and individual adjustment. More specifically, they examined the difference in two different types of coping styles; problem-solving and emotional coping. They found that similarity between the partners in emotional coping was adaptive however high emotional coping scores were related to greater collective distress and poorer adjustment scores. On the other hand, dissimilarity between partners in the problem-solving coping style was related to lower levels of collective depression and better adjustment. Therefore it was concluded that the problem-solving coping style was more adaptive. The researcher suggested that this coping style was more adaptive due to the changeable nature of MS and diverse range of difficulties which arise.

However, emotional coping should not be discounted as at certain times it may be useful for partners to express their feelings to one another, just not excessively so that it is distressing. The researcher reflected that the scale assessing emotional coping style

was restricted to mainly focusing on participants' level of avoidant emotional coping. Therefore, avoiding emotions which are difficult to discuss was found to be maladaptive and led to poorer adjustment to the illness. Further research should therefore focus on whether 'emotional approach coping' is more beneficial, e.g. expressing and identifying emotions, when compared to the problem-solving coping style.

There are a number of important clinical implications of this research. At assessment the couple's level and type of coping style should be considered. If the partner and patient's coping is incongruent and is deemed distressing or to be maladaptive to their level of adjustment then clinicians could help facilitate more effective coping styles. Coping skills training is one method in which clinicians could help increase the likelihood of patients and their partners adjusting more adaptively to the MS through identifying problematic coping, modelling, rehearsing and advising on more effective coping styles.

Pakenham's (1998) study obtained a score of 17 on the quality assessment checklist. Overall it had a number of strengths as it employed a longitudinal design and considered a range of confounding variables such as level and congruency of coping in addition to coping style. Also, the study recruited participants from a number of different research sites making the results more reliable and generalisable. However, there were a number of limitations such as the already mentioned emotional coping scale which did not fully account for all types of emotional coping. In addition, overall level of coping accounted for a significant yet small amount of the variance (11%-13%) in individual adjustment, therefore suggesting other factors that were not assessed may be impacting more on level of adjustment. However, overall coping congruency explained 20% of collective distress in couples suggesting coping is an important factor

to consider when assessing relationship factors which may impact on patients' well-being.

Type of partner response and family environment

Kleiboer et al. (2007) investigated the relationship between negative responses and end-of-day mood and whether offering emotional support would buffer the detrimental impact of negative responses. They found that for both patients and partners receiving negative responses led to higher end-of-day negative mood, when controlling for daily hassles and MS symptoms. Negative responses were unrelated to end-of-day positive mood. The adverse effect of received negative responses on end-of-day mood was moderated by receiving emotional support on the same day for both patients and partners. This may be due to partners feeling less rejected or that their relationship is less threatened when they received emotional support on the same day as receiving negative responses. The researchers suggest that clinicians could help partners and patients recognise that it is ok to express how they are feeling, both negative and positive emotions. However, the clinician should also offer additional emotional support techniques which may moderate against any detrimental effects of their negative responses. Furthermore, both patients and partners may benefit from advice on how to reduce their negative responses in general such as through relaxation techniques and accessing individual support.

Schwartz and Kraft (1999) also investigated the effects of spouse response on psychological functioning. However, they investigated whether negative responses could be moderated by social support, depression and the type of family environment. The researchers examined two types of response from the spouse; solicitous

(caring/attentive) and negative response. Solicitous responses were found to be associated to greater physical disability. This could be interpreted in two ways, either a solicitous response was required more by patients with greater physical disability or the spouses encouraged greater disability through providing more solicitous responses. It was also found that spouses who encouraged well behaviours were associated with lower patient emotional distress and negative responses to patient behaviours were associated to poorer mental health. Therefore these findings indicate that if spouses encourage well behaviours then patients may feel more supported and less depressed. Also, it seems that spousal support could buffer against depression in patients and so it may be useful for clinicians to help spouses identify and appropriately reinforce patient well behaviours and decrease negative responses to the patient's disability.

In addition to their main findings, Schwartz and Kraft (1999) also found that higher conflict and/or controlling family environments were associated with poorer psychological functioning in patients. Whereas, higher independence levels within the family were associated to better patient psychological and physical functioning. Therefore clinicians should always be encouraged to work systemically, taking into account how the patient's family has been affected by the MS and how this may be impacting on their well-being.

Schwartz and Kraft (1999) scored 15 on the quality assessment which was a relatively low score compared to Kleiboer et al.'s (2007) study which scored 18. Schwartz and Kraft (1999) scored lower because only patient data was used in the analysis and so family environment and spouse responses were only measured by the patients' perspective. In addition to this limitation they also failed to report the full characteristics of their sample, such as relationship duration and had a smaller sample size compared to

Kleiboer et al. (2007). Schwartz and Kraft (1999) did however take into account the impact of the patient's wider system, their family environment in addition to the other variables considered. They also highlighted the importance of clinician responses when working with patients with MS as professionals may also encourage or discourage patient behaviour through negative of solicitous responses. Further research is necessary in order to clarify whether this association also exists between patients and their key workers, e.g. their MS specialist nurse.

As previously mentioned the diary method design used in Kleiboer et al.'s (2007) study is prone to eliciting response bias from participants as their end-of-day mood may influence the scores they record. However it is useful to collect the data closer to the time it occurs rather than gaining a retrospective response. Yet again the sample under-represented distressed couples and patients who were more physically disabled and there was a bias towards female MS patients. Kleiboer et al. (2007) also suggest that other factors could moderate the patient's negative end-of-day mood other than response from spouse, such as their reaction to the negative response, interpersonal sensitivity and level of self-esteem. The researchers also reflect that future research should consider the spouses' responses during times of patient relapse as negative/solicitous responses may vary and impact the patient differently.

The studies reviewed highlight the need to help couples become more aware of how they respond to one another and if necessary identify more effective responses to avoid deterioration in patient mood. Couples may also need to support to communicate how their partner's responses make them feel as some responses may inhibit or encourage patient behaviour. Therefore couple responses are important when considering the

patient's well-being but other factors such as their family environment may also be influence the patient's physical and psychological functioning.

Attitude to illness and adversarial growth

Three studies reviewed investigated how different patient and partner attitudes to the MS may impact on the patient's wellbeing. Firstly, Ackroyd et al. (2011) took a unique look at the positive growth that can occur subsequent to being diagnosed with MS, otherwise known as adversarial growth. They demonstrated that patients with MS and their partners do show adversarial growth, with patients showing significantly higher adversarial growth than their partners. Furthermore, partner growth significantly predicted patient adversarial growth, and vice versa. This research supports the notion that patients and partners share a communal search for a positive meaning subsequent to being diagnosed with MS and can support one another's adjustment to the illness. This research is important to highlight as it demonstrates how partners and patients can find positive aspects of the MS together and thus not all consequences of MS are negative.

Ackroyd et al. (2011) also investigated the impact of patient and partner illness representations on patient mood and adversarial growth. It was found that dissimilar scores between patients and partners illness representations, specifically the 'consequences of the MS' item, were related to partner growth but not patient growth. The researchers interpreted this as meaning that patients were slower to adjust to and realise the consequences of their MS, whereas partners had a clearer idea of realistic goals and what could not be achieved and so impacted on the partner's positive growth more than patients'. However the research did find that when patients understood their own vulnerabilities and could create a new assumptive world meaning, they could then

adopt new perspectives and develop a more positive identity, leading to greater adversarial growth. These findings were unrelated to MS type, severity or duration of the illness, hence suggesting that the patient's perception of their illness is independent to disease factors. Also, greater partner growth was associated to increased patient distress and greater patient impairment in cognition and illness representations. These results indicate that as carers develop clearer, more defined roles then their role becomes more rewarding as the care they provide is in more demand. This research highlights the diversity in illness representations for both patients and partners and that the dissimilarity could affect positive growth. Interventions should aim to increase adversarial growth by including both the patient and partner in therapy, specifically focusing on patient and partner attitude to the illness and how they feel about a change in their roles and identities.

Ackroyd et al. (2011) had a strong methodology and scored 18 on the quality assessment. However, they did not report or measure the quality of the couple's relationship or relationship duration. Therefore the sample may have been biased as only stable couples may have put themselves forward for taking part in the study; hence these findings may only be applicable to couples who are adjusting well to the MS. Further research is needed to help clarify the relationship between perceived control and adversarial growth as the researchers highlighted this may also be an important factor affecting patient growth.

Wineman et al. (1993) investigated the impact of patient and partner illness uncertainty on patient mood. They found that for both those who reported higher levels of uncertainty were more likely to have lower moods and feel dissatisfied with family life. The main predictor of patient dissatisfaction was their own perception of illness

uncertainty; partner uncertainty was unrelated to patient mood. However partner family satisfaction was related to congruency between patient and partner illness uncertainty. Despite there being a lack of relationship between partner uncertainty on patient mood, these results indicate that higher levels of uncertainty may slowly erode the well-being of both in the relationship. It may be that patients are focused on managing their MS symptoms and so may not be affected by others' perceptions of uncertainty; their own uncertainties are burdensome enough. Congruence and shared understanding of illness uncertainty may be more important to partners because the 'togetherness' helps them better able to manage the changing demands of being a caregiver. A qualitative design may help clarify why partner uncertainty does not impact on patient mood or why partners feel it is more important to have similar levels of uncertainty.

Despite a lack of interaction found in illness uncertainty it was still found that higher individual levels of uncertainty lead to lower mood. Therefore, it is still important for clinicians to offer increased education about the illness, include partners and patients in support groups and assess whether patients and partners have similar or discrepant views about the illness. Wineman et al. (1993) scored 15 on the quality assessment which is relatively low compared to the other studies reviewed. They recruited a large sample of 61 dyads but these participants were recruited from the MS Society and so participants may have been relatively well informed about their illness compared to patients who were not part of the support group, hence results may be biased. Also the study lacked a critical evaluation of their own limitations and did not include a clear inclusion/exclusion criterion making it difficult to compare results to other studies or further these findings. Further research into the impact of illness uncertainty is needed and how professionals could help alleviate these concerns more effectively.

Lastly, Harrison et al. (2004) investigated the differences between gender in acceptance of disability and perceived impairment in patients who were married or divorced. For both men and women, independent of marital status, acceptance of disability and perceived impairment increased significantly over time. For women, acceptance of disability increased over time but this was unrelated to marital status. However, for men, being consistently married was associated to higher levels of acceptance of disability and less perceived impairment. As previously mentioned, this may be due to marriage being a source of mental and physical health benefits for men whereas for women being married was one of many sources of support. Also men were found to be more concerned about how their MS affected their sexual relationship, therefore supporting the notion that their well-being is more dependent on being in a relationship than female patients' well-being. Harrison et al. (2004) scored 16 on the quality assessment and was mainly criticised for lacking data from spouses as all the information was taken from the patient's perspective and may not be as reliable as other studies were both partners were assessed. Also, they did not report disease factors or how these may have impacted on the patient's level of acceptance/perceived impairment. Further research is needed to replicate these findings but overall there is a lack of research into gender differences in MS patients and so future research should include big enough samples to allow for statistical analysis between the sexes.

Overall the studies reviewed indicate that on the whole the patient's own attitude to their illness, specifically illness uncertainty and illness representation, has more of an effect on their mood than their partner's attitude to illness on patient well-being. Partner adversarial growth has been shown to impact on patient growth and vice versa, and being married has been associated to greater acceptance of the illness and lower perceived impairment in men, but not women. Therefore discrepancies or similarities in

attitude to illness between partners may be less important when compared to other aspects within the couple's relationship which impact on the patient's well-being. It seems that the patient's own perception of their illness is more important and should be a key area for clinical intervention.

Discussion

Overview of Research Findings

This review aimed to explore which aspects within a couple's relationship impact on the patient's psychological and physical functioning. In line with this aim the findings from the review will be discussed under two headings; how aspects within the relationship affect the patient's physical functioning and psychological functioning.

Which aspects within the couple's relationship impact on the patient's physical functioning?

There were only a few studies that specifically investigated the association between relationship factors and the physical functioning of the individual with MS. The studies reviewed suggest that if the patient is in a happy, well-adjusted relationship then they are more likely to experience better physical functioning (McPheters & Sandberg, 2010). This was found to be more relevant and significant for men in Harrison et al.'s (2004) study. Schwartz and Kraft (1999) also found that the patient's family environment was an important factor to consider when assessing a patient's physical wellbeing. They found a strong association between families who were more controlling and/or demonstrated higher conflict and a decrease in patient physical and psychological functioning. Furthermore, if the patient's partner is suffering from depression then the patient was found to experience greater deterioration in their physical, emotional and overall health status (Pozzilli et al., 2004; McPheters & Sandberg, 2010). Partner depression was also associated with increased severity of MS symptoms (Pozzilli et al., 2004). Lastly, the way in which a partner responds to the patient's disability could be detrimental to the patient's physical functioning. It has been

suggested that if the partner provides more solicitous responses to the patient this may encourage greater disability and lessen the possibility that the patient would partake in 'well behaviours' (Schwartz & Kraft, 1999). Well behaviours are activities that are challenging but possible for the patient to complete such as walking further than anticipated or pushing themselves to go to a social event when they lack confidence in their abilities. Patients are more likely to engage in 'well behaviours' when partners express happiness and encouragement when the patient completes or attempts these activities.

Therefore the partner's mood and response to the patient, and the patient's perception of the quality of their relationship, are important factors to consider when assessing patient physical functioning. Studies have suggested that if the patient's relationship is of low quality then the patient is likely to experience more symptoms of physical distress during difficult times in their lives which may lead to poorer health outcomes (Gulick, 1994). Additionally, the studies reviewed support previous research into other health patients who found that high marital functioning was related to improved survival rates after heart failure (Coyne et al., 2001) and enhanced physiological functioning (Uchino, Cacioppo & Kiecolt-Glaser, 1996).

The clinical implications of this research are substantial. Pozzilli et al (2004) suggest that patients should receive multi-disciplinary home care which would then facilitate increased coping in partners and therefore reduce carer burden and depression, which would in turn improve the patient's health status and reduce service involvement in the long-term. They go on to advise that both partners and patients would benefit from education and information about emotional support and practical help and when one coping strategy may be more appropriate in different situations. These interventions

should be specific and personalised to the couple's relationship. As relationship difficulties may have a pronounced impact on the patient's physical and emotional wellbeing it has also been recommended that partners and patients should be equally involved in therapeutic input. This may also help alleviate any psychological or physiological distress the partner may be experiencing (McPheters & Sandberg, 2010).

It cannot be overlooked that Woollett and Edelmann (1988) found no relationship between physical disability, life satisfaction and marital satisfaction. These results suggest the influence of relationship satisfaction/quality may not be as reliable or consistent as suggested in the other studies reviewed. It is also important to remember that none of the studies reviewed could determine a causal relationship between the relationship quality and patient physical functioning due to their cross-sectional designs. This interconnection between biological and social factors is less defined and has been researched least compared to the association between social factors and patient psychological well-being. Therefore future research should focus on including both physical and psychological outcomes for patients when investigating how aspects of the couple relationship impact on patient well-being.

Which aspects within the couple's relationship impact on the patient's psychological functioning?

Most of the studies reviewed examined aspects of the couple relationship in relation to the patient's psychological functioning, such as depression, self-esteem, adjustment to their illness and end-of-day mood. The findings from these studies will now be summarised.

There were a number of aspects within the couple relationship which were found to increase the likelihood of the patient developing depression. Schwartz & Kraft (1999) found that the patients were more likely to become depressed if partners responded negatively to patients and if patient 'well behaviours' were not encouraged by the partner. Kleiboer et al. (2007) furthered these findings as they found that if the partner offered emotional support subsequent to their negative response then the likelihood of patients becoming depressed or low in mood was reduced. Also, greater conflict and low independence levels within the family were associated to poorer patient psychological functioning. In addition to these findings, overall relationship satisfaction was associated to patient mood, as poorer relationship satisfaction was found to be related to increased patient depression scores (McPheters & Sandberg, 2010).

The type of support offered to patients by their partners also impacted on patient mood. It was found that if patients received excessive amounts of instrumental (practical) help then they were more likely to score lower on measures of self-esteem, possibly as this reminded the patient of their increased dependence on their partner (Kleiboer et al., 2006). Patient end-of-day mood was improved if patients were able to provide emotional and instrumental support to their partners. Hence, both the patient's ability to provide support to their partner and the response and support offered by partners are equally important in moderating the patient's end-of-day mood. Furthermore, patients reported that the most helpful form of support from their partners were expressions of love, concern and understanding (Lehman & Hemphill, 1990). Clinicians should reflect on these findings if the patient and their partner are struggling to find helpful ways of supporting one another.

