Patients' Perspectives in Multiple Sclerosis

Uncertainty and anxiety hinder psychological wellbeing

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Abstract

Multiple sclerosis (MS), diagnosed at young age, is characterised by fluctuating symptoms, treatment ambiguity and uncertain prognosis. Depression and anxiety are generally considered as comorbid responses, with anxiety and denial as temporary phases in models of adjustment to chronic illness. This thesis proposed that early fears could persist to promote maladaptive coping and hinder adjustment. The research comprised four studies aimed at investigating anxieties, measuring their association with adjustment and assessing the feasibility of piloting an intervention to address anxiety.

Narrative analysis of experiences recorded for study one (N=7) highlighted emotional isolation and future-oriented fear as important responses, particularly related to disability. A systematic review of literature in this area spotlighted published indications that anxiety may be health specific, separate from depression and requiring investigation.

Study two (N=238) provided evidence from self-report cross-sectional data that diagnosis anxieties and fear predicted avoidance at 12 to 18 months. Avoidance predicted maladaptive coping, which contributed negatively to long-term outcome. Study three (N=41) focussed on data from an optional section of the study two survey to assess the feasibility of drawing concerns, whether this visual method would be acceptable to participants, and if the data could be suitable for evaluating and rescripting inappropriately negative responses. Participants who provided visual representations of responses to MS were found to be representative of the main sample. Findings also indicated that data demonstrated descriptive content, symbolism, syntax and holistic representations that could be evaluated and rescripted. Based on the well-researched method of expressive writing, study four (N=21) piloted visual methods as an intervention for rescripting disproportionately fearful heuristic responses.

Thesis findings provided a thread of patient-centred experiences and research evidence revealing an insightful montage of coping approaches. The diagnosis environment, patient perceptions, cognitive interpretations, emotional reactions and behavioural responses concurred with existing literature. The novel finding across all studies was that anxiety processes may not reflect temporary stages of coping. They represent a complex interactive and potentially fluctuating response in the face of future-oriented threat imposed by MS. An art-based intervention could usefully access and adjust adverse heuristics that hinder adaptation.


Declaration

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the text, bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification. I agree that the University has the right to submit my work to the plagiarism detection service TurnitinUK for originality checks. Whether or not drafts have been so-assessed, the University reserves the right to require an electronic version of the final document (as submitted) for assessment as above.
To Neill

Thank you for sharing
the lived experience of PhD.

Without your love and care this work would not have been possible.
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Contents

Chapter 1 Literature Review ................................................................. 1

1.1 Chapter Overview ........................................................................... 1
1.2 Multiple Sclerosis: A Costly and Uncertain Condition ................. 2
  1.2.1 Evolving research into MS
  1.2.2 Epidemiology
  1.2.3 Disability and MS
  1.2.4 Health economics: The cost of MS
1.3 Difficulties in Diagnosing MS ....................................................... 7
  1.3.1 Invisible MS
  1.3.2 Clinical subtypes
  1.3.3 Diagnosis criteria
  1.3.4 Applying criteria in practice
1.4 Treatment Status ........................................................................... 11
  1.4.1 Treatment adherence and complementary therapies
  1.4.2 Diet and exercise as complementary therapies
  1.4.3 The role of support groups
1.5 Psychological Responses to Chronic Illness ................................... 15
  1.5.1 Depression and anxiety
  1.5.2 Emotional responses: Fear, anger, frustration
  1.5.3 What is an emotion?
1.6 Challenged Identity ...................................................................... 19
  1.6.1 Defining identity: Identity as processes
  1.6.2 Chronic illness, loss and unwanted identities
  1.6.3 Protecting identity
  1.6.4 Constructing new identity
  1.6.5 Identity transition: Adjusting to chronic illness
1.7 Illness Beliefs or Cognitions ......................................................... 24
  1.7.1 Leventhal's self-regulatory model
  1.7.2 Measuring beliefs: Illness perception questionnaire
  1.7.3 Illness perception questionnaire – revised
  1.7.4 Brief illness perception questionnaire
  1.7.5 Illness perception and outcome
1.8 MS and Illness Perceptions ............................................................ 29
1.9 Alternative Theories and Models .................................................... 30
  1.9.1 Social aspects of identity threat
  1.9.2 Disrupting and restoring narrative of identity
  1.9.3 Illness perceptions and the narrative of illness
  1.9.4 Crisis theory
  1.9.5 Meaning, mastery and enhancing life
1.10 Call for Revised Models ............................................................... 34
  1.10.1 Models of interactive perceptions, emotions and processes
1.11 Addressing Implications in Interventions ..................................... 39
  1.11.1 Published reviews
  1.11.2 Reviewing CBT interventions
  1.11.3 Reviewing group therapy
  1.11.4 Examples of randomised controlled trials (RCTs)
  1.11.5 Internet trials
  1.11.6 Alternative interventions
  1.11.7 Overall evaluation of interventions for MS
Chapter 1