The coping styles employed by the partner and patient have been found to influence and shape each other's adjustment in clients suffering from different health conditions (Coyne & Smith, 1991). In patients with MS, it was found to be more adaptive if partners had dissimilar coping styles, specifically when the problem-solving coping style was utilised. Dissimilar problem-solving coping style was related to lower levels of collective depression and better adjustment to the MS (Pakenham, 1998). The researcher suggested that this coping style was more adaptive due to the changeable nature of MS and diverse range of difficulties which the couple are faced with throughout the disease course. Increased avoidance of identifying and expressing emotions (emotion coping style) was associated to increased global distress, however further research into emotional coping is needed as other forms of emotion coping styles may be beneficial, e.g. expressing emotions to one another. The researcher suggested that the key to adapting to MS is to use both styles of coping and remain flexible dependent on the situation (Pakenham, 1998). If both partners are focused on overcoming the same problem this may not be an effective coping strategy as the couple's resources are less likely to be co-ordinated. Whereas a more efficient division of labour may be if one partner supports the other to solve the problem and offer emotional support, the two styles of coping would then complement one another.

Caregiver depression has been well-documented in MS research (McPheters & Sandberg, 2010). The association between health status of the patient and depression of the caregiver could be two-way. Increased caregiver depression may be influenced by greater severity in health status of the MS patient, however inversely; health status of the patient may be exacerbated by a decrease in the psychological functioning of their caregiver (Pozzilli et al., 2004). The causal direction of this relationship remains unknown and further longitudinal and intervention studies are necessary. Despite the

fact it is uncertain whether caregiver depression impacts on the physical or psychological functioning of the patient, there is research which suggests caregiver depression is a common occurrence and so it should be recommended that both the patient and partner receive therapeutic input.

Illness representations (Leventhal et al., 1997) have been found to affect the patient's adaptation to the illness in a wide range of conditions (Orbell & Hagger, 2003). It is hoped that by processing information about their illness and developing a range of cognitive representations, that patients can make sense of their symptoms and develop effective coping strategies. Positive interpretation and seeking emotional support has been related to positive psychological outcomes (Moss-Morris et al., 1996). However, it is not solely the patient's illness representations that may influence how they cope with their illness. It has been found in patients suffering from psoriasis that if patient and partner illness representations are dissimilar then this can lead to increased psychological distress for both (Richards et al., 2004).

Conversely, Ackroyd et al. (2011) found that dissimilar scores between patients and partners illness representations, specifically the 'consequences of the MS' item, were related to partner positive growth but not patient growth. The results from this study suggest that patient illness representations are more influential to their adjustment to their illness than their partner's illness representations. Therefore, illness representations should be considered when working individually with a patient and it may be useful to explore how this is managed within the couple's relationship. As mentioned previously partner response to the patient's illness was found to impact on patient mood (Kleiboer et al., 2006) and it may be that the partner's illness representations influence how they respond to the patient. Hence it may still be beneficial to explore partner illness

representations, despite no significant correlation being found between partner illness representation and patient growth (Ackroyd et al., 2011).

In addition to partner illness representations, partner illness uncertainty was also found to be a minor aspect within the couple's relationship when considering the impact on the patient's psychological functioning. It was found that patient illness uncertainty was more related to patient low mood and reduced family satisfaction than partner illness uncertainty (Wineman et al., 1993). However, greater incongruence between patient and partner illness uncertainty was found to relate to deterioration in family satisfaction and possibly worsened relationship quality (Wineman et al., 1993). This may then indirectly lead to poorer patient psychological functioning, as relationship quality has been strongly related to patient well-being (McPheters & Sandberg, 2010; Harrison et al., 2004). Hence, as with partner illness representations, it is still important to discuss the uncertainty of the disease as this could indirectly impact on patient mood. Furthermore offering more information about the disease and helping manage the couple's uncertainties could help both partners develop a greater understanding of MS and subsequently better prepare the couple for possible challenges which may arise.

Research has also shown that when faced with adversity such as a chronic illness some patients develop positive changes to the self and their philosophy of life; this has been termed as posttraumatic or adversarial growth (Tedeschi & Calhoun, 2004). Ackroyd et al. (2011) found that partner adversarial growth impacted on the level of growth in the patients and vice versa, therefore supporting the notion that partners share a communal search for a positive meaning and can support one another's adjustment to the illness. These findings are in line with previous research which demonstrated that adversarial growth has been shown to occur and to be adaptive in MS patients (Mohr et al., 1999).

Summary and Clinical Implications

The studies reviewed support the notion that there is an interaction between social relationships and the patient's physical and psychological functioning. Certain aspects within the couple relationship have been found to impact on the patient's well-being and severity of the illness. Therefore it is useful for clinicians to reflect upon the biopsychosocial model (Engel, 1977) when working with MS patients to encourage them to explore the wider systemic impact and influence on MS rather than focusing on MS as an illness that resides solely with the patient.

Specific aspects of the couple's relationship that impact on both the patient's psychological and physical functioning include marital satisfaction, the family environment, congruency and style of coping styles used, negative partner responses, partner emotional support which may moderate any detrimental impact of negative responses, partner depression and lastly the patient's perceived quality of their relationship.

These findings highlight the importance of clinicians offering partners either joint or individual therapeutic input. The MS guidelines by NICE (2004) have a recurring theme of offering support to those caring for patients with MS. However the evidence used in these guidelines are based on research with patients who have suffered a stroke, therefore the recommendations cannot be generalised to people caring for those with MS. Also the impact of relationship factors on the patient are not discussed and thus there are no recommendations that partners should be offered couple therapy. There were no intervention or randomised-control trials used in this review and so it is beyond the scope of this review to suggest the effectiveness of clinical interventions based on the couple relationship. However, the findings from the studies reviewed can highlight

possible clinical implications that may be useful for clinicians to consider implementing.

The form of support offered to the couple is dependent on the couple's wishes and needs, therefore a full multi-disciplinary assessment should be carried out which takes into account not only the physical health of the patient but also the quality and supportive nature of the patient's relationships. It is then the clinician's responsibility to offer the patient the option of including their partner in their on-going support throughout the disease course.

McPheters and Sandberg, (2010) suggest that preventative family and couple therapy could be offered alongside the support provided by the health care team. It may be useful for the family and couple to have support when topics that are usually unspoken arise such as disability, death and dying which will inevitably surface. Some couples may not need additional support however for others these topics may trigger difficult emotions which may lead to conflict in the relationship. Clinicians could offer the couple support with the aim of increasing physical and emotional well-being for both the patient and their partner. It has also been recommended that it could be helpful for clinicians to focus on the couple's strengths and encourage more positive emotions and thoughts about their hopes and future aspirations. It may be that when a family are struggling the focus is on trying to solve a problem and they get drawn into ruminating on the negative aspects of their situation. Also normalising and offering more information about what couples usually find challenging may be helpful to the couple. Overall, the clinician should focus on the resiliency the couple have demonstrated in the past and how this may help reduce hopelessness in the present (Pozzilli et al., 2004).

The couple may need further support on their acceptance and attitude to the illness. Key factors that may contribute to poorer relationship quality may be dissimilar illness representations and illness uncertainty within the couple. In this case it may be beneficial to offer more psycho-education on MS and help clarify any misinterpretations that may have arisen. The studies reviewed also highlighted the possible differences between how men and women cope with being diagnosed with MS and how men may depend more on the support provided from their marital relationship (Harrison et al, 2004). Therefore, in addition to clinicians exploring the aspects of the relationship already discussed it should also be noted that gender differences may be relevant to how the couple are coping.

In summary, couple's may find it useful to be given the opportunity to discuss difficult emotions and topics within a safe, therapeutic environment. The aim of the clinician is to facilitate improved communication between the partners around difficult topics such as the patient's disabilities and how their relationship may not always have a positive influence on both their physical and psychological functioning. A multi-disciplinary approach is not always possible due to service limitations. However, this review highlights the importance of relationships to MS patients and so individual clinicians who are working directly with the patient can use a biopsychosocial approach to guide their assessment and way of working. If the service is unable to offer support to the couple or wider system around the patient then other services should be signposted.

Limitations and Methodological Issues of Studies Reviewed

There were both methodological and theoretical limitations to the studies used in this review. Firstly, the participants used in the studies were mainly recruited from an MS

Society branch which consequently led to a selection bias of mostly well-adjusted couples who were in stable relationships. This is unsurprising as most these participants had been receiving support from the Society and were in long-term relationships, the majority had also been diagnosed with MS for at least ten or more years. Therefore, couples who had been together less than ten years, who were not accessing the available support and who may be struggling most were under-represented in the studies reviewed. However, the results from the studies reviewed remain relevant to the wider MS population as aspects within a relationship were found to be important to the patient's well-being, even in relatively well-adjusted couples. Even so, future studies should aim to recruit participants from more than one base such as neurology departments, different hospitals or through out-patient clinics to obtain a diverse range of couples who may not be coping as well as those attending support groups and who may not have been together for more than ten years.

There were two other keys limitations, other than selection bias, which existed in the participants recruited. Patients who were experiencing moderate to severe physical disabilities and those who had just been diagnosed with MS were underrepresented in the study samples reviewed. These patient characteristics may provoke or cause different difficulties or emotions within a relationship between partners and so clinical interventions may vary for these couples. Hence future research should also try to recruit patients experiencing more severe physical symptoms of MS and those who have been newly diagnosed. It may be that there are preventive interventions or support that could be offered to couples at this early stage in the disease course which could impact on how the couple later copes with their adjustment to the illness and increase patient well-being.

In addition to the limitations discussed a number of smaller methodological issues were found. None of the studies used in the review reported a sample size calculation and some studies did not fully describe the characteristics of their participants. Additionally, the studies considered in this review employed a mixture of old and new measures and few used the same measure to assess the same aspect, e.g. relationship quality or disability. This made it difficult to compare the findings of the studies used in this review and also the power in these studies could have been too low to detect a significant relationship that may have otherwise existed. Also three studies did not include data from the patient's partner and so the information collected was from the patient's perspective. It may be more reliable to collect data from both partners in order to gain a full picture of the couple's functioning.

Whilst searching for studies to use in this review it became clear that there is a lack of longitudinal studies or studies implementing interventions and randomised-control trials which investigate the aspects within a couple's relationship. In order to clarify any causal relationship between couple relationship factors and patient well-being more of these types of studies are necessary. A longitudinal study would be able to investigate how relationship factors influence changes in disease activity of if increased disease activity leads to greater strain on the patient's relationships. In order to clarify cause and effect more intervention studies are needed and would help clarify which clinical interventions are most effective. It would be beneficial to explore the effectiveness of offering support to the couple versus individual support to the patient or a combination of both. Additionally, more studies are needed which employ a qualitative design. This would provide a more detailed account of what couple's find most difficult or helpful about their relationships.

Lastly, there were only a small number of studies which investigated the effects of MS using a biopsychosocial approach. Most studies only focused on the psychological impact of difficulties in the couple relationship and did not consider others outcomes such as increased physical symptoms or change in disease activity. MS has been shown to affect the individual in a number of different areas of their life, including cognitively, physically and socially (Rao et al., 1991), therefore it seems logical to assume that these factors could be interlinked and therefore should be investigated (McPheters & Sandberg, 2010). In order to comprehensively investigate the impact of relationship factors on the patient, a full range of outcomes should be assessed, including physical disability and other MS symptoms such as fatigue. Future research in this area would help clarify the interconnection between social relationships and physical functioning in MS patients.

Limitations of Review

There were a number of limitations to this systematic literature review. Firstly, the search terms used produced a large number of search results which led to a large number of article abstracts being searched for relevancy. Implementing the use of the database limit options reduced the number of articles but a substantial number still remained. The vast number of articles searched makes the replication of this review difficult however it was important to search through the articles in order to confirm that relevant information was not missed. Many of the studies searched appeared to explore relationship factors however after further reading of the abstract it was clear that the focus of the article was not the couple relationship or focused on sexual difficulties.

The review did not include studies which investigated the relationship between patient well-being and sexual difficulties experienced in the couple's relationship due to the vast number of studies in this area. This does not signify that the sexual aspect to the couple's relationship is irrelevant as Harrison et al. (2004) highlighted the importance of sexual satisfaction in male MS patients and how this impacts on their psychological functioning, however it was beyond the scope of this review to include studies which solely investigated the sexual relationship in MS patients. Furthermore, this review did not specify or investigate the differences in relationship factors for patients who had different types of MS. This would be a useful factor to consider when working with patients as type of disease may have different implications for patients and their partners, factors to consider include; the severity and type of symptoms experienced, the speed of deterioration, the changeable nature of the disease and the disease activity in general. A more in depth analysis of the physical and psychological outcomes for patients with different disease types would help further develop more detailed clinical interventions.

An additional limitation to this review is that studies were included if they had a majority of the participants were in a couple relationship. Therefore two study samples (Pakenham, 1998; Pozzilli et al., 2004) investigated other relationships such as siblings, friendships or parents, although the majority of participants were married or being cared for by their partner. The results of these two studies remain relevant to aspects of the couple relationship however in the future, when more studies exist, it may be beneficial to replicate this systematic review and only include spousal relationships.

Future Research

Further areas of interest have been touched upon throughout this review. In summary intervention studies which investigate the effectiveness of couple therapy with the aim of reducing patient psychological distress and offering support to the patient's partner which may have an indirect impact on the patient's well-being. It may be useful to investigate the effectiveness of group sessions for partners, support groups or individual couple therapy. Future studies need to make a conscious effort to explore gender differences when coping with MS and how the impact of their relationship may differ between sexes. This may have clinical implications for how clinicians work with male and female MS patients or at least offer a more comprehensive account of which factors may be more important to the different sexes. In addition, research should include up to date measures that, if possible, have been validated with an MS population.

It is hoped that further research will help clarify the cause and effect of the association found between relationship factors and patient well-being. Additional research should continue to investigate whether an interconnection between the couple relationship and patient physical and psychological functioning exists so that services can offer appropriate support and advice. This would provide a more detailed account of what couple's find most difficult or helpful about their relationships. Lastly, more studies using a qualitative approach would help clinicians and researchers gain a better understanding of other possible aspects of the couple relationship which may impact on the patient's well-being.

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PART 2: Empirical Research

This paper is written in the format ready for submission to the Journal of Neurological

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Memory, information processing speed and social functioning in multiple sclerosis using the BIRT Memory and Information Processing Battery (BMIPB)

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Abstract

Background: This study aimed to investigate the impact of memory and information processing speed (IPS) deficits on social functioning in individuals with multiple sclerosis (MS), taking into account physical disability and mood. The current study also investigated participant insight into how their memory difficulties influenced their social functioning.

Method: Thirty-four participants completed the Hospital Anxiety and Depression Scale, the Barthel Activities of Daily Living Index, the Environmental Status Scale (ESS) and a subjective measure of how they perceive their memory impacts on their everyday functioning. They then completed the BMIPB.

Key Findings: IPS predicted a significant proportion (24.8%) of the variance in participants' scores on the ESS. The subjective measure of memory significantly correlated with social functioning (ESS) and actual memory scores. IPS, when compared to memory scores, explained a greater proportion of the variance in scores on the subjective questionnaire.

Conclusions: These results indicate that IPS and perceived memory abilities are significantly associated to the individual's completion of everyday social tasks such as work and social activities. This research suggests implications on rehabilitation and therapeutic input for individuals with MS. The strengths and potential challenges of using the BMIPB are discussed.

Keywords: MS, BMIPB, social functioning, subjective memory.

Introduction

Multiple sclerosis (MS) is characterised by inflammation, demyelination and neuronal loss in mainly white matter and some grey matter areas [1]. The broad range of symptoms reported in MS are due to the widespread development of plaques or lesions in the brain or spinal cord. Symptoms include physical and cognitive deterioration, although cognitive deficits can occur without severe physical disability and can be equally if not more debilitating to the person's social and everyday functioning [2, 3].

Previous neuropsychological studies have found various aspects of cognitive functioning to be affected in patients with MS [1, 4, 5]. It has been reported that overall cognitive impairment is related to a decline in everyday functioning, quality of life and affects the individual's ability to work [5]. Consequently, cognitive deficits may have an enormous impact on a person's functioning and possible future rehabilitation and therapeutic input [6]. It is therefore essential that neuropsychologists detect cognitive deficits early in the disease progression due to the potential negative impacts of such deficits. This study aims to focus on two of the most commonly reported cognitive deficits which affect approximately 43%-70% [7] of patients with MS; information processing speed (IPS) and memory.

Memory and Information Processing Speed (IPS) in MS

Memory impairment in MS has been characterised by long-term retrieval deficits with the primary problem being in initial learning of information rather than the storage and retrieval of information [8, 9]. MS patients usually have relatively intact short-term and semantic memory, recognition and implicit learning [1]. Additionally, reduced IPS is

considered a distinguishing cognitive deficit in MS with patients reporting slower reaction times and difficulty processing everyday life and job activities quickly [10].

Research investigating the difference between verbal and visual memory in MS remains varied. A number of studies have found visual memory performance to be significantly poor, in particular with respect to geometric figures [11, 12]. In contrast, Higginson et al. [6] reported that participants performed better on visual memory than verbal memory subtests and Diamond, DeLuca, Kelley and Kim [13] found no difference between performance on visual and verbal working memory tasks. Whereas Clemmons, Fraser, Rosenbaum, Getter, and Johnson, [14] found both verbal and visual-spatial memory to be impaired. The inconsistent findings in verbal and visual memory performance may be the result of different tests used to assess these aspects of memory and therefore assessing different functions, e.g. motor speed or ability to write as opposed to assessing visual memory. Furthermore, the different types of stimuli found in verbal and visual memory tasks may require the participant to engage in different types of processing as opposed to assessing impairments in verbal or visual memory.

Hence, an additional aim of the current study was to explore the differences between verbal and visual memory scores. The location of lesions in MS are varied and as highlighted there is no clear research indicating that one is more affected than the other; any differences in scores may be more indicative of the type of test stimuli rather than verbal and visual memory functioning.

Consequently, the current study aims to investigate memory and IPS deficits in MS and explore if any differences exist between verbal and visual memory in MS, taking into

account a critical analysis of the stimuli used and processing required for the subtest in question.

Impact of Memory and IPS on Everyday Functioning in MS

MS has been found to disrupt the overall lifestyle and employment status of individuals [15]. Physical disability alone cannot account for all the difficulties patients with MS encounter in their daily functioning [6]. In support of this view point, LaRocca, Kalb, Scheinberg, and Kendall [16] found that physical disability and demographic factors only explained 14% of the variance in employment status in 312 individuals with MS, hence is it possible that cognitive impairments in MS may have diverse effects on their daily functioning.

Overall, research shows that cognitive dysfunction, as an umbrella term, is closely associated with everyday functioning in MS [2, 17, 9]. Kalmar et al., in 2008 investigated the relationship between cognitive difficulties and the ability to perform everyday life activities in individuals with MS. They found that individuals with and without cognitive impairment differ in everyday functioning and proposed that aspects of cognition are predictive of the ability to complete everyday activities in MS patients. Furthermore, Rao et al. [2] found that cognitive impairment was important in determining the work status of individuals with MS, even when groups were matched on several measures of disease severity (the expanded disability status scale scores, disease course, and disease duration). Therefore, physical disability is important for the performance of everyday activities, but it cannot account for the extent of difficulties that individuals with MS encounter for many everyday activities [3, 18].

As Higginson et al. [6] states most studies investigating the impact of cognition on everyday functioning use global indices of cognitive impairment and fail to use specific individual measures. Kessler et al. [9] is an exception as they looked specifically at how memory impacted on everyday functioning. They found that variance of everyday functioning could be accounted for by memory loss, independent of demographic or physical disability variables. Higginson et al. [6] also found that deficits in memory and attention signficantly predicted functional impairment in 31 individuals with MS. Lastly, Kalmar et al., [15] found that a combination of deficits in executive functions, new learning, and processing speed deficits predicted the degree of independence on activities of daily living.

Memory deficits were found to be associated to everyday functioning in the three studies highlighted. As previously stated in this study, IPS deficits in MS are commonly reported and yet few studies have specifically investigated if both memory and IPS deficits impact on social functioning in MS. It is evident that the relationship between the detrimental effects of memory and information processing deficits on everyday functioning is under researched [6, 9, 15]. Therefore the primary aim of the current study is to expand this research.

As previously stated physical functioning has been found to account for at least 14% of difficulties in daily functioning [16]. Hence, this study, similar to Higginson et al., [6] and Kessler et al., [9] wanted to take physcial disability into account when investigating the impact of specific cognitve domains on everyday functioning. However, previous studies have used a variety of measures to assess physical functioning. The majority of studies have used the Extended Disability Status Scale [19] but this is a time-consuming and difficult measure to administer which also needs a neurologist to be present at

assessment. Therefore a different measure of physical disability was utilised in this study; the Barthel Index, (BI) [20]. The BI is an ordinal scale that measures functional independence in the domains of personal care and mobility. The BI has been shown to be a valid and reliable measure for assessing functional impairment in stroke patients, and changes in the scale correlate well with physician assessment of progress [21]. Additionally, in MS patients it has been found to be sensitive enough to detect change in functional status in patients receiving inpatient rehabilitation [22]. Therefore this measure was chosen to assess physical disability. Mood was also taken into consideration when assessing the impact of cognition on social functioning as previous research [6, 7] has demonstrated that depression also accounted for some of the variance in MS patients' social functioning.

The current study administered the Environmental Status Scale [23] as a measure of social functioning. This scale was chosen because it assesses daily and social activities which are affected by cognitive as well as physical impairments, unlike other measures such as the Activities of Daily Living Scale [24] used in Kessler et al.'s [9] which is mainly focussed on the assessment of motor function. The term 'social functioning' used in this study relates to the participant's ability to function socially within their community, including the ability to work and attend social events. This differs from measures investigating 'functional disability' such as the IADL which does not assess the participant's ability to complete both daily and social activities.

Lastly, in addition to the objective measure of cognitive abilities (BMIPB) and social functioning (ESS), this study developed a short questionnaire to investigate whether participants' perception of how their memory affects their ability to complete everyday tasks was accurate. The current study did not aim to design a new questionnaire, but

rather to investigate participant's beliefs about their memory in a qualitative fashion using a series of simple general questions.

A small number of studies have found a lack of association between patient-completed memory questionnaires and cognitive performance [25, 26, 27]. Furthermore, research has found that many MS patients often underestimate their memory difficulties on a memory questionnaire [28]. Therefore previous research suggests that participants may lack insight into their memory difficulties. However, the weak association between perceived and actual memory performance may be due to inadequate subjective memory questionnaires being used in previous research. Additionally this research has not been replicated and their findings are limited as the objective measures were administered over the telephone and small samples were used [25, 28].

This study proposes to ask participants directly if they perceive themselves to have memory impairments, and if so do their memory difficulties impact on specific social functioning tasks e.g. conversations and remembering events. It is thought that as participants are asked directly how their memory difficulties impact on their social functioning, that they would accurately report how much of an impact memory deficits accounted for the variance in their social functioning. If there is no relationship found between actual and perceived performance then participants may lack insight into their difficulties which may have clinical implications for further interventions. It is predicted that participants will accurately report their social and memory functioning as the questions used focus on asking participants about how memory affects specific social functioning tasks, which are also assessed in more general terms by the ESS. The ESS has two domains that correspond to the memory questionnaire questions; social activities and work status. It is hypothesised that scores on the memory questionnaire

will significantly correlate only with the work status question as this represents participant's ability to complete social tasks (e.g. unable to do work). Whereas the social activities question asks participants about how many social activities they are partaking in, rather than their ability to complete social activities. Therefore, it is hypothesised that scores on the subjective memory questionnaire will significantly correlate with the total ESS score (general social functioning), specifically the work status question and with participants' objectively measured memory scores (BMIPB).

In summary, the ESS will be used to investigate the relationship between social functioning, memory and IPS scores, whilst taking into account physical disability (BI) and mood (HADS). Participants will also be asked questions regarding their perception of whether their memory impacts on their social functioning to investigate participants' insight into their difficulties.

The BMIPB

As previously discussed the impact of cognitive deficits on individuals with MS may be substantial. Therefore, it is important to detect these impairments as early as possible in order for clinicians to help the individual develop coping strategies to develop and maintain a better quality of life. Hence, an objective assessment for assessing impairments in memory and information processing is necessary.

A relatively new measure, the BMIPB [29] is widely used to assess memory and information processing in neuropsychological settings, including patients with MS. The BMIPB is a useful measurement when assessing MS patients as there are four parallel forms (versions); hence re-assessments can be carried out without the contamination of

practise effects [30]. Re-assessments are especially important when offering the appropriate treatment to MS patients due to the quick and changeable nature of the disease course [7].

The current study aims to investigate memory and IPS deficits in MS and how these may relate to the participant's social functioning. As previously highlighted research has rarely investigated both IPS and memory functioning in MS. Furthermore, only one study found a relationship between IPS and social functioning and this study proposes this may be due to the measure used. Higginson et al., [6] used the Paced Auditory Serial Addition Test (PASAT) to measure IPS. This assessment tool has been recommended for testing IPS in MS patients [31]. However, Higginson et al., [6] reported that five participants were unable to complete the measure. Furthermore, Clemmons et al., [14] stated that in their research only 18 of 37 participants were able to complete the PASAT in their assessment. Many of the participants reported being frustrated or confused by the test. Therefore it is not surprising that IPS was found to be unrelated to everyday functioning in Higginson et al.'s [6] study. The previous version of the BMIPB, the AMIPB, has been proposed as a more effective measure of IPS in individuals with MS [32] as it is less stressful for participants to complete. Consequently, all participants should be able to complete the IPS subtest on the BMIPB unless they suffer from severe motor impairment, yet this is an exclusion criterion for participant recruitment in this study. Therefore, it is hoped that the IPS subtest on the BMIPB will obtain a more accurate account of IPS in individuals with MS.

The BMIPB is beneficial to MS patients as it assesses for numerous cognitive deficits which have been associated to MS, such as impairments in memory and information processing speed. Previous research has highlighted the need for an early screening

measure which would assess for these deficits, this in turn would better inform rehabilitation programmes and enhance appropriate support for the individual [1]. Consequently, the potential advantages or disadvantages of using the BMIPB in an MS population will be discussed.

The Current Study

It is important to further explore the relationship between cognitive deficits and social functioning. If social functioning is significantly affected by cognitive impairment then this will highlight the importance of assessing cognitive ability early in the disease course. This will in turn enable clinicians to administer intervention strategies early in the disease course [33] and allow patients to prepare for problems that may occur in the future.

It is the researcher's aim to expand on Higginson et al.'s [6] research by using the BMIPB to investigate both IPS and memory deficits in individuals with MS. The relationship between specific cognitive domains and social functioning will be investigated, whilst taking into account the impact of physical disability and mood. The current study will also assess the participant's insight into how their memory difficulties influence their social functioning. Lastly, this study will also explore if any differences exist between verbal and visual memory in MS, taking into account a critical analysis of the stimuli used. Demographic variables, mood, and disease factors, such as type and duration will also be considered in the analyses.

Hypotheses

It was hypothesised that; (a) IPS and memory impairment will account for a significant portion of the variance in scores on the social functioning measure (ESS); and (b) participants' subjective memory score will significantly correlate with actual performance on the objective measure of memory and ESS scores, specifically work status.

Method

Design

The study took a quantitative approach and employed a cross-sectional design to investigate relationships between mood, education, age, disease type, disease duration and everyday functioning and cognitive impairments. 'Disease type' was on three levels; primary progressive MS, secondary progressive MS and relapsing-remitting MS.

Participants

Thirty-four participants were recruited, and all had a clinically definite diagnosis of relapsing-remitting MS (RRMS), secondary progressive MS (SPMS) or primary progressive (PPMS), according to McDonald criteria [34]. The inclusion criteria for all participants included; must be proficient in English, above 18 years of age, and able to give full informed consent. Participants were excluded from the study if they had not been diagnosed for at least one year as it was deemed inappropriate to discuss possible cognitive impairments so close to the time of diagnosis. The exclusion criteria included: (a) unable to comprehend or produce speech to the levels necessary for the tasks, (b) severe motor or visual impairment that might interfere with cognitive testing, (c) under

the influence or had a history of drugs or alcohol abuse, (d) diagnosis of any neurological disease besides MS, (e), unable to give consent to take part, and (f) a previous history of severe mental health difficulties (defined as care of a community mental health team or an inpatient admission). The study was approved by the National Research Ethics Committee and local Research and Development Ethics Committees (see Appendix 3).

Sample Size Calculation

There was no published research that used the BMIPB and ESS in an MS population available to accurately estimate effect sizes in the current study. Also, due to the patient group and testing taking up to 2 hours to complete it was realistic that only a small sample could be obtained. The following sample size calculation was based on the primary research question; will IPS and memory scores, predict a significant amount of the variance in ESS scores (i.e. a significant increase in R-squared) after controlling for disease disability and mood? (Hypothesis a). Higginson et al.'s [6] research is the closest match to this research question as they also investigated the impact of cognitive deficits on social functioning. Therefore, based on this previous research it was expected that after accounting for the R-squared change in physical disability (33%) and mood (8%), that memory would elicit an R-squared change of 11%. Higginson et al., [6] found that IPS did not predict scores on the ESS. However, Kalmar et al., [15] reported that IPS predicted an R-squared change of 6% in everyday functioning scores in individuals with MS. Therefore, the current study anticipated an R-squared increase similar to those found in Higginson et al., [6] and Kalmar et al., [15] studies. Consequently, a calculation using GPower (Version 3.1) software [35] showed that, with a sample size of 28, 80% power could detect an increase in R-Squared of 17%

attributed to the 2 independent variables; information processing speed and memory, when controlling for disease disability and mood, which are assumed to give an R-Squared increase of 41% in a multiple regression model for everyday functioning, using a 5% significance level. According to guidelines [36], this is a large effect size.

Measures

Demographic Questionnaire

All participants completed a questionnaire which obtained demographical and disease related information (see Appendix 5.1). The questionnaire also included four questions relating to their subjective experience of their memory and how they think it affects their everyday functioning; the questions were: (a) do you feel your memory has deteriorated? (b) do you feel your memory affects your ability to complete everyday tasks, such as remembering where you put things, remembering a shopping list? (c) do you feel your social activities are affected by your memory, such as planning events, remembering appointments? (d) do you feel your ability to have a conversation is affected by your memory, such as remembering what someone has said previously or following a conversation? The questions were scored on a 3-point Likert scale ranging from 0 (not at all), 1 (a little) and 2 (yes, significantly) to obtain a total score of 8. Higher scores reflect greater functional impairment due to memory deficits from the participant's point of view.

Hospital Anxiety and Depression Scale [HADS, 37]

The HADS was used to explore differences in the level of anxiety and depression among participants (see Appendix 5.2). The measure is designed specifically for use

with physically ill patients and has been shown to have good internal consistency, with Cronbach alphas of 0.80 to 0.93 for the anxiety sub-scale and 0.81 to 0.90 for the depression subscale [38]. It consists of 7 items for each subscale and is self-rated on a 4-point scale ranging from 0 (no evidence of symptoms) to 3 (strong evidence for of symptoms).

Environmental Status Scale [ESS, 23]

The ESS is a broad measure of higher, more demanding, social and everyday activities. It is based on an interview with the patient and was developed specifically for patients with MS (see Appendix 5.3). It has been found to have high internal consistency reliability with Cronbach's alpha of 0.83 [39]. Kidd et al., [39] also reported that the ESS is a valid measure of social functioning in patients with MS. It consists of seven items on a 0 (no difficulty) to 5 (significant difficulty) Likert Scale. The scale assesses MS patients' ability to perform everyday tasks across eight dimensions; work status, financial/economic status, transportation, changes to personal home, community assistance, and social activity. Higher scores reflect greater impairment in completing social and everyday activities.

Barthel Index [20]

The Barthel Index (BI) is a measure of independence in performing various self-care and mobility tasks (see Appendix 5.4). It is used in this study to summarise the participant's level of physical disability. It is widely used in neurological rehabilitation and assesses overall functional disability [40]. The Index consists of 10 items; bowel, bladder, grooming, feeding, mobility, transfers, stair climbing, bathing, dressing and toilet use. The total score ranges from 0 to 20. The BI has been shown to be a reliable, valid and sensitive measure of basic physical functioning in patients with stroke [41]. In

MS patients it has been found to be sensitive enough to detect change in functional status in patients receiving inpatient rehabilitation [22]. Lower scores reflect greater impairment in physical functioning.