1.12 Expressive Methods and Rescripting ...................................................... 52
   1.12.1 Expressive writing
   1.12.2 Visual versus verbal
   1.12.3 Important influence of images
   1.12.4 Identifying and rescripting images

1.13 Summary ..................................................................................................... 58

1.14 Research Aims .......................................................................................... 59
   1.14.1 Summary of thesis and research aims

Chapter 2 Study One ....................................................................................... 61

Emotional responses to multiple sclerosis: A narrative study of pivotal idiographic
experiences and processes

2.1 Chapter Overview ....................................................................................... 61

2.2 Introduction ............................................................................................... 62
   2.2.1 Narrative and psychology
   2.2.2 Narrative and health
   2.2.3 Narrative analysis
   2.2.4 Doing narrative analysis: Approaches and models
   2.2.5 Structural analysis
   2.2.6 Linguistic analysis

2.3 Aims and Objectives ................................................................................... 69

2.4 Method ....................................................................................................... 69
   2.4.1 Participants
   2.4.2 Analytic method
   2.4.3 Identifying relevant narratives
   2.4.4 Linguistic analysis of separate narratives

2.5 Findings ...................................................................................................... 74
   2.5.1 Summary overview of findings
   2.5.2 Cross-case summary

2.6 Discussion ................................................................................................... 106
   2.6.1 Identity process theory
   2.6.2 Models of coping and emotional processes
   2.6.3 Emotions in newly processed models of adaptation to MS

2.7 Reflective account: Research position ..................................................... 111
   2.7.1 Research-interviewer-analyst perspectives
   2.7.2 Perspective on narrative selection
   2.7.3 Support group influence: Consideration of sample bias
   2.7.4 Non-verbal narrative

2.8 Conclusion and Contribution to Understanding Adjustment to MS....... 114

Chapter 3 Systematic Review ........................................................................ 115

Anxiety-related Responses and Adjustment to Multiple Sclerosis: A Systematic Review

3.1 Chapter Overview ....................................................................................... 115

3.2 Introduction ............................................................................................... 116

3.3 Aims and Objectives ................................................................................... 116

3.4 Method ....................................................................................................... 117
   3.4.1 Search methods and inclusion criteria
   3.4.2 Quality assessment
   3.4.3 Data synthesis

3.5 Findings ...................................................................................................... 127
   3.5.1 Psychological comorbidity: Anxiety and depression
   3.5.2 Disability, disease progression and duration
3.5.3 Psychological factors as predictors
3.5.4 Adjustment and coping
3.5.5 Distress and uncertainty: Fear, threat and intrusion

3.6 Discussion
3.6.1 Aetiology of psychological comorbidities
3.6.2 MS factors, phase and duration
3.6.3 Implications for adjustment
3.6.4 Limitations of reviewed research

3.7 Limitations of This Review

3.8 Conclusion and Contribution to Understanding Adjustment to MS

Chapter 4 Study Two
Anxiety Responses to Multiple Sclerosis: Potential predictors of poor adjustment and coping

4.1 Chapter Overview
4.2 Introduction
4.2.1 Theoretical background
4.2.2 Existing research
4.3 Aims and objectives
4.4 Method
4.4.1 Design
4.4.2 Measures: Current and recalled responses
4.4.3 Data preparation and analysis
4.4.4 Procedure
4.4.5 Participants and sample size
4.5 Results: Demographics and descriptive statistics
4.5.1 Demographics
4.5.2 Descriptive statistics
4.6 Results: Regression Analyses
4.6.1 Regressing on GHQ
4.6.2 Regressing on WASAS
4.6.3 Regressing on current coping
4.6.4 Regressing on early stage impact
4.7 Discussion
4.7.1 Perceptions of MS
4.7.2 Coping and support
4.7.3 Recalled responses to diagnosis
4.7.4 Supporting and challenging existing research
4.7.5 Study limitations
4.8 Conclusion and Contribution to Understanding Adjustment to MS