BMIPB [29]

The BMIPB is commonly used in clinical practise to assess the cognitive abilities of patients with MS. As mentioned previously the BMIPB is useful as it consists of four parallel forms thus enabling the clinician to re-test patients. Form one was used for this study which contains three verbal memory tasks (story recall, list learning and list recognition), three visual memory tasks (figure recall, design learning and design recognition), and an information processing (number cancellation) and motor speed task. There is no overall memory quotient produced, instead, the individual's strengths and weaknesses are produced which can then be related to everyday tasks the individual may find difficult, this is especially useful in rehabilitation settings. Furthermore many of the subtests have been reported as reliable with inter-rater reliability being $r = 1.0$ for many of the subtests and $r = .9$ on the more subjectively scored measures (i.e. story recall and figure recall) [29].

Procedure

Participants were recruited through MS Specialist Nursing staff working in outpatient services from the Hull Royal Infirmary (NHS Hull and East Yorkshire Hospitals) and the York Teaching Hospital (Foundation NHS Trust). The Nurses were informed of the inclusion and exclusion criteria and given a criteria checklist. Once the participants had read the information sheets (Appendix 5.5 and 5.6) they then sent a reply slip to the

researcher or contacted their MS Nurse to agree the researcher could contact them directly to arrange an assessment time. Participants were given the opportunity to ask further questions before the researcher obtained formal consent (Appendix 5.7). Participants also had the option of receiving their BMIPB results via a letter subsequent to completing the research.

The researcher administered the assessment schedule, in the same order, for all participants. Participants were able to complete the assessment measures on their own and in a quiet setting either at the University of Hull, at the hospital or in their own home. The administration of measures was not counter-balanced as previous studies had found no impact of fatigue on the completion of cognitive or social functioning measures in MS participants [6]. Therefore it was felt that fatigue would not impact the results of the cognitive testing. Also, regular breaks were offered to participants. To begin with, the demographic questionnaire was completed by participants, followed by the completion of the HADS, ESS and BI. Participants' HADS score were discussed with the participant before the end of the assessment schedule, enabling the researcher to give appropriate advice. The BMIPB was then administered using the standard written instructions from the manual, with a 40 minute interval between the immediate and delayed recall subtests. The overall time taken to administer the full assessment was between 1½ to 2 hours.

Results

Data Analysis

Preliminary analyses

Established guidelines were applied for data screening in relation to accuracy and assessing normality [42]. Descriptive statistics were used to characterise the sample and examine the means and standard deviations of variables. The relationship between demographic variables, self-report measures (HADS), memory/IPS scores, social functioning (ESS) and physical disability (BI) were investigated using Pearson product-moment correlations and Spearman rank-order correlations when data showed Shapiro-Wilk test to be $p < .05$. An alpha level of .05 was used for all statistical tests.

BMIPB scores

BMIPB test scores for MS participants were converted to z scores based on the means and standard deviations from the aged UK norms developed by [29]. Cognitive impairment was operationally defined as performance at or below the 2nd percentile of the published aged normative sample [29]. The data for BMIPB subtest scores for the three different disease type groups was not normally distributed. Therefore the Kruskal-Wallis test was used to determine whether there were any statistically significant differences between the three different MS type groups.

Principal Components Analysis

Preliminary analyses showed that the four subtests of the BMIPB were highly correlated with one another. The story immediate and story delay subtests were normally distributed (Shapiro-Wilk test; $p= .156$, $p= .287$ respectively) and so Pearson product-moment correlations were used to analyse this data. The figure immediate and figure

delay subtests were not normally distributed (Shapiro-Wilk test; *p<.001*) and so Spearman rank-order correlations were used to analyses this data. These correlations can be found in Table 1. Therefore it was possible that some of the variables were measuring the same underlying construct and a single memory composite score may more appropriately represent participants' memory scores as a whole. Consequently, the researcher decided that a principal components analysis (PCA) would be implemented. This is a variable-reduction technique which reduces a larger set of variables (figure immediate, figure delay, story immediate and story delay) into fewer variables, called a principal component which accounts for most of the variance in the original variables [43].

Table 1. Pearson product-moment and Spearman rank-order correlations between BMIPB subtests.

Subtest	Story immediate	Story delay	Figure immediate
Story delay	$r = .953**$		
Figure immediate	$rho = .255$	$rho = .348*$	
Figure delay	$rho = .230$	$rho = .391*$	.852**

*$p < .05$. **$p < .001$.

The PCA revealed that one component explained 68% of the total variance. This component represented an average of the memory scores as the components matrix highlights all the scores are around 0.8, see in Table 2. The four subtests, in addition to memory component 1, were used in the following data analysis.

Table 2. Components Matrix to illustrate component 1.

Subtest	Component 1
Story immediate	.802
Story delay	.860
Figure immediate	.823
Figure delay	.813

Research Hypothesis A

Spearman rank-order correlations were used to investigate the relationship between ESS scores and BMIPB scores as the data was not normally distributed (Shapiro-Wilk test; *p* < .05). Multiple linear regression analysis was used to investigate the impact of memory and IPS on social functioning, when controlling for physical disability and mood. As recommended by Field [42] a number of assumptions were checked. Assumptions tested include; linearity, no significant outliers, homoscedasticity of residuals (equal error variances), and normality of residuals. Individual questions on the ESS will also be investigated for differences using the Friedman Test and Wilcoxon Signed-Rank Tests due to data being not normally distributed. The relationship between individual ESS questions and the measures; IPS, memory, physical disability and mood scores, will be investigated using correlations and multiple linear regressions will be subsequently used to explore which variable explains the most variance in specific ESS domains.

Research Hypothesis B

Correlations were used to investigate the relationship between the subjective memory score and ESS total scores and individual questions. Correlation analyses were also used to investigate the relationship between the subjective memory score and objective memory scores as measured by the BMIPB. Multiple linear regression analyses were used to investigate the amount of variance in subjective memory scores explained by objective IPS and memory scores.

Verbal and Visual Memory

In order to investigate significant differences between verbal and visual memory subtests, paired t-tests and the non-parametric alternative to the paired t-test, the

Wilcoxon signed-ranks test were used. The test used was dependent on normal distributions of the data, both verbal memory subtests were normally distributed (Shapiro-Wilk test; $p < .05$) whereas visual memory subtests were not normally distributed (Shapiro-Wilk test; $p > .05$).

Preliminary analyses - Participant Characteristics

An overview of participant characteristics, including self-reported measures and clinical symptomatology can be found in Table 3. The number of females (62%) in the sample was reflective of the MS population [44]. The sample lacked ethnic diversity as 95% of participants were Caucasian. The majority of participants had education up to degree level and were unable to work due to their MS symptoms. None of the participants were experiencing a relapse at the time of testing or 6 months previous to completing the measures, therefore disease activity was not investigated. Participants' scores on the BI (range = 0-20), ($M = 15.59$, $SD = 2.7$) and ESS (range = 0-55), (median = 16, IQR = 11-18) suggest participants had a 'low to moderate' physical disability/dependency [45] and moderate functional impairment [22]. Mean scores on the HADS suggest that participants were not clinically depressed ($M = 3.7$, $SD = 2.2$) or anxious ($M = 5.2$, $SD = 3.3$) and were found to be in the normal range [46].

Table 3. Participant Characteristics.

Variable	Total sample (n=34)
Gender, % (n)	
Male	38% (13)
Female	62% (21)
Age, mean (SD), min-max	50.62 (10.14), 33-71
Educational attainment, % (n)	
No qualifications	3% (1)
GCSE level	20% (7)
Up to 2 A levels	12% (4)
2+ A levels	15% (5)
Degree	41% (14)
Higher degree	9% (3)
Employment status, % (n)	
Full-time work	9% (3)
Part –time work	12% (4)
Retired	3% (1)
Unable to work	76% (26)
Disease duration (from diagnosis), median (IQR), min-max	7.5 years (3 – 14), 1-33
Admitted to hospital in last 6 months?	No
HADS	
Anxiety, mean (SD)	5.2 (3.3)
Depression, mean (SD)	3.7 (2.2)
Total Score, mean (SD), min-max	8.9 (4.5), 1-17
BI, mean (SD),	15.6 (2.7)
ESS, median (IQR), min-max	16 (11-18), 3-24

Notes: IQR = interquartile range. Median and IQR scores were reported when the variable had a skewed distribution.

Correlations for overall sample

Relationships between measure scores and demographic variables were examined using correlations for continuous demographic variables. Spearman rank-order correlations and Pearson product correlations were used dependent on the distribution of the data as tested by the Shapiro-Wilk test. Weak yet significant relationships were found between education and the memory subjective score (*rho(32)*= -.421, *p* = .013), and IPS (*rho(32)*= .396, *p* = .020) suggesting there is a weak association between higher education and better perceived memory abilities and quicker IPS. There were significant negative correlations found between ESS and figure immediate (*rho*(32)= -.392, *p* = .022), and IPS (*rho*(32)= -.502, *p* = .002) indicating that there is an association between poor social functioning and decreased IPS and visual memory. There was found to be a significant positive correlation between IPS and visual memory (figure immediate: *rho*(32)= .437, *p* = .01; figure delay: *rho*(32)= .561, *p* = .001). In relation to the relationship between IPS and recognition and recall subtests, there were two significant correlations found between IPS and visual recall (design subtest, *rho(32)*= .517, *p* = .002) and verbal recognition (list subtest, *rho(32)*= .558, *p* = .001). There was also a positive correlation found as expected between disease duration and age (*rho(32)*= .359, *p* = .037). The BI and ESS strongly correlated (*rho*(32)= -.596, *p* < .001) suggesting that as physical functioning increased, social functioning also increased. There were no significant correlations between BMIPB scores and participants' scores on the BI. Additionally, physical disability (BI) did not correlate with any demographic variables including disease duration, disease type or mood.

Analyses between groups

Using the Kruskal-Wallis test, the only significant differences between MS type were on the ESS ($H(2)$=7.56, p=.023) and disease duration ($H(2)$=10.003, p=.007). One-way ANOVA tests demonstrated there were significant differences between MS type on the BI ($F(2,31) = 3.793$, $p = .034$) and age ($F(2,31) = 12.171$, $p < .001$). The means and standard deviations for each group can be found in Table 4. The RRMS group was less functionally impaired on both measures (ADL and ESS) than the PPMS and SPMS groups. The RRMS group also had the shorter disease duration and had younger participants than the PPMS and SPMS groups. The SPMS group had the longest disease duration which is understandable as approximately 65% of RRMS develops into SPMS, therefore it is expected that this group would have a longer disease duration [47]. No other measure scores significantly related to age, gender, education, mood, MS type or duration disease.

Table 4. Mean and standard deviation scores for each group/disease type.

	Disease Type		
	PPMS	**RRMS**	**SPMS**
Age, mean (SD)	57.7 (8.6)	42.4 (5.6)	54.2 (9.2)
Disease duration (from diagnosis), median (IQR), min-max	6 years (2-11) 1-33	4 years (2-6), 1-20	14 years (10-20) 5-29
BI, mean (SD)	14.8 (2.6)	17.1 (2.2)	14.6 (2.7)
ESS, median (IQR), min-max	18 (14-21) 9 -23	13 (5-16) 3-17	17 (14-22) 4-24

Notes: PPMS = Primary progressive MS; RRMS = Relapsing-remitting MS; Secondary progressive MS; SD = standard deviation; IQR = interquartile range. Median and IQR scores were reported when the variable had a skewed distribution.

Table 5. Percentage of sample impaired, mean, standard deviation, median and IQR scores for BMIPB subtest and memory composite scores.

Scale	Percentage impaired	Mean	SD	Median	IQR (min -max)
Story Immediate	11.8%	-.46	.94		
Story Delay	8.8%	-.38	.97		
Figure Immediate	5.9%	-.37	1.1	-.38	-.75 - .27 (-4.89 – 1.52)
Figure Delay	2.9%	.01	1	.09	-.33 - .55 (-.4.7 – 1.42)
List Recall	8.8%	-.26	1		
Design Recall	8.8%	-.06	.86	.07	-.37 - .46 (-2.27 - 1.29)
List Recognition	2.9%	-.61	1.3	-.5	-1.2 - .45 (-5.56 – 1.08)
Design Recognition	2.9%	.31	.83	.59	.41 - .69 (-3.28 - .86)
IPS	26.5%	-.61	1.3	-1	-1.6 - .4 (-2.48 - 2.29)
Memory composite 1	2.9%			-.07	-.39 - .47 (-3.7 - 2.24)

Notes: IQR = interquartile range. Median and IQR scores were reported when the variable had a skewed distribution.

BMIPB Scores

An overview of participants' scores on the BMIPB, including percentage of the sample classified as impaired, can be found in Table 5. Any percentile of 2 or below was classified as impaired using Coughlan et al.'s [29] aged norms. As demonstrated in Table 5, the study sample was more impaired on the measure of IPS (26.5%), followed by the story immediate subtest (11.8%).

Hypothesis A: IPS and memory impairment will account for a significant portion of the variance in the social functioning measure (ESS)

As previously stated social functioning significantly correlated with the figure immediate subtest (rho(32)= -.392, p = .022), and IPS (rho(32)= -.502, p = .002). There was also a moderate positive correlation found between scores on the BI and ESS (rho(32)= -.596, p < .001). As only figure immediate correlated with ESS it was decided that only figure immediate would be used in the regression to represent memory scores. However, subsequent to inspecting scatterplots it was determined that a linear relationship existed between memory composite 1 and ESS, in addition to figure immediate and physical disability. Therefore, two separate multiple linear regressions were conducted, one for figure immediate and one for memory composite score, to test if memory and IPS scores significantly predicted participants' ratings on the ESS when controlling for physical disability. Before conducting the regressions assumptions were checked. Regressions had no significant outliers, homoscedasticity of residuals (equal error variances) were found, and subsequent to checking the Normal P-P plots and histograms, normality of residuals was also assumed.

Table 6 and Table 7 summarise the regression statistics. Physical disability significantly accounted for 35.2% of the variance in ESS scores (R^2 change = .352, β = -.423, SE = .279, t(28) = -3.400, p = .002). Mood did not account for any of the variance in ESS (R^2 change = .000, β = .069, SE = .158, t(28) = .575, p = .570). Memory composite 1 and figure immediate scores were put into two separate regressions to investigate if IPS or memory predicted any of the variance in ESS. In the first regression (Table 6) the overall model was significant (F(4,29)=11.029, p < .001). Memory composite 1 was

found to not be a significant predictor (R^2 change = .003, β = .058, SE = .744, $t(28)$ = .468, p =.643) and IPS significantly accounted for 24.8% (R^2 change = .248 ,β = -.547, SE = .600, $t(28)$ = -4.214, $p < $ .001) of the variance in ESS scores. In the second regression (see Table 7), the overall model was found to be significant ($F(4,29)$=10.937, $p < $ .001). Figure immediate was found to not be a significant predictor (R^2 change = .001, β = -.036, SE = .731, $t(28)$ = -.270, p =.789) and IPS significantly accounted for 24.8% (R^2 change = .248, β = -.515, SE = .630, $t(28)$ = -3.774, p = .001) of the variance in ESS scores. These results indicate that greater physical disability and IPS impairment are associated with poorer social functioning. Memory scores did not significantly relate to social functioning.

Table 6. Results of regression analysis for memory composite 1 predicting ESS total score.

Scale	R^2 Change	β	SE	t	p
	0				
Physical disability (BI)	.352	-.423	.279	-3.400	.002
Mood (HADS)	.000	.069	.158	.575	.570
IPS	.248	-.547	.600	-4.214	< .001
Memory composite 1	.003	.058	.744	.468	.643

Total R^2 = 60.3

Table 7. Results of regression analysis for figure immediate subtest predicting ESS total score.

Scale	R^2 Change	β	SE	t	p
	0				
Physical disability (BI)	.352	-.420	.281	-3.344	.002
Mood (HADS)	.000	.080	.161	.660	.514
IPS	.248	-.515	.630	-3.774	.001
Figure immediate	.001	-.036	.731	-.270	.789

Total R^2 = 60.1

Individual questions on the ESS were examined and it was found that participants' MS symptoms impacted most on their social activities, need for more personal assistance and ability to work. Table 8 summarises the median scores for the different ESS domains, the higher scores indicate poorer functioning in that social functioning domain. As the Shapiro-Wilk test indicated that the data from individual questions on the ESS were not normally distributed the Friedman Test was used to investigate if the median scores on the ESS were significantly different. There was a statistically significant difference in ESS domains, $X^2(6, N = 34) = 125.53, p < .001$. The three highest scores, so the participants' poorest social functioning domains were chosen to be investigated further; work status, social activities and personal assistance. Post-hoc analysis with Wilcoxon Signed-Rank Tests was conducted with Bonferroni correction applied resulting in a significance level set at $p < 0.017$. There was a significant difference between work status and need for personal assistance ($Z = -3.745, p < .001$) and social activities ($Z = -3.070, p = .002$) therefore work status was statistically the most affected social functioning domain.

Table 8. Median and Interquartile range (IQR) for ESS domains.

Work status	Economic Status	Home changes	Personal assistance	Transport	Community help	Social activities
5 (4.8-5)	1 (0-2)	2 (1-4)	3 (2-4)	1 (0-2)	0	3 (2-4)

Table 8 demonstrates that none of the participants required help from the community such as social or care workers helping them at home. Although, participants reported that they often required personal assistance from family members or friends. Furthermore, the majority of participants reported that the severity of their MS symptoms meant they were unable to work.

Correlations were used to investigate the relationship between individual ESS questions and the measures; IPS, memory, physical disability and mood scores. Table 9 summarises the Spearman-rank order correlations between measures and ESS domains.

Table 9. Spearman rank-order correlations (rho) between measures and individual ESS questions.

Subtest	Work status	Economic Status	Home changes	Personal assistance	Transport	Social activities
Physical disability	-.389*	-.355*	-.345*	-.541***	-.340*	-.454**
Mood	.150	.259	-.226	.118	-.110	.292
IPS	-.644***	-.397*	-.387*	-.324	-.412*	-.266
Memory Composite 1	-.205	-.156	-.143	-.090	.021	-.023

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

As is evident from Table 9 physical disability significantly correlated with all of the ESS domains. Memory and mood did not correlate with any of the ESS domains. Lastly, IPS significantly correlated with work status, economic status, home changes and transport. The most clinically significant of these findings is that both IPS and physical disability correlated with work status so a multiple linear regression was used to explore how much of the variance in the work status was explained by IPS and physical disability. Before conducting the regressions assumptions were checked. Linear relationships existed between physical disability and IPS with work status. The regression had one outlier (on IPS) but it was left in the regression as it had no significant impact on the regression statistics when removed. Homoscedasticity of residuals (equal error variances) were found, and subsequent to checking the Normal P-P plots and histograms, normality of residuals was also assumed. The results are highlighted in Table 10.

Table 10. Regression for IPS and physical disability predicting work status.

Scale	R^2 Change	B	SE	t	p
Physical disability (BI)	.116	-.340	.112	-2.047	.049
IPS	.344	-.616	.193	-4.446	< .001

The regression model was significant overall (F(2,31)=13.209, $p < .001$). IPS predicted more of the variance (34.4%) in work status scores than physical disability (11.6%). Therefore IPS and work status are significantly related (from Table 9) and this relationship is maintained when physical disability is controlled for in a regression model. There was no significant relationship between IPS and the social activities question in the ESS.

In summary, IPS and physical disability did account for a significant amount of the variance in ESS scores. When ESS domains were investigated individually it was found that IPS explained a significant amount of the variance in work status, more than the amount explained by physical disability. However, physical disability correlated with all of the ESS domains. Overall memory scores and individual memory subtests, except figure immediate, and mood scores did not correlate with ESS scores.

Hypothesis B: Participants' subjective memory score will significantly correlate with actual performance on the objective memory and ESS measures.

Correlations were used to investigate the relationship between total ESS scores, ESS individual questions and the memory subjective score. As the Shapiro-Wilk test indicated that the data from individual questions on the ESS were not normally

distributed Spearman rank-order correlations were used, the results from these are summarised in Table 11.

Table 11. Spearman rank-order correlations (rho) between ESS and subjective memory scores.

	Total ESS score	Work status	Economic Status	Home changes	Personal assistance	Transport	Social activities
Subjective memory score	.431**	.627***	.439**	.334	.286	.204	.275

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

Therefore participants' perceptions of how their memory abilities impact on their social functioning significantly correlated with their ability to work and need for more financial help. Additionally, there was no relationship found between level of social activities and participants' subjective memory score.

Subjective memory scores were then analysed using Spearman rank-order correlations to investigate the relationship with objective memory scores from the BMIPB. The results from these correlations can be found in Table 12.

Table 12. Spearman rank-order correlations (rho) between BMIPB scores and subjective memory scores.

	Memory composite 1	Story Immediate	Story Delay	Figure Immediate	Figure Delay
Subjective memory score	-.524***	-.392*	-.460**	-.491**	-.466**

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

The results from Table 12 suggest that participant's subjective memory score did correlate significantly with all memory subtests. However, when preliminary analyses were carried out it was found that IPS correlated strongly with the subjective memory score (rho(32) = -.694 .000). Therefore multiple linear regression analyses were used to test if memory and IPS scores significantly predicted participants' ratings on the subjective memory questionnaire. Before conducting the regressions assumptions were checked. Linear relationships existed between IPS and memory composite score 1 with scores from the subjective memory questionnaire. The regression had one outlier (on IPS) but it was left in the regression as it had no significant impact on the regression statistics when removed. Homoscedasticity of residuals (equal error variances) were found, and subsequent to checking the Normal P-P plots and histograms, normality of residuals was also assumed. The results indicated that the two predictors explained 64.1% of the variance (R^2 change =.641, F(2,31)=27.639, p<.001). IPS scores significantly accounted for 54.8% (R^2 change =.548, β = -.640, SE = .191, t(28) = -5.656, p<.001) and memory composite 1 significantly accounted for 9.3% (R^2 change =.093, β = -.321, SE = .248, t(28) = -2.834, p =.008) of the explained variability in perceived memory ability scores. These results suggest that IPS scores are impacting more on participants' overall subjective memory score than memory difficulties. Therefore participants may misinterpret reduced IPS for memory difficulties.

Verbal and Visual Memory

Wilcoxon signed rank and paired t-tests were conducted to investigate differences between verbal and visual measures on the BMIPB. Significant differences were found between story immediate and figure immediate (Z = -5.086, $p<.001$), and story delay and figure delay subtests (Z = -2.342, $p=.019$). Table 5 illustrates mean and standard deviations for the subtests investigated. These results indicate that participants scored significantly better on measures of visual memory compared to verbal memory.

Post-hoc analyses

Wilcoxon signed rank tests and paired sample t-tests were conducted, dependent on normal distributions of the data, to investigate differences between recall and recognition measures, and delay and immediate subtests on the BMIPB. The mean and standard deviations for the subtests investigated can be found in Table 5. There was no significant difference between list recall and list recognition subtests (Z = -1.376, p =.169). However there was a significant difference found between design list and design recognition subtests (Z = -2.413, p =.016). These results indicate that participants scored significantly better on measures on visual recognition than visual recall.

Lastly, the study sample scored significantly better on the figure delay subtest when compared to figure immediate scores (Z = -4.155, p <.001). The difference between story immediate and story delay subtests was found to be not significant ($t(33)$ = -1.550, p = .131). Therefore participants scored higher on the visual delay memory measures compared to the visual immediate recall measures.

Summary of Findings

An overview of the findings from this study can be found in Table 13.

Table 13. Summary of Findings.

	Main findings
Demographic variables	• The study sample included more females, lacked ethnic diversity, and had low to moderate physical disability (BI) and moderate functional impairment (ESS). No participants were experiencing relapses during the time of assessments. Overall participants were not clinically depressed or anxious. • Only significant differences between MS type were on measures of ESS, BI, age and disease duration. • Weak relationships were found between education and perceived memory abilities and IPS.
Social functioning, physical disability, memory and IPS	• BI and ESS were positively correlated. • Physical disability did not correlate with any scores on the BMIPB. • A significant negative correlation was found between IPS, the figure immediate subtest and ESS. • Physical disability significantly explained 35.2% of the variance in ESS scores. • Memory scores did not significantly explain variance in ESS scores. • IPS explained 24.8% of the variance in ESS scores after controlling for physical disability. • Participants' ESS scores suggest that individuals' MS symptoms impacted most on social activities, ability to work and needing more personal assistance. • Physical disability correlated with all ESS questions however IPS predicted more of the variance (34.4%) in work status scores than physical disability (11.6%).
Subjective measure of memory on everyday functioning	• Participants' perceptions of how their memory abilities impact on their social functioning significantly correlated with their ability to work and need for more financial help. There was no relationship found between level of social activities and participants' subjective memory score. • IPS (54.8%) and memory (9.3%) explained variance in perceived memory ability scores. Therefore participants may be misinterpreting reduced IPS for memory difficulties.
Memory and IPS	• Overall the sample was more impaired on IPS than memory.
Verbal vs. visual memory	• Participants scored higher on visual memory measures compared to verbal memory.
Post-hoc analyses	• Participants scored significantly higher on visual recognition compared to visual recall. • Participants scored higher on measures of visual delayed memory than visual immediate recall measures.

Discussion

Overview of Findings

The current study aimed to investigate the relationship between specific cognitive domains and social functioning in individuals with MS.

Demographic variables

This study took into account demographic variables such as mood, disease type and disease duration when investigating relationships between variables. Findings were consistent with Kessler et al.'s [9] research as disease type, disease duration and age did not significantly correlate with any cognitive measures. Similar to Higginson et al.'s [6] research no relationship was found between more years in education and longer disease duration with social functioning. These results may be due to the majority of participants in this sample attended higher education and the majority of participants were diagnosed with RRMS which was found to have the shortest disease duration and smallest amount of social and physical impairments.

Education did however correlate with the subjective memory questionnaire and IPS suggesting there may be an association between higher education, better perceived memory abilities and quicker IPS. These results may support previous research which has suggested that cognitive reserve (higher education or premorbid intelligence) may moderate the negative effect of MS on cognitive functioning [48]. They found that cognitive reserve significantly predicted better IPS and those participants with higher reserve were better able to withstand the neurological changes in MS without

experiencing cognitive impairment. This is an interesting area of further research which may have important clinical implications for patients with MS, such as whether cognitive interventions (cognitive training and cognitive leisure activities) could improve cognitive reserve, thus delaying the onset of cognitive impairment [48].

Social functioning, memory and IPS

This study aimed to replicate and further the findings from Higginson et al.'s [6] study which found a relationship between ESS and participants' memory scores. Similar to Higginson et al.'s study, physical disability was the best predictor of social functioning. Due to the nature of MS symptoms mainly affecting motor and sensory impairment it is not surprising that these difficulties impacted on participants' social functioning.

It was hypothesised that IPS and memory may explain a significant proportion of the variance in social functioning scores. The most affected domains of social functioning were the participant's ability to work, need for personal assistance and level of social activities. This study, in contrast to previous research [9, 6] found no relationship between social functioning and memory scores. However, the current study did find a significant relationship between IPS and social functioning as measured by the ESS. In addition to these findings, IPS predicted a significant amount of the variance in work status, even when compared to the impact of physical disability. These findings can be explained by looking at several social abilities that depend on an efficient IPS [49]. Reduced IPS may impact on the individual's ability to take in information quickly and to respond to questions in an appropriate time frame. These abilities could be seen as essential skills for completing and maintaining a successful job. Also, processing

sentences may become difficult due to reduced IPS and therefore having a conversation may become problematic. These difficulties may lessen the possibility of the individual wanting to socialise or being able to work effectively. Therefore it is understandable that IPS difficulties could impact an individual's ability to work or socialise.

Given the pervasive memory complaints among MS patients [9, 7], the finding that there was no relationship between memory difficulties and social functioning was surprising. These findings may relate to the sample used in this study having more IPS difficulties than memory problems. However, a more likely explanation may be that memory deficits are easier to identify and therefore individuals are more able to effectively compensate for them. For example throughout this research participants often commented that they were using coping strategies such as taking notes, making lists, using mnemonics and various electronic reminders, to help them overcome for their memory difficulties. Whereas reduced IPS is less identifiable and is more resistant to compensatory techniques as it affects cognition across various domains. IPS can affect the individual's ability to quickly problem solve, comprehend and produce language, react and respond effectively to others and may impact on focusing and dividing attention in busy environments [50]. As such IPS is more likely than memory to interfere with an individual's social functioning. These results are also supported by the finding that participants seemed to misinterpret reduced IPS for memory difficulties on the subjective memory questionnaire.

In summary, this study found that after controlling for physical disability, IPS accounted for a significant amount of the variance in social functioning scores, specifically participants' ability to work. These findings highlight the need for

individuals with MS to be assessed for IPS deficits and further educate individuals on the differences between memory and IPS difficulties. It may also be beneficial to inform and provide guidance to organisations in order to better support the individual with MS at work and offer coping strategies specific to overcoming IPS difficulties.

Subjective memory questionnaire

It was hypothesised that participants' subjective memory scores would significantly correlate with their actual performance on their objective measure of memory and ESS scores, specifically work status. This hypothesis was supported to a certain extent. Participants' subjective memory score significantly correlated with their total social functioning score and their ability to work and need for more financial support. Furthermore, subjective memory scores significantly correlated with participants' objective assessment of memory. These results suggest participants' perceptions about the extent to which their memory difficulties impact on their social functioning were accurate as they were significantly related to their work status and objective memory scores. However, when analysed further it was found that the results of the questionnaire were explained more by IPS scores than memory scores. Therefore, despite the questions referring to memory abilities, it seems that participants misinterpreted IPS difficulties for deficits in their memory, hence supporting Higginson et al.'s [6] findings that participants lack an accurate perception of their cognitive difficulties. This finding may also be related to the previously mentioned possibility that memory difficulties are more identifiable and more commonly known than IPS problems.

Given the strong correlation found between work status (unable to work) and the subjective memory scores, these results suggest a perception of memory problems (even if they are in fact IPS deficits) may produce poorer social functioning, specifically their ability to work. These results could be explained by participants not attempting to complete work activities because they feel unable to due to their perceived (mostly accurate) memory difficulties. Alternatively, if they were not working participants may have been more focused on their difficulties and so perceived greater deficits in their memory.

Despite being unable to confirm a causal relationship, these results indicate that psychologists should consider an individual's perception of their difficulties in addition to also investigating memory and IPS difficulties objectively. The findings also suggest individuals with MS may need psycho-education on the differences between IPS and memory and then be offered both IPS and memory coping strategies to help them improve their social and occupational functioning.

As expected there was no relationship found between level of social activities and participants' subjective memory score. This indicates that the social activities question on the ESS does not represent the social skills necessary in order to function socially; rather it measures the number of activities the individual still attends. Whereas the subjective memory questionnaire asked participants about specific social tasks affected by memory impairments, e.g. going shopping, making an appointment, or having a conversation. Therefore the ESS is a useful measure for a general overview of a person's social functioning but the subjective memory questionnaire may elicit more information about specific social tasks the individual can or cannot complete. This study is not suggesting the subjective memory questionnaire should be used as an alternative

but it highlights the need for a more detailed measure of assessment of social functioning when an individual is demonstrating memory or IPS difficulties. The Everyday Memory Questionnaire-revised [51] may be such a measure. It is quick and may obtain a detailed account of which social activities the individual with MS is struggling with on a daily basis due to their memory or IPS difficulties.

Verbal and Visual Memory

Participants scored significantly higher on visual memory subtests than verbal memory measures. These findings may indicate that visual memory is less susceptible to the effects of MS and therefore individuals with MS perform better on visual memory tasks. However, as stated previously these results should be taken cautiously as differences in test administration may impact on the findings reported. In the verbal memory test participants hear the story once and are then asked to recall the story back to the researcher. In the visual memory task participants are asked to copy the figure first, and then recall it from memory. Therefore, the time participants spent looking and interacting with the visual stimuli may mean they are expected to perform better on the visual memory subtest than the verbal task; unless the participant is experiencing clear visual memory impairments as then there will be a distinct disparity between visual and verbal memory scores.

Participants' scored significantly higher on measures of delayed visual memory compared to immediate visual memory. These results support the notion that individuals with MS experience 'forgetting' not due to a defect in storage or consolidation but due to a primary deficit in acquisition or encoding [9]. Kessler et al. [9] suggests that this

acquisition deficit may be due to reduced IPS. Immediate memory may be more associated with demyelination in white matter areas but delayed memory is not necessarily affected due to it being more dependent on cortical representation [52]. Demyelination in white matter areas is also associated to IPS [1] therefore immediate memory may be more susceptible in individuals with MS. The current study found a moderate relationship between IPS and both immediate and delayed visual memory. This association may be due to reduced IPS impacting on the participant's ability to encode information during the immediate memory task which may then lead to a lack of information being available for later recall. However, the researcher cannot conclude from the findings from this study that acquisition deficits in MS are related to reduced IPS as other possible factors were not investigated such as motivation, attention or executive function deficits.