Chapter 5 Study Three
A feasibility study of using visual methods for expressing and amending responses to MS

5.1 Chapter Overview
5.2 Introduction
5.2.1 Visual versus verbal
5.3 Aims and Objectives
5.4 Method
5.4.1 Design
5.4.2 Materials
5.4.3 Participants
5.4.4 Analytic approach to visual data
(Continued: Chapter 5, Findings)

5.5 Findings ................................................................. 179
  5.5.1 Participant readiness to engage with visual methods
  5.5.2 Using visual methods: Comparison of volunteers and non-respondents
  5.5.3 Differences between visual and verbal: Participants' qualitative feedback
  5.5.4 Overview of visual data: Did images provide detailed responses?
  5.5.5 Summary of methods used for creating an image
  5.5.6 Research panel findings: Potential approach to framework for analysis
  5.5.7 Research panel findings: Defining visual language analysis framework
  5.5.8 Overview of rescripting potential

5.6 Discussion ............................................................... 190

5.7 Conclusion and Contribution to Understanding Adjustment to MS .... 191

Chapter 6 Study Four .................................................. 192
Images of Multiple Sclerosis: Uncovering the Unsaid

6.1 Chapter Overview .................................................. 192

6.2 Introduction ........................................................ 193
  6.2.1 Influence of emotional responses: Present research evidence
  6.2.2 Important influence of images
  6.2.3 Identifying and rescripting images
  6.2.4 Summary

6.3 Aims and Objectives ............................................. 196

6.4 Method ............................................................... 197
  6.4.1 Design
  6.4.2 Experimental and control conditions
  6.4.3 Measures
  6.4.4 Materials
  6.4.5 Participants
  6.4.6 Demographics
  6.4.7 Ethical considerations
  6.4.8 Procedure

6.5 Data Preparation .................................................. 205

6.6 Results ............................................................... 206
  6.6.1 Summary descriptive statistics
  6.6.2 Inferential statistics

6.7 Case-wise Interpretations and Qualitative Data .................. 210
  6.7.1 Comments and feedback from control group: Non-MS images
  6.7.2 Comments and feedback from experimental group: MS images

6.8 Examples of Rescripting ...................................... 213
  6.8.1 Michael (C15)
  6.8.2 Anne (C19)
  6.8.3 Linda (C7)