Additionally, participants in the current study performed better on measures of visual recognition than visual recall. It has been reported that recognition requires less effortful processing than recall [53] and therefore supports the notion that acquisition deficits in MS may be due to reduced IPS. However, Kessler et al. [9] suggests lower immediate memory scores could also be explained by an executive function deficit or attention/motivation difficulties. This study did not investigate these additional deficits and found that IPS was significantly correlated to both recognition and recall measures. Hence, further research into this area is necessary and a wider range of cognitive and motivational measures should be implemented to fully investigate possible causal explanations for better recognition scores.

Researchers are often presented with the difficult task of making verbal and visual memory tests equally difficult and easily comparable so that the individual can be made aware of their cognitive strengths and weaknesses, this in turn would aid future coping strategies. The results from this study indicate the need for psychologists to take into consideration the differences in stimuli when interpreting psychometric results. Lastly, clinicians working with patients with MS are pressurised to complete a brief cognitive screening measure due to service limitations and the need for a quick screening measure [1]. The results from this study highlighted (Table 5.) that not all participants experienced difficulties in both memory and IPS functioning, i.e. some participants demonstrated IPS deficits but not memory deficits. Therefore in order to fully assess all possible cognitive deficits and offer patients appropriate interventions a 'quick screening' measure will not suffice and a comprehensive neuropsychological assessment will most likely be needed.

The BMIPB

The BMIPB is a useful measure of memory and IPS in individuals with MS however it does present some challenges. As mentioned previously differences in the stimuli presented to participants for verbal and visual memory measures on the BMIPB must be considered when interpreting the results. It may be beneficial to take out the copy figure subtest, as long as visual neglect or impairments have been investigated using other tests, in order to make the visual memory subtest more comparable to the verbal memory subtest. The BMIPB is not alone as these difficulties are encountered by all memory assessments that investigate differences between verbal and visual memory. Another weakness of using the BMIPB with MS patients is that there are no

standardised norms for this specific population. Therefore, it is difficult to reliably interpret the results of the BMIPB for an MS population as current norms are based on a UK general population which was screened for neurological diseases such as MS. It would be beneficial in future research to develop a cut-off point of cognitive impairment specific to individuals with MS. As the BMIPB is used across the UK to assess MS patients it would be clinically useful to investigate the sensitivity and specificity of the BMIPB compared to other memory and IPS measures.

Despite this potential challenge, the BMIPB is a useful, relatively quick measure of memory and IPS in individuals with MS. Results from the BMIPB offer the clinician a detailed summary of the client's strengths and weaknesses in IPS and various memory domains including verbal, visual, immediate, delayed, recall and recognition. Few memory assessments look into as many memory domains as well as IPS, and even fewer take into consideration the impact of motor speed on IPS. As many individuals with MS struggle with motor impairments this part of the BMIPB is extremely useful. Vlaar and Wade [32] investigated using verbal responses for the IPS subtest on the former version of the BMIPB, the AMIPB. They found that when using verbal responses as opposed to the patient writing their answers, the IPS subtest when used over 120 seconds, was still a reliable and reasonable test for major information-processing deficits. Therefore, future research should consider the reliability and validity of using the IPS subtest on the BMIPB in this format in order to make administration less distressing and uncomfortable for individuals who are 'moderately to severely' physically disabled.

The findings from this study are not that dissimilar to Kalmar et al.'s [15] as they found IPS, as measured by the PASAT, was nearly significant at predicting 6% of the variance in everyday functioning. Kessler et al. [9] did not investigate IPS and Higginson et al. [6] used the PASAT to assess information processing. The downfall of using the PASAT is that it is a more distressing and confusing measure and participants often fail to complete the full test. Whereas, all participants in this study were able to complete the IPS subtest on the BMIPB, furthermore none of the participants complained or appeared distressed completing the test. As demonstrated in this study, IPS was found to be associated to social functioning. Therefore this study suggests that the IPS subtest in the BMIPB is a more sensitive measure for assessing IPS impairments. Consequently, it is recommended that the IPS subtest on the BMIPB should be used as one of the screening and monitoring measures in neurological settings. If the IPS is administered in addition to other objective screening measures in addition to subjective measures such as the Everyday Memory Questionnaire [51] and the ESS, the clinician would have greater understanding of which MS symptoms may be impacting on the individuals social functioning and which factor they should investigate further.

Limitations

The present study was subject to a number of important limitations. Firstly, unfortunately due to time and capacity restrictions the researcher was unable to recruit equal numbers of participants in each disease type group. This meant that analyses between group types were limited as the sample size was uneven and small; with a small sample it is more likely to find non-significant differences because of low power

when a real difference may exist. Therefore the reliability of these findings is questionable.

A strength of this research is that the overall the sample size recruited was larger than the sample size calculation originally stated, therefore power was slightly increased, however this is still a relatively small sample size. Also, the study sample recruited lacked variability in level of physical disability and disease activity and so a lack of relationship between physical disability and disease activity with cognitive measures may be due to the sample bias. This impacts on the generalisability of the findings as it is unclear whether individuals with MS who experience more physically disabling MS symptoms have the same relationship to the cognitive variables assessed in this study. The study was also limited by the lack of ethnic diversity in the sample recruited.

Additionally, the cognitive measures assessed were found to have large standard deviations. These results may reflect the huge variability in symptoms in MS due to the different pattern in lesion locations; nevertheless the variation in performance suggests that participants were not performing in a similar way and therefore reduces statistical power.

The study is further limited as the measures used required participants to self-report their difficulties therefore it is unknown whether participants' reports of their everyday activities or physical abilities were accurate. It would be beneficial in future research to include the results from a significant other in order to compare perceived difficulties from a different perspective. Also there are many different versions of the Barthel Index used in research and so it is difficult to directly compare results to previous research.

Other studies [54, 55] have implemented the use of the ADL-MS [56] which may have been more appropriate to use as it was specifically designed to be used for the MS population. The measure takes into account MS symptom severity and how this impacts on the individual's ability to complete a range of everyday activities, including physical and social activities. Unfortunately this measure was not found until after the research had been completed.

The ESS is recommended as a useful measure of everyday social functioning. However, it would have been more beneficial when comparing social versus physical everyday functioning to have these different levels of functioning on the same scale. The Functional Independence Measure [FIM, 57] has been found to be a more reliable measure and the 'gold standard' of physical and functional impairment in individuals with MS [58]. The Functional Assessment Measure (FAM) is an addition to the FIM and is used alongside the FIM; they have been developed into a UK version [59]. Together they are a global measure of disability, cognitive and psychosocial function and would therefore be appropriate for use in further research into MS and everyday functioning. This measure was considered in this study however it requires a full multi-disciplinary team to score individuals and this was not possible due to service limitations. However, for future research it should be utilised due to its global measure of disability and everyday activities. Furthermore, as previously mentioned a more reliable and valid, detailed assessment of the specific social skills that are affected by memory and IPS impairments would be beneficial. This study suggests the use of the Everyday Memory Questionnaire-revised [51] as it has been shown to be a quick, valid and reliable tool that has good face validity for use with MS patients. It also takes into account activities which may be affected by memory and IPS difficulties therefore clear

intervention points and coping strategies relating to everyday activities can be offered. This study did not measure participants' level of fatigue due to previous studies finding no impact of fatigue on cognitive measures or social functioning [6]. However in order to complete a comprehensive assessment, participants could complete the Fatigue Severity Scale [60] which has been recommended for clinical use with MS patients [61].

Lastly, unlike many other studies this research included the patient's perspective on their cognitive and social functioning and it was concluded to be a useful measure to investigate patient insight. Yet, the subjective memory questionnaire has not been used in previous research and it has not been shown to be a reliable or valid measure of perceived memory abilities. The reliability and validity of the questionnaire is uncertain as participants may have been biased to thinking they had a memory deficit as the questions were focused on memory difficulties impacting on everyday activities. Participants who found completing everyday activities difficult may have automatically assumed it was a result of memory deficits due to the research topic. Therefore the findings from this questionnaire are not fully reliable or generalisable. However, descriptive statistics indicated that the results from the questionnaire were normally distributed and not skewed, suggesting good variability on the 3-point Likert scale used to answer questions. The questionnaire could be improved and developed to include open-ended questions to avoid response bias. Despite the measure relating more to IPS difficulties than memory impairments, the questionnaire was a useful indicator of participants' perception of how their cognitive difficulties, when compared to objective measures of cognition, impacted on their social functioning.

Clinical implications

This study found that physical disability was found to be unrelated to measures of cognition. Therefore how someone presents physically was found to not be representative of their cognitive impairment. However, physical disability did relate to all measures of social functioning and so may reflect the individuals need for adaptations and easier access to additional support in the work place. This research highlights the need for clinicians to complete a comprehensive assessment of the individual's physical and cognitive abilities, in addition to considering their psychological functioning such as their perceptions of how their difficulties may be impacting on their social functioning. Without this comprehensive assessment clinicians may not be able to offer an effective intervention which could possibly improve the individual's quality of life.

Previous research has highlighted the need for an effective monitoring measure which would assess for cognitive deficits, this in turn would better inform rehabilitation programmes and enhance appropriate support for the individual [1]. The BMIPB enables both the psychologist and patient to directly infer which everyday activities may be affected by such impairments as the tests used have been found to be relevant to everyday social tasks. The BMIPB has been shown to be a sensitive measure of IPS and a less stressful alternative to the PASAT and should therefore be used by psychologists as an assessment tool for IPS difficulties. The BMIPB is also a valuable test for investigating a variety of memory difficulties in MS patients. Additionally, parallel forms enable the clinician to easily re-assess patients and this is especially important

when offering the appropriate treatment to MS patients due to the quick and changeable nature of the disease course.

This study found that patients may misinterpret IPS difficulties for memory difficulties. Therefore clinicians should offer psycho-education on the different types of cognition which may be impacting on the individual's everyday functioning. Coping strategies can then be implemented to help patients overcome their specific cognitive difficulties.

The notion that patients should have at least a brief neuropsychological screening assessment is supported by NICE guidelines [62]. The current study recommends that patients as part of their treatment should be continuously monitored for cognitive impairments and this study suggests IPS, in addition to memory, should be included in this comprehensive cognitive assessment battery.

Furthermore, Rogers and Panegyres [1] report that certain medications, such as corticosteroids amongst others, may impact on cognition therefore patients with MS need to be regularly assessed for cognitive deficits. Research has also demonstrated that disease-modifying drugs such as glatiramer acetate (GA) or interferon (IFN) beta [63] and acetylcholinesterase inhibitors (AChEIs) [64] may have a beneficial impact on cognitive function. Hence, the continuous monitoring of cognitive impairments in MS is also useful when considering effective drug treatments.

Future research

Future research should aim to further explore the relationship between specific cognitive impairments and social functioning in individuals with MS. As previously stated a wider range of cognitive and psychological measures should be used, including the assessment of executive function, attention, motivational factors, fatigue and a more detailed measurement of specific social tasks affected by cognitive deficits.

Furthermore, as the subjective measure of memory is a new questionnaire further research testing the validity and reliability of the measure is needed. Also further research is necessary in order to clarify whether actual or perceived cognitive impairment, or a combination of both impacts more on everyday functioning. The findings from this study suggest actual IPS scores predict more of the variance in everyday social activities however these findings need to be replicated in a larger sample size before being able to generalise these findings. It is important to further investigate the possible impact of the patient's perceptions of their abilities. Maladaptive or unrealistic thoughts about their abilities and cognitive impairments may lead to greater anxiety or low mood and could affect the patient's ability or motivation to complete everyday tasks. If this is the case then clinicians can help the patient form more realistic and adaptive perceptions during therapy. Hence there are potentially important clinical implications which may arise from further research in this area.

Also, due to the limited sample size this study did not investigate the impact of disease activity on cognitive variables. Both Higginson et al. [6] and Kessler et al., [9] support the notion that disease activity rather than disease type is more indicative of cognitive

difficulties. Therefore longitudinal studies should be used as these would monitor and record changes in disease course and activity such as number and severity of relapses, over time. It may then be possible to investigate whether disease activity is associated to cognitive deficits. Additionally, with a larger sample size it is hoped that there would be greater variation in physical disability and ethnicity, therefore improving the generalisability of results to the wider MS population.

Lastly, this study has highlighted the importance of assessing the patient's perception of how their cognitive difficulties influence their social abilities as there was a strong relationship found between perceived and actual social abilities. However, if clinicians were to assess participants' perceptions previous research suggests a significant others' ratings may be additionally informative. Correlations with performance measures have been found to significantly increase when the questionnaires are completed by significant others [65, 66]. However, few studies have investigated the differences between significant other and patients' perceptions [6]. Therefore further research is necessary in order to clarify these differences and investigate the variance explained by both significant other and patient perceptions on performance on actual cognitive and social functioning measures.

Conclusion

When working with individuals with MS it is important to recognise that deficits in basic cognitive processes, such as processing speed, may detrimentally affect performance in other areas, such as social activities in everyday life. There are now more and more fMRI studies investigating white matter regions and pathways related to MS [67]. It is beneficial to individuals with MS to map out and better understand MS symptoms in order to prepare them for what may occur in the future. However, this study has also highlighted the usefulness of psychometric testing, specifically the IPS subtest of the BMIPB, in informing individuals about specific cognitive impairments which may impact on their social functioning. Psychometric testing as opposed to scans is cheaper, quicker and can identify specific cognitive deficits. These test results then inform clinicians about which interventions would be most effective in improving the individual's ability to cope with changes in their cognitive and social functioning. These changes and interventions can be monitored and assessed at periodic time intervals. This type of on-going assessment and support is a necessity for individuals with MS given the possible impact that cognitive impairments could have on their social functioning and consequently, quality of life.

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PART 3: Appendices

Appendix 1: Reflective statement

Throughout the research process I documented my reflections when facing the challenges and exciting milestones of completing such an exhilarating journey. It is the aim of this reflective statement to share this research journey, focusing on the initial planning stages, the experiences of recruitment and meeting with participants, and what I have personally learnt from this experience.

Designing the Research

The planning stage of the research was both exciting and daunting. I was keen to be involved and create a research project that would have both clinical and research implications not only for clinicians but also for service users. I also wanted to focus my research on something which would reflect my interests in clinical psychology that I would like to pursue later in my career. However, finding a gap in the research specific to multiple sclerosis (MS) and an idea that was unique was difficult. My supervisor and I bounced some ideas around and it became clear that cognition, specifically memory and IPS difficulties were becoming more widely recognised in MS. I felt it was important at the early stages of the research to gain advice from service users themselves. After attending and meeting with a number of people at the MS centre it was apparent that the social impact of these deficits could be enormous and thus the focus of the research became clear.

Throughout the initial planning stages it was important to gain ideas and advice from various health professionals who worked directly and alongside individuals with MS. The working alliance and relationships I developed with the MS specialist nurses were especially valuable. The support and enthusiasm they gave me throughout the project was greatly appreciated. However, the wide range of ideas from my supervisor and other professionals meant that it was at times hard to balance everyone's expectations about the research. In the end a compromise was met and the study incorporated both the development of a psychometric measure and the investigation of the social impact of memory and IPS deficits.

Whilst sharing the final research proposal it became evident that the aims of the research were over ambitious. The sample size needed, in order to make the norms valid and reliable, would have been above 90 which was unrealistic given the time-frame available. This was disheartening but I was reminded that I had to remain open and ready for unexpected changes in order to make the research possible, nothing was set in stone. So the research was downsized and made more practically realistic to complete.

Throughout the research process it was important for me to keep in mind the possible clinical implications and experiences of the MS patients who would take part in this research. Due to service limitations psychological support (referral) was unavailable to the majority of participants taking part in the research. Hence, it was a major ethical issue to consider how to support participants subsequent to them receiving their memory test results. Therefore participants were offered the chance to discuss their results with the researcher and a one-off workshop was offered to all participants and their carers which offered help interpreting their results and basic coping strategies.