6.9 Summary of Findings .......................................... 221

6.10 Discussion ........................................................ 222

6.11 Study Limitations .............................................. 224

6.12 Conclusion and Contribution to Understanding Adjustment to MS .... 225

Chapter 7 Discussion .................................................. 226

7.1 Chapter Overview .............................................. 226

7.2 Research Overview ............................................ 227

7.3 Study-wise Summary of Findings .......................... 228
  7.3.1 Study one
(Continued: Chapter 7)
7.3.2 Study two
7.3.3 Study four
7.4 Discussion Overview .......................................................... 230
7.5 Cross-thesis Discussion of Findings ........................................... 232
  7.5.1 Pivotal emotional responses: Fear
  7.5.2 Critical processes: Emotional isolation
  7.5.3 Disability identity: Focus for fear
  7.5.4 Illness perceptions: Consequences and control
  7.5.5 Theoretical models of coping: Explaining pivotal emotional processes
  7.5.6 Intervention based on models of coping: Amending illness perceptions
  7.5.7 Drawing on models of expressive writing: Findings from visual methods
  7.5.8 Findings in context: Considering illness perceptions, identity and coping
7.6 Implications for Practice .......................................................... 246
7.7 Implications for Research ....................................................... 247
7.8 Strengths and Limitations of Research ...................................... 248
  7.8.1 Study design
  7.8.2 Measure of fear
  7.8.3 Sample, recruitment and participants
7.9 Concluding Comments ............................................................ 250
References ..................................................................................... 251
Appendices ....................................................................................... 266
Appendix I (Study One) ................................................................. 267
  a) Gee’s (1991) analysis: Diagrammatic summary of structure analysis process
  b) Transcript annotation following Labov’s (1972) analysis: Identifying and differentiating specific storied experiences relating to MS
  c) Narrative extracts in order of told (narrative order): Showing narrative structure
  d) Annotation applying Gee’s (1991) analysis: Transcripts analysed in narrated order
  e) Annotation on formatted narratives using Gee’s (1991) analysis
  f) Case-wise findings: Emotional responses revealed by Gee’s analysis within narratives defined by Labov’s analysis
Appendix II (Systematic review) ...................................................... 305
  a) Systematic Review: Criteria and ratings used for quality assessment of papers
  b) 3.4.3, Table 4, Summary information on papers and findings: Abbreviations
Appendix III (Study Two) ............................................................... 310
  a) University of Surrey Ethics Committee letter of favourable ethical opinion
  b) Questionnaire
  c) Factor analysis matrices
  d) Letter introducing study to MS groups
  e) Letter of thanks for assistance with research
  f) Participant information sheet
  g) Participant consent form
  h) Guidelines for assisting with questionnaire completion
  i) Debriefing information
  j) Recruitment poster
  k) Regression analyses model summaries and correlation tables
Appendix IV (Study Four) ............................................................... 338
  a) University of Surrey Ethics Committee letter of favourable ethical opinion
  b) Letter introducing study to MS groups
  c) Letter of thanks for assistance with research
  d) Participant information sheet
  e) Recruitment flyer
  f) Participant consent form
(Continued: Appendix IV)

g) Debriefing information
h) Questionnaire
i) Researcher Guidelines: Final Open-ended questions
j) Researcher standard guidelines: experimental condition
k) Researcher standard guidelines: control condition
l) Experimental group visual methods rescripting
m) Case-wise descriptive statistics for MS (experimental) group
n) Case-wise descriptive statistics for NMS (control) group
**List of Tables in Main Chapters**

**Chapter 1 Literature Review**
- Table 1: Disability status percentages by country

**Chapter 2 Study One**
- Table 2: Participant details
- Table 3: Case-wise summary of narratives identified by Labov's analysis and concepts attributed using Gee's linguistic analysis

**Chapter 3 Systematic Review**
- Table 4: Summary information on papers and findings

**Chapter 4 Study Two**
- Table 5: Demographic information and MS status
- Table 6: Perceptions of current influence of MS on everyday life: Descriptive statistics and reliability (Cronbach's alpha score)
- Table 7: Recalled phases of diagnosis and relapse information: Descriptive statistics and reliability (Cronbach's alpha score)
- Table 8: Current influence of MS
- Table 9: Post-diagnosis anxiety and depression, and impact at 12 to 18 months
- Table 10: Recalled Fears and concerns 1-3 months following diagnosis
- Table 11: Responses to relapse
- Table 12: Model summary and significant predictors in standard regression of anxiety, fear, impact and coping on GHQ
- Table 13: Model summary and significant predictors in hierarchical regression of demographics, diagnosis variables, early impact, and coping on GHQ
- Table 14: Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on GHQ
- Table 15: Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on WASAS
- Table 16: Model summaries and significant predictors in regression of early impact and emotional support on to maladaptive coping (malcope) and escape-avoidance (WOC6)
- Table 17: Model summaries and significant predictors of IES avoidance
- Table 18: Model summaries and significant predictors of IES intrusion

**Chapter 5 Study Three**
- Table 19: Demographic information
- Table 20: Comparison of demographic mean values for volunteers (v) and non-respondents (n/r) to optional visual response section of questionnaire
- Table 21: Comparison of descriptive statistics for current influence of MS on everyday life for volunteers (v) and non-respondents (n/r)
- Table 22: Comparison of descriptive statistics for recalled influences during phases of diagnosis and relapse for volunteers (v) and non-respondents (n/r)

**Chapter 6 Study Four**
- Table 23: Summary of age, education and diagnosis status
- Table 24: Types of diagnoses (by number of participants)
- Table 25: Employment and marital status (by number of participants)
- Table 26: Procedure summary
- Table 27: Comparative summary group descriptive statistics for MS and NMS groups
List of Figures in Main Chapters