Gaining ethical approval for the study was a surprisingly straight forward experience. However, the process was time-consuming and it felt very much out of my hands. I used the time to think about my systematic literature review and organise the practicalities of testing participants, such as booking rooms and getting all the measures printed/ordered. Yet, I felt frustrated that I had everything ready to go in order to start recruiting and meeting participants but had to wait for each research site to approve the study. I was anxious about time but it was important to remain confident that the next stage would happen soon and that I'd be able to cope with the reduced time to recruit participants.

Data Collection

I felt relieved but knew the hard work was only just about to begin when approval was obtained for both research sites. The MS nurses were fantastically organised and a wave of referrals to the study came in. It was difficult managing the demands of the research whilst on placement and alongside completing other pieces of work. It was also tiring travelling all around Yorkshire and the East Riding to visit participants and then inputting the data. But, it was completely worth it. The people I met whilst conducting this research were awe-inspiring. The participants, and their family members, welcomed me and were incredibly open to sharing their experiences, the good and the bad, with me. I learnt about how resilient and adaptive people are and was amazed by their strength to keep on going despite suffering very challenging and life-changing symptoms. I will not forget these inspiring stories. I learnt about the process of adjustment, different ways of coping and the importance of supportive family and friends.

At times it was difficult working on my own when listening to highly emotional stories and so it was important that I had a reassuring supervisor and colleagues to support me

when needed. As opposed to my placement work, it was refreshing to work with a group of people who were coping relatively well. It was however difficult talking to someone about emotionally hard topics and not being able to offer any planned therapeutic input. Yet, I was struck by the importance of just listening and 'being there' for someone and I knew the MS nurse was a great support to those participants who may have needed additional support.

I would not have been able to recruit as many participants as I did without the support from the MS nurses. Despite my polite nagging and emails they were always enthusiastic and optimistic about recruiting more participants. I learnt the importance of building good working alliances and my confidence grew when liaising with other professionals and services. The referrals came in waves and as my pre-planned deadline for recruitment came closer it was obvious that I wouldn't reach my target sample size. I pushed the deadline back and continued to recruit participants. This was a stressful time as I was writing up the thesis at the same time as meeting participants and finishing my placement. Nevertheless I had faith the work would get done and the participants would be recruited. I was reminded of my own limitations and that I could only do so much in the time available and so decided to stop recruiting when I reached just over my target sample size.

Overall, data collection was a tiring yet rewarding experience. I enjoyed meeting with the participants and listening to their stories, they reminded me about the importance of doing the research and I could reflect on this during the stressful times.

Choice of Journals

I decided to write my systematic literature review (SLR) for the Clinical Psychology Review. This journal was chosen as my SLR paper highlights clinical implications specific to clinical psychologists who work with MS patients. It is hoped that by targeting this large audience that professionals who work therapeutically with MS patients will become more aware of the importance of involving partners in therapeutic work.

The Journal of Neurological Sciences was chosen for the empirical paper due to my paper focusing on the psychological impact of cognitive deficits reported in MS patients. This journal has a multidisciplinary audience including professionals interested in medical, psychological, social and rehabilitation issues related to MS. The empirical paper has implications relevant to all these areas and so this journal was thought appropriate.

Report Writing

The time taken to input the data, organise the spreadsheets and arrange the data so that it could be easily analysed took longer than expected. However I soon got into a routine and I became more efficient. The analysis was definitely challenging due to the overwhelming amount of data that I had. It felt daunting at first trying to link and analyse the data whilst attempting to hold the different ideas and interpretations in my head. The support from other trainees and my supervisor was incredibly valuable during this time. At times it felt like the empirical paper was separating into two sections but as ideas came together it felt more interconnected.

It was exciting when findings were significant and I enjoyed talking to my supervisor about the interpretation and clinical implications of these findings. It was easier to hold the different findings together once they were written down, however getting the idea on paper was at times difficult. The constant feeling of on-going anxiety about the vast amount of work needed to complete the thesis was tiring but it also helped me manage my time better and I gained a better understanding of how to manage my own stress. My confidence about my research was boosted when I got the opportunity to share my findings at the first MS Cognition conference in France. It was nerve-wracking but also exciting to be surrounded by the people who had influenced by own study. It was a great opportunity to ask the lead researchers in this field of psychology about my findings and also listen to upcoming research areas. I was impressed by the amount of research going into this area of MS and I was glad that my findings seemed to interest people, despite it being one of the smallest studies there!

When writing my SLR and reflecting on other people's research from the conference I was made more aware of the studies methodological flaws. I was mindful that the validity of subjective memory questionnaire was questionable and that it would have been useful to further validate the BMIPB by comparing it to other memory and IPS measures. I also wished I'd used additional research sites to gain a more diverse sample population. Writing about my limitations was frustrating and but also made me keen to complete more research in this field of psychology and build on ideas that have developed whilst writing this research.

Summary

As I am nearing the end of this research journey I look back at this process with a sense of achievement but it will also be sad to move on and end the project. I have enjoyed

working in this area of psychology and learning about how to manage and develop a study from beginning to end. I have learnt to better manage the anxiety that arises from uncertainty and I feel I have developed my academic skills whilst writing up this thesis. Attending the conference made me realise that I am at the early stages of my career in clinical psychology and I have time to develop on ideas and learn from the limitations of this study. The importance of family and friends was made obvious when meeting participants but also personally it was important to reflect on the value of supportive relationships during times of stress.

The most significant and valuable moments of this research for me are the times when participants were incredibly open and willing to share their story with me. I will never forget how inspiring their stories were and I am truly grateful for them sharing their experiences with me. My interest in MS continues and I hope I can further help individuals suffering from MS both clinically and through future research.

Appendix 2: Guidelines for Submission to Journals

Appendix 2.1: Clinical Psychology Review Author Guidelines

Ethics in publishing

For information on Ethics in publishing and Ethical guidelines for journal publication seehttp://www.elsevier.com/publishingethics and http://www.elsevier.com/ethicalguidelines.

Conflict of interest

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Preparation

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009).

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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Abstract

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Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

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Appendix 2.2: Journal of the Neurological Sciences Author Guidelines

Journal of the Neurological Sciences

Guide for Authors
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[1] Bondi M, Kaszniak A. Implicit and explicit memory in Alzheimer's disease and Parkinson's disease. J Clin Exp Neuropsychol 1991;13:339-58.
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Schulz, KF. The quest for unbiased research: Randomized clinical trials and the CONSORT reporting guidelines. Ann Neurol 1997; 41:569-573.

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Appendix 3: Ethical and Research Governance Approval

Appendix 3.1: NHS Ethical Approval

Appendix 3.2: Research Governance Approval for HEY NHS Foundation Trust

Appendix 3.3: Research Governance Approval for York Teaching Hospital NHS

Foundation Trust

Appendix 3.1: NHS Ethical Approval

REMOVED FOR HARD-BINDING

Appendix 3.1: NHS Ethical Approval continued

REMOVED FOR HARD-BINDING

Appendix 3.1: NHS Ethical Approval continued

REMOVED FOR HARD-BINDING

Appendix 3.1: NHS Ethical Approval continued

REMOVED FOR HARD-BINDING

Appendix 3.2: Research Governance Approval for HEY NHS Foundation Trust

REMOVED FOR HARD-BINDING

Appendix 3.3: Research Governance Approval for York Teaching Hospital NHS Foundation Trust

REMOVED FOR HARD-BINDING

Appendix 4: Supplementary Information for the Systematic Literature Review

Appendix 4.1: Rationale for the inclusion and exclusion criteria used within the

systematic literature review

Appendix 4.2: Data Extraction Form

Appendix 4.3: Quality Assessment Checklist for Studies

Appendix 4.4: Sources of items included in checklist

Appendix 4.5: Quality Assessment by Rater A and Rater B for Studies

Appendix 4.6: Reasons for rejected studies not used within the systematic literature

review

Appendix 4.1: Rationale for the inclusion and exclusion criteria used within the systematic literature review

Inclusion/Exclusion Criteria	Rationale
Studies were included if the majority of the sample were married or partners.	- Due to the limited research in this field there is a variety in type of relationship in the samples, e.g. partner, family member, friend. Therefore, instead of rejecting all studies that had mixed relationship types, it was thought appropriate to include only those studies whose majority of the sample were married. The findings of these studies would therefore be appropriate for this review.
Studies were not included if the outcome measures were based solely on caregiver/partner. Neither were studies included if the aim of a study was to investigate the impact of MS on the relationship or partner.	- There are many previous studies focused on the impact of caring for an individual with MS for the caregiver/partner. This review is focusing on the limited research that exists that aims to investigate the impact of relationship factors on the individual with MS or their partner.
Studies were not included if they only reported the prevalence of marital status in MS patients.	- Marital status alone is not informative enough for informing clinicians on how best they can intervene in individual or couple therapy. This study is focusing on relationship factors within the couple's dyad rather than the effects of whether they are married or not.
Studies were not included if they focused on the impact of MS on sexual relationships/satisfaction.	- It has been well documented that MS can affect the individual's sexual relationship. The review's aim was to focus on the psychological and disease related impacts of *psychological* factors within the couples' relationship. Therefore the sexual element of the relationship was not the focus of this review. Furthermore there are a vast number of studies published in this area and it was felt that a separate systematic literature review focusing solely on the sexual relationship in MS would be more appropriate.
Studies were not included if the sample included individuals with other medical conditions.	- It has been highlighted that relationship factors impact on the well-being of other medical populations such as in cancer patients. Therefore this review aimed to investigate if these findings were also found in individuals with MS.
Not printed in English	- The articles could not be translated due to financial and time constrictions.

Appendix 4.2: Data Extraction Form

Study title:

Authors:

Year of publication:

Source (i.e. Journal: Volume / Pages / Country of Origin) and reference:

Study Characteristics

Research question/aims:

Duration of study:

Quality Score:

Study design

Quantitative/Qualitative:

Participant Characteristics

Number of people (or dyads):

Age of participants:

Relationship duration:

Relationship type:

Gender ratio (female:Male):

 Ethnicity:

Geographical region:

Disease type:

Disease duration:

Employment status:

Other information:

Participant Recruitment

Recruitment methods:

Inclusion criteria:

Exclusion criteria:

Participation rate:

Procedure

Details of data collected

Method of data collection:

What was measured?

Which outcome measures were used?

Number of times data collected :

Results & Analysis

Qualitative:

Analysis method:

Theoretical perspective:

Themes/ Main findings:

Quantitative:

Statistical tests?

Summary of Results (main findings and statistical significance):

Conclusions

Interpretation of results:

Limitations:

Key links to theory/literature:

Implications of findings:

Further research:

Notes/comments:

Appendix 4.3: Quality Assessment Checklist for Studies

Section	Question	Yes (1)	No (0)	Unable to determine (0)
Abstract	1. Provides an informative and balanced summary of what was done and what was found? (Both)			
	2. Does the study explain the scientific background and rationale for the investigation being reported? (Both)			
Introduction	3. Is the hypothesis/aim/objective of the study clearly described?(Both)			
	4. Are the main outcomes to be measured clearly described in the Introduction or Methods section? (Quan only)			
Methods	5. Were the main outcome measures used in the study valid and reliable? (Quan only)			
Design	6. Is a qualitative approach appropriate? (Qual only)			
	7. Is the qualitative methodology used appropriate to the research question(s)? (Qual only)			
	8. Are the underpinning values and assumptions in relation to the qualitative method (questions used) discussed? (Qual only)			
	9. Does the study describe a power calculation to determine sample size? (Quan only)			
	10. Have the inclusion and exclusion criteria been clearly described?(Both)			
	11. Are the characteristics of the participants included in the study clearly described? Must include at least; diagnosis type, duration of disease, age, gender, and relationship duration. (Both)			
Participants	12. Is the 'relationship type' described? (Both)			
	13. Is data collected from both partners, as opposed to just the carer or just the person with MS?(Both)			
	14. Were the subjects asked to participate in the study representative of the MS population? Were participants recruited from more than just one MS Society? (Both)			

Appendix 4.3: Quality Assessment Checklist for Studies continued

Section	Question	Yes (1)	No (0)	Unable to determine (0)
Results	15. Does the study provide estimates of random variability in the data for the main outcome? (In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.) (Quan only)			
	16. Has the strategy of statistical analysis been clearly stated? (Quan only)			
	17. Is the statistical analyses strategy used to analyse the main outcomes appropriate? (Quan only)			
	18. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?(Quan only)			
	19. If any of the results of the study were based on 'data dredging', was this made clear? (Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.) (Quan only)			
	20. Is the data analysis sufficiently rigorous? (Qual only)			
	21. Are the findings internally coherent, credible? (Qual only)			
	22. Is the data analysis strategy reported, i.e. how themes and concepts were derived? (Qual only)			
	23. Was there more than one rater? (Qual only)			
	24, Are the findings relevant? (Qual only)			
Discussion	25. Does the study summarise key results with reference to study objectives? (Both)			
	26. Does the study discuss clinical relevance and generalisability of the results? (Both)			
	27. Does the study give a cautious overall interpretation of results considering objectives, limitations, analyses, results from other relevant studies? (Both)			
	28. Does the study discuss limitations? (Both)			

Appendix 4.4: Sources of items included in checklist

Section	Question	Type	Original source*
Abstract	1. Provides an informative and balanced summary of what was done and what was found? (Both)	Reporting	STROBE
Introduction	2. Does the study explain the scientific background and rationale for the investigation being reported? (Both)	Reporting	STROBE
	3. Is the hypothesis/aim/objective of the study clearly described?(Both)	Reporting	D&B
Methods *Design*	4. Are the main outcomes to be measured clearly described in the Introduction or Methods section? (Quan only)	Reporting	D&B
	5. Were the main outcome measures used in the study valid and reliable? (Quan only)	Internal validity	D&B
	6. Is a qualitative approach appropriate? (Qual only)		NICE (2007)
	7. Is the qualitative methodology used appropriate to the research question(s)? (Qual only)		NICE (2007)
	8. Are the underpinning values and assumptions in relation to the qualitative method (questions used) discussed? (Qual only)		NICE (2007) (adapted)
	9. Does the study describe a power calculation to determine sample size? (Quan only)	Power	D&B (adapted)
	10. Have the inclusion and exclusion criteria been clearly described?(Both)	Reporting	STROBE (adapted)
Participants	11. Are the characteristics of the participants included in the study clearly described? Must include at least; diagnosis type, duration of disease, age, gender, and relationship duration.(Both)	Reporting	D&B

Appendix 4.4: Sources of items included in checklist continued

Section	Question	Type	Original source*
Participants	12. Is the 'relationship type' described? (Both)	Reporting	Specific extension of the question above
	13. Is data collected from both partners, as opposed to just the carer or just the person with MS?(Both)	Reporting	Specific extension of the question above
	14. Were the subjects asked to participate in the study representative of the MS population? Were participants recruited from more than just one MS Society? (Both)	External validity	D&B (adapted)
Results	15. Does the study provide estimates of random variability in the data for the main outcome? (In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.) (Quan only)	Reporting	D&B
	16. Has the strategy of statistical analysis been clearly stated? (Quan only)	Reporting	STROBE (adapted)
	17. Is the statistical analyses strategy used to analyse the main outcomes appropriate? (Quan only)	Reporting	D&B
	18. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?(Quan only)	Reporting	D&B
	19. If any of the results of the study were based on 'data dredging', was this made clear? (Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.) (Quan only)	Internal validity	D&B

Appendix 4.4: Sources of items included in checklist continued

Section	Question	Type	Original source*
Results	20. Is the data analysis sufficiently rigorous? (Qual only)		NICE (2007)
	21. Are the findings internally coherent, credible? (Qual only)		NICE (2007)
	22. Is the data analysis strategy reported, i.e. how themes and concepts were derived? (Qual only)		Specific extension of the question above
	23. Was there more than one rater? (Qual only)		Specific extension of the question above
	24. Are the findings relevant? (Qual only)		NICE (2007)
Discussion	25. Does the study summarise key results with reference to study objectives? (Both)	Reporting	STROBE
	26. Does the study discuss clinical relevance and generalisability of the results? (Both)	Reporting	STROBE
	27. Does the study give a cautious overall interpretation of results considering objectives, limitations, analyses, results from other relevant studies? (Both)	Reporting	STROBE
	28. Does the study discuss limitations? (Both)	Reporting	STROBE

*Type of question taken from the Downs and Black Checklist for measuring quantitative study quality; D&B: Downs & Black Quality Checklist (1998); STROBE: Strengthening the Reporting of Observational studies (2007). The qualitative study quality questions were taken from NICE: Appendix H, Methodology checklist (2007).