Chapter 1 Literature Review................................................................................ 1
Figure 1: Leventhal's (1980) self-regulatory model
Figure 2: Moos and Shaefer (1984) proposed coping with illness crisis theory
Figure 3: Sharpe and Curran (2006) model of adjustment (adapted from Park and Folkman, 1997)
Figure 4: A working model of adjustment to MS (Dennison, Moss-Morris & Chalder 2009)
Figure 5: A working model of adjustment to chronic illness (Moss-Morris, 2013)

Chapter 2 Study One....................................................................................... 61
Figure 6: Labov's (1972) structural narrative analysis
Figure 7: Key steps in Gee's (1991) linguistic analysis
Figure 8: Emotional responses to MS

Chapter 3 Systematic Review......................................................................... 115
Figure 9: Gay et al. (2010) [21] model of variance, indicating strength of relationship between state anxiety and depression

Chapter 4 Study Two...................................................................................... 140
Figure 10: A working model of adjustment to MS (Dennison et al., 2009)
Figure 11: Possible associations between anxiety and coping

Chapter 5 Study Three................................................................................... 172
Figure 12: Qualitative questionnaire used for pilot study
Figure 13: Summary of aims, researcher identification and coding form
Figure 14: Summary of research panel interpretations of visual data
Figure 15: Testing analysis framework for preliminary coding of visual data as a basis for rescripting consideration and/or analysis

Chapter 6 Study Four................................................................................... 192
Figure 16: Comparison of pre- (1) post-intervention (2) IPQ consequences scores by MS and NMS group
Figure 17: Comparison of pre- (1) post-intervention (2) anxiety scores by MS and NMS group
Figure 18: Comparison of pre- (1) post-intervention (2) depression scores by MS and NMS group

6.8 Examples of Rescripting
6.8.1 Michael (€15)
Figure 19: Session 1, image 1
Figure 20: Rescripting notes for image 1
Figure 21: Rescripting image 1
Figure 22: Session 2, image 1
Figure 23: Session 2, rescripting image 1

6.8.2 Anne (€19)
Figure 24: Session 1, image 1
Figure 25: Session 1, overlay on image 1
Figure 26: Session 1, rescripting image 1
Figure 27: Session 2, non-MS

6.8.3 Linda (€7)
Figure 28: Session 1, image 1
Figure 29: Session 2 collage
Figure 30: Session 2 collage detail

Chapter 7 Discussion.................................................................................... 219
Figure 31: Overview of literature background, research framework and key findings
Figure 32: Participant's representation of being diagnosed with MS (Study Three)
Chapter 1

Literature Review

1.1 Chapter Overview

This chapter provides a broad overview of MS, including the status of research and psychological understanding of this chronic condition. The diagnosis culture and medical environment people face when first dealing with MS is relevant to their understanding, interpretation and emotional responses. It is in this context that initial illness perceptions and beliefs about the future are instigated. Psychological, emotional and behavioural responses, meaning making, long-term outcomes and theoretical perspectives on adaptation to chronic illness are considered.

Sections 1.2 to 1.4 summarise the profile of MS, including biomedical and epidemiology background; the diagnosis process; and psychological aspects, respectively. Section 1.5 considers implications of diagnosis with chronic illness. Relevant theoretical models of patient responses are discussed in section 1.6, with perspectives on psychological interventions in section 1.7.
Multiple sclerosis (MS) is a progressive condition, diagnosed at relatively young age when people expect to be in the prime of life and it has life-long impact. It is characterised by uncertainty and individuality in symptom presentation, diagnosis and prognosis. MS affects twice or three times as many women as men, usually between twenty and forty years of age, but it can be diagnosed at any age (Alonso et al., 2007). Section 1.3 discusses the difficulties associated with diagnosis, including the individual, unusual and fluctuating nature of symptom presentation and the need to eliminate possible other causes or conditions; this means the diagnosis process is slow, involving neurological history, tests, magnetic resonance imaging scan and lumbar puncture (MS Society, 2008). Prognosis is unpredictable, with relapse onset, duration and intensity varying and remission periods undefined. Three main types of MS are defined as relapsing-remitting, secondary progressive and primary progressive: these clinical subtypes are discussed in section 1.3.2.

The lack of a single, clearly defined illness pathway or definition of disease progress is unsurprising in the context of the condition's pathology. MS is internationally recognised as a neurological autoimmune disease characterised by deterioration of the myelin sheathing in the central nervous system (demyelination). Inflammation of the white matter in the brain or spinal cord causes the damage that results in 'hardened scars' or 'scleroses' in 'multiple regions' (NICE, 2003; Tortora & Grabowski, 2000). Some repair (remyelination) replaces the loss but this is not complete and damage is cumulative. In addition, as the disease progresses, it is now known that axons are also damaged or lost (Compston & Coles, 2002).

1.2.1 Evolving research into MS

Although MS has been loosely defined since the nineteenth century, it is only in the last two to three decades that understanding of MS as a damaging neurological condition has advanced. Murray (2009) summarised the history of MS since Jean-Martin Charcot's lectures in 1868 first described the damage caused by hardened scleroses or scars on myelin sheathing surrounding axons. It was as early as the 1880s when Sir Byron Bramwell identified links between prevalence and higher latitudes. Genetic links were investigated and familial clustering found in the 1930s and confirmed during the 1980s in Canada. Underlying theories of infection have
existed since the nineteenth century but the potentially important role of viruses is now prominent. Correlations between latitude, exposure to sunlight in childhood, low levels of vitamin D and MS have been demonstrated and supported by migration studies from areas of low to high levels of sunlight.

Evolving research poses the question of whether MS should be re-defined as more than one condition and this continues to be controversial (Poser & Brinar, 2004). However, the current focus is on objectives to limit and prevent damage, and promote repair (Compston & Coles, 2002). There is also a need for future focus into understanding, predicting and defining disease progression in order to clarify diagnosis of progressive symptoms and evaluate appropriate treatment (Lubin, 2007; Rovaris et al., 2006; Scott, 2013; Scott, Lafaret, & Your, 2013; Vukusic & Confavreux, 2003). Research into disease progression and prognosis could alleviate the psychological suffering patients experience due to uncertainty and fears about the future, as well as the perception of poor communication resulting from patients' and professionals' differing perspectives on diagnosis (Heeson, Kolbeck, Gold, Godl, Schulz, & Shulz, 2003; Solari et al, 2010). Patients want information and consider medics to be uncaring and poor at communicating. Medics, on the other hand, are constrained by uncertainty not only around initial diagnosis but also particularly when MS begins to progress. In addition to medical ambiguity, doctors may delay delivering a diagnosis when they consider the future prospects to be distressing.

These expert opinions and discussion on the direction that future research should take highlight the problem of persistent uncertainty.

1.2.2 Epidemiology

Although MS is not a common disease and it is rarely related to premature death, it is a life-long progressive condition with high psychological as well as physiological impact. Lengthy prognosis and early life-stage diagnosis make it the most common disabling neurological disease among younger people.

The incidence of MS increases with distance from the equator (including UK, Northern Europe and Canada). Global estimates are 2.5 million, with 400,000 people affected in the USA. Statistics on MS are subject to variation due to the diagnosis procedure and the point at which a case of MS is defined as such. The following figures are estimated from UK local health authority records. According to National Institute for Clinical Excellence (NICE, 2004) guidelines, estimated diagnoses in the
UK are 3.5 to 6.6 per 100,000 population annually or 1,820 to 3,380 new cases annually in England and Wales. Prevalence is estimated at 100 to 120 per 100,000 which translates into 52,000 to 62,400 cases in England and Wales. To give some idea of how familiar doctors are likely to be with MS, this is the equivalent of approximately two cases per General Practitioner. By comparison, NICE (2004) figures for stroke are 240 diagnoses per 100,000 annually, with a prevalence of 700 per 100,000 or a total of 364,000 cases. This is equivalent to fourteen cases per General Practitioner.

A 2007 study of new cases in the UK between 1993 and 2000 estimated UK lifetime risk of 5.3 per 1,000 in women and 3.1 per 1,000 in men; incidence rates for 1993 to 2000 peaked at age 30 to 35 years for relapsing-remitting and age 40 to 45 years for primary progressive MS (Alonso, Jiek, Olek, & Hernan, 2007). Donnan et al. (2005) estimated that Scotland had the highest rates in the world, with a prevalence of 236 per 100,000 on 31 January 2002, and where an annual incidence of 7.2 per 100,000 was found in Tayside between 1970 and 1997.