Appendix 4.5: Quality Assessment by Rater A (and Rater B) for Studies

Authors	Item														Key:
	Abstract	**Introduction**				**Design**						**Participants**			1=yes,
	1	2	3	4 (Quan)	5 (Quan)	6 (Qual)	7 (Qual)	8 (Qual)	9 (Quan)	10	11	12	13	14	0 = no or unable to deter-mine
Lehman & Hemphill (1990)	1 (1)	1 (1)	1 (1)	-	-	1 (1)	0 (0)	1 (1)	-	1 (0)	0 (0)	1 (1)	0 (0)	0 (0)	
Woollett & Edelmann (1988)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	
Kleiboer et al (2007)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	
Kleiboer et al (2006)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	
Pakenham (1998)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	
Ackroyd et al (2011)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (0)	0 (0)	1 (1)	1 (1)	1 (0)	
Wineman et al (1993)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	0 (0)	1 (1)	1 (1)	1 (1)	0 (0)	
McPheters & Sandberg (2010)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	0 (0)	
Pozzilli et al (2004)	1 (1)	1 (1)	1 (1)	1 (0)	1 (1)	-	-	-	0 (0)	1 (1)	0 (0)	1 (1)	1 (1)	1 (1)	
Schwartz & Kraft (1999)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	1 (1)	0 (0)	1 (1)	0 (0)	0 (0)	
Harrison et al (2004)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	1 (1)	
Percentage Agreement	100%	100%	100%	90%	100%	100%	100%	100%	100%	81.8%	100%	100%	100%	90.9%	

Appendix 4.5: Quality Assessment by Rater A (and Rater B) for Studies continued

Authors	Item														Total score (20)
	Results										Discussion				
	15 (Quan)	16 (Quan)	17 (Quan)	18 (Quan)	19 (Quan)	20 (Qual)	21 (Qual)	22 (Qual)	23 (Qual)	24 (Qual)	25	26	27	28	
Lehman & Hemphill (1990)	-	-	-	-	-	0 (0)	0 (0)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	14 (13)
Woollett & Edelmann (1988)	1 (1)	0 (0)	1 (1)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	0 (0)	0 (0)	14 (14)
Kleiboer et al (2007)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	18 (18)
Kleiboer et al (2006)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	19 (19)
Pakenham (1998)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	0 (0)	17 (17)
Ackroyd et al (2011)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	18 (16)
Wineman et al (1993)	1 (1)	1 (1)	1 (0)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (0)	1 (1)	0 (0)	15 (13)
McPheters & Sandberg (2010)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	17 (17)
Pozzilli et al (2004)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	18 (17)
Schwartz & Kraft (1999)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	15 (15)
Harrison et al (2004)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)	-	-	-	-	-	1 (1)	1 (1)	1 (1)	1 (1)	16 (16)
Percentage Agreement	100%	100%	90%	100%	100%	100%	100%	100%	100%	100%	100%	90.9%	100%	100%	

Appendix 4.6: Reasons for rejected studies not used within the systematic literature review

Rejected study	Reason
King and Arnett (2005)	- Explored how factors associated with MS impacted on dyadic adjustment (wrong direction).
Starks, Morris, Yorkston, Gray and Johnson (2010)	- Identified strengths and possible risk factors that influence relationship stress within couple (wrong direction).
Gold-Spink, Sher and Theodos (2000)	- Mostly examined the psychological effects of MS on caregiver.
Zeldow and Pavlou (1984)	- Investigated how MS impacts on the person's interpersonal functions

King, K. E., & Arnett, P. A. (2005). Predictors of dyadic adjustment in multiple sclerosis. *Multiple Sclerosis, 11*, 700-707.

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Starks, H., Morris, M. A., Yorkston, K. M., Gray, R. F., & Johnson, K. L. (2010). Being in- or out-of-sync: Couples' adaptation to change in multiple sclerosis. *Disability and Rehabilitation, 32*(3), 196-206.

Zeldow, P. B., & Pavlou, M. (1984). Physical disability, life stress, and psychological adjustment in multiple sclerosis. *The Journal of Nervous and Mental Disease, 172*(2), 80-84.

Appendix 5: Supplementary Information for Empirical Paper

Appendix 5.1: Demographics Questionnaire

Appendix 5.2: Hospital Anxiety and Depression Scale (HADS)

Appendix 5.3: Environmental Status Scale (ESS)

Appendix 5.4: Barthel Index

Appendix 5.5: Participant Information Sheet one

Appendix 5.6: Participant Information Sheet two

Appendix 5.7: Participant Consent Form

Appendix 5.1: Demographics Questionnaire

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Demographic Questionnaire

Please answer the following questions regarding general information about yourself and some questions about your MS

1. What is your gender?

   Female ☐   Male ☐

2. How old are you?

   …………………………..

3. Did you attend full time education, if yes what level of education did you go up to?

   Yes ☐   No ☐

   ………………………………………………………………………………………………

4. Are you currently employed? If yes, what is your job title?

   Yes ☐   No ☐

   ………………………………………………………………………………………

5. On average, how many hours of **face to face** support do you have per week?

   ☐ none

0-7 hours per week	More than 21 hours per week
8-14 hours per week	Don't know
15-21 hours per week	Other (please specify) …………….......

6. What type of MS are you currently diagnosed with?

   ☐ Relapsing-Remitting MS
   ☐ Secondary Progressive MS
   ☐ Primary Progressive MS

7. What date/year did you first notice your MS symptoms?

   ……………………………………………………………………………………………

Appendix 5.1: Demographics Questionnaire continued

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8. What date/year were you formally diagnosed with MS?

   ……………………………………………………………………………………

9. How many times have you been admitted to hospital, due to your MS, in the **last 6 months**?

   ……………………………………………………………………………………

10. How many relapses have you had (which have been confirmed by a nurse) in the **last 6 months**?

   ……………………………………………………………………………………

11. Did you use oral steroid therapy during this time?   Yes ☐   No ☐

Memory questions

1. Do you feel your memory has deteriorated?

   Not at all (0)   A little (1)   Yes (2)

2. Do you feel your memory affects your ability to complete everyday tasks? Such as remembering where you put things, remembering a shopping list?

   Not at all (0)   A little (1)   Yes (2)

3. Do you feel your social activities are affected by your memory, such as planning events, remembering appointments?

   Not at all (0)   A little (1)   Yes (2)

4. Do you feel your ability to have a conversation is affected by your memory such as remembering what someone has said previously or following a conversation?

   Not at all (0)   A little (1)   Yes (2)

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Appendix 5.2: Hospital Anxiety and Depression Scale (HADS)

REMOVED FOR HARD-BINDING

Appendix 5.3: Environmental Status Scale (ESS)

REMOVED FOR HARD-BINDING

Appendix 5.3: Environmental Status Scale (ESS) continued

REMOVED FOR HARD-BINDING

Appendix 5.3: Environmental Status Scale (ESS) continued

REMOVED FOR HARD-BINDING

Appendix 5.4: Barthel Index

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Appendix 5.5: Participant Information Sheet one

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Memory and information processing speed and everyday functioning in individuals with MS

What is the purpose of the study?

The aim of this study is to help improve the quality of life of individuals with MS by identifying memory and information processing speed difficulties, which would in turn enable clinicians to offer improved support and intervention strategies earlier in the disease course. Currently it is not compulsory that patients with MS are assessed on changes in their cognitive ability. However, cognitive difficulties may have a detrimental effect on the individual's ability to perform everyday activities. Therefore the aim of this study is to investigate the effects of memory and information processing speed on the ability to perform everyday activities in individuals with MS. This study is being undertaken for educational purposes, as part of my Doctorate in Clinical Psychology.

What would be involved in taking part?

You will be asked to complete a number of questionnaires about your ability to perform everyday activities and answer questions regarding disease specific information such as, when did you first notice your symptoms of MS? A finger tapping test will be administered which will take no more than 5 minutes. Mood will also be assessed as it is important to explore the potential influence it may have on the other results. Lastly, you will be asked to complete a measurement which assesses your memory and information processing speed. You could complete these questionnaires and assessment at the University of Hull (Hertford Building) or at your home with the researcher. The questionnaires and assessment will take up to 1 hour and 40 minutes to complete.

What would I contribute by participating?

You would help individuals with MS better understand how cognitive difficulties may impact on their ability to perform everyday activities. These findings could also help inform clinicians and the National Health Service in how to improve future intervention strategies for individuals with MS.

What should I do next?

If you think you would like to take part please read the Information Sheet which starts on the next page.

Thank you.

Helen Broome (H.Broome@2009.hull.ac.uk) (07843484824)

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Appendix 5.6: Participant Information Sheet two

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Memory and information processing speed and everyday functioning in individuals with MS

We would like to invite you to take part our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

Part 1 of this information sheet tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

If you have any questions, please get in touch with us by phone or email.

PART 1

What is the purpose of the study?

The aim of this study is to help improve the quality of life of individuals with MS by identifying memory and information processing speed difficulties, which would in turn enable clinicians to offer improved support and intervention strategies earlier in the disease course. Currently it is not compulsory that patients with MS are assessed on changes in their cognitive ability. However, cognitive difficulties may have a detrimental effect on the individual's ability to perform everyday activities. Therefore the aim of this study is to investigate the effects of memory and information processing speed on the ability to perform everyday activities in individuals with MS. This study is being undertaken for educational purposes, as part of my Doctorate in Clinical Psychology.

Why have I been invited?

We have given this information sheet to you because you asked for further information about the study in response to being informed about the study by your named professional.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care that you receive.

Appendix 5.6: Participant Information Sheet two continued

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What will happen to me if I take part?

You will be asked to complete a number of questionnaires about your ability to perform everyday activities and answer questions regarding disease specific information such as, when did you first notice your symptoms of MS? A finger tapping test will be administered which will take no more than 5 minutes. Mood will also be assessed as it is important to explore the potential influence it may have on the other results. Lastly, you will be asked to complete a measurement which assesses your memory and information processing speed. You could complete these questionnaires and assessment at the University of Hull (Hertford Building) or at your home with the researcher. The questionnaires and assessment will take up to 1 hour and 40 minutes to complete.

Expenses and payments

Unfortunately, as this is a thesis project the researchers are not funded to cover your travel costs. The researcher will try and be flexible and arrange a meeting at a time and place best suited to you.

What are the possible disadvantages of taking part?

It may be tiring to complete the measurements. To overcome this, you are able to take breaks between questionnaires and assessments.

It may be emotionally upsetting answering questions on your MS, your ability to perform everyday functioning and your current mood. Furthermore, some of the tests may be difficult to complete when assessing your memory and information processing. However, everyone finds a number of the questions on the memory/information processing assessment difficult, the assessment is designed so the questions get harder to answer, and therefore it is unlikely anyone will answer all the questions correctly. The researcher will be there to support you throughout the assessments/questionnaires and you can decide to withdraw at any time during the study.

What are the possible benefits of taking part?

We cannot promise that the study will help you, but it may encourage you to think more about the changes in your own cognitive ability and enable you to receive the correct support. The information we get from the study may help other individuals with MS better understand how cognitive difficulties may impact on their ability to perform everyday activities. These findings could also help inform clinicians and the National Health Service in how to improve future intervention strategies for individuals with MS. Little research has been done in this area of MS and so you will also aid in expanding the current literature on how cognitive changes impact on everyday functioning in individuals with MS.

Appendix 5.6: Participant Information Sheet two continued

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What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes Part 1. If the information in Part 1 has interested you and you are considering taking part, then please read the additional information in Part 2 before making a decision.

PART 2

Will my taking part in the study be kept confidential?

- We shall write a code number on your questionnaires and score sheets completed in our meeting. Your name, your address or any other personal information will not be on your data stored. We shall store your questionnaires and score sheets in a locked filling cabinet. Only Helen Broome will have access to that cabinet.
- We shall store your consent form that links your code number to your name (and address if assessments are requested to be completed at home) in a securely locked filling cabinet that only the Academic Supervisor, Miles Rogish, has access to.
- Helen Broome and Miles Rogish have a duty of confidentiality to you as a research participant.
- We shall combine your data with data gathered from other individuals with MS. We shall analyse your data anonymously.
- We shall retain your questionnaires and score sheets from our meeting for five years and shall then dispose of them securely.
- If you request your memory and information processing speed assessment results, Miles Rogish will supervise Helen Broome in the writing of your results and then send the results to your address. Helen Broome will not see your name and the results together at any point during the study, however in order to send the results letter, Miles Rogish will have to add your name onto the completed results letter. The data collected during the study will remain stored anonymously.
- Only Helen Broome and Miles Rogish will have access to your data collected in this study.

Appendix 5.6: Participant Information Sheet two continued

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What will happen to the results of the study?

We shall report the results of the study to you (if requested) and at medical and scientific meetings. It is also possible that we shall publish the results in medical and scientific journals. You will not be identified in reports or publications.

Who is organising the research?

The study is organised by Helen Broome, a Trainee Clinical Psychologist studying at the University of Hull. All Trainee Psychologists are expected to create and run a research study. Dr James Harley is acting as Field Supervisor for the study and Miles Rogish is the Academic Supervisor (University of Hull) for the study, he is a Consultant Clinical Psychologist.

What will happen if I do not enjoy completing the questionnaires/ the meeting?

You can end your participation in the study at any time. If you decide to leave the study for good, we would keep the results of the questionnaires/scores that you had completed up until that point. All data will remain anonymous.

What if there is a problem?

If you have a concern about any aspect of the study, you should speak to Helen Broome who will do her best to answer your questions. Her addresses, telephone number and email address are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through the complaints procedure of the University of Hull. You can start that procedure by getting touch with the Head of the Department and course Director of Clinical Psychology and Psychological Therapies, Dr Peter Oakes.

Dr Peter Oakes
Department of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
Cottingham Road
Hull HU6 7RX
Telephone: (01482) 464164/464101
Email: d.lam@hull.ac.uk

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay your legal costs.

Appendix 5.6: Participant Information Sheet two continued

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Who has reviewed the study?

All research which involves patients of the National Health Service is looked at by an independent group of people; this study was reviewed by the North East Research Ethics Proportionate Review Sub-Committee. This study has been reviewed and given a favourable opinion by the local Research Ethics Committee of the National Health Service associated with your hospital.

What if you want more information?

If you want more information about the study, please get in touch with Helen Broome.

Helen Broome
Department of Clinical Psychology and Psychological Therapies
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Telephone: 07843484824

Email: H.Broome@2009.hull.ac.uk

If you want to talk to someone else about whether or not to take part, you could get in touch with the doctors and/or the MS Nurse who looks after you, family or friends.

What should I do next?

If you are interested in taking part in this study please send the **reply slip** (which can be found on the next page) to Helen Broome in the freepost envelope provided. Once Helen receives the reply slip she will ring you on the number you have given on the reply slip in 7 days to arrange a venue and time to meet. Alternatively, you can ring Helen on 07843484824 to arrange a meeting instead of sending the reply slip.

The meeting can take place at the University of Hull (Hertford Building) or at your home. **Please bring your consent form to your meeting with Helen Broome**. Furthermore, **please bring your reading glasses or hearing aid, if you need them.**

If you have any further questions please do not hesitate to contact Helen Broome (researcher), your Neurologist or MS Nurse.

Thank you for reading this information sheet.

Appendix 5.7: Participant Consent Form

Research site:

Participant Identification Number for Study: _____

When completed: 1 for the participant; 1 for research site file (if participant agrees).

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CONSENT FORM

Title of Study: Memory and information processing speed and everyday functioning in individuals with MS **Names of Researcher:** Helen Broome

Please carefully read each statement and initial each of the corresponding boxes to show that you consent to each part and then please sign in the space below.

Please initial box

1. I confirm that I have read and understood the information sheet dated _____ (version_____) for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected.

3. I understand that the relevant sections of my medical notes may be looked at by my Neurologist or MS Nurse, where it is relevant for the research. I give permission for these individuals to have access to those sections of my medical records.

4. I am aware of the potential for emotional distress and the benefits of taking part in this study.

5. I am aware that this study will require me to answer questions regarding my ability to perform everyday activities, my memory, information processing speed and disease specific information.

6. I wish to request my BMIPB scores. I agree that the Academic Supervisor, Dr Miles Rogish (Consultant Clinical Psychologist), will be able to supervise the writing of the results letter and send out the letter to my address. The address I agree for the results letter to be sent to is: _____

_____

_____   (Optional)

7. I agree to a letter summarising the overall findings of the above study to be sent to my home address (write address in the space above).   (Optional)

8. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

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