This regional variation highlights different levels of experience of diagnosis and treatment of MS that probably exist among practitioners. When awareness of MS is not necessarily high, the potential of this being the reason for an unusual combination of early symptoms could easily be overlooked. People with MS often comment not only on the long time taken to begin the MS diagnosis process but also that they felt their credibility was questioned when they presented unusual and non-specific early symptoms.

1.2.3 Disability and MS

Current UK guidelines on diagnosis and management of MS point out that there is no certainty that MS will progress, only a small number of people will develop severe impairment and this is usually later in life (NICE, 2004).

A longitudinal study (1972 to 1984) of the natural history of MS among 1,099 Canadian patients evaluated disability levels among patients who were not on immunosuppressive drugs to alter the progression (Weinshenker, Bass, Rice, Noseworthy, Carriere, Baskerville, & Ebers, 1989). Disability was measured by the Kurtzke disability status scale (DSS), which differentiated between moderate disability (DSS 3); ambulatory but requiring walking aids (DSS 6); 'restricted to bed but with effective use of arms' (DSS 8) and death as a result of MS (DSS 10). DSS 6
would represent severe disability, in terms of being unable to transfer from a wheelchair and having upper body disability. The median time in years for the total population to reach levels DSS 3, 6 and 8 were 7.69, 14.97 and 46.39, respectively. The cohort included two sub-groups, one in which all participants had been monitored by a neurologist from condition outset and another that was 90% registered to the clinic. The remaining participants were not registered at the clinic but were mainly institutionalised. Among the group that had consistently been monitored, it took 6.28 and 9.42 years to reach DSS 3 and 6 respectively. At final review, 53% of participants who were registered with the clinic were rated lower than DSS 6 and 47% required assistance with walking. The researchers found that thirty years from onset of MS, 83% of patients had reached DSS 6 and 34% had reached DSS 8. Among patients with progressive disease, 50% reached DSS 6 in 5 years and DSS 8 in 22 years. The study demonstrates the difficulties of providing guidance on the likelihood of disability and the possible associations with disease type. The figures also show that, without any of the disease modifying treatments now available, being diagnosed with MS is not necessarily a wheelchair sentence.

More recently, Edmonds, Vivat, Burman, Silber and Higginson (2007) estimated that, from prevalence of MS at 0.1 to 0.2% of the population in Southeast London, 10% would be unable both to walk and transfer from a wheelchair. Kobelt, Berg, Lindgren and Jonsson (2006) studied cost and quality of life among a sample of over 13,186 people with MS across nine European countries. A self-report version of the Expanded Disability Status Scale (EDSS) was used to assess disability and scores were grouped into three levels at 0 to 3, 4 to 6.5, and 7 to 9, summarised as follows.

1. Level 3  No limitations to walking.
2. Level 6  Walk up to 100 metres with cane, holding furniture or other support, plus possible use of wheelchair for longer distances.
3. Level 7  Using two canes, crutches or walker for up to 20 metres.
4. Level 8  Wheelchair use without assistance.
5. Level 9  Restricted to wheelchair and needing assistance.

Results (summarised in Table 1) indicated that fewer than 25% people with MS use wheelchairs and 35 to 59% need mobility aids. A breakdown of Swiss scores was included, indicating that 14.3% people were rated at disability level eight to nine.
Table 1: Disability status percentages by country

<table>
<thead>
<tr>
<th>Country</th>
<th>Participants</th>
<th>EDSS 0-3</th>
<th>EDSS 4-6.5</th>
<th>EDSS 7-9</th>
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</table>

Note: Variation in total percentages reflects variation in response rate.

Researching disability as a means of predicting prognosis among MS patients, Daumer, Neuhas, Herbert and Ebers (2009) assessed the Multiple Sclerosis Severity Score (MSSS) for measuring progression compared to the Expanded Disability Status Scale (EDSS) and concluded that predicting prognosis represented a major challenge. The fluctuating nature of MS means that disability varies and although there is long-term deterioration, the influence of acute disability contributes to ambiguity in cross-sectional data. By following 197 of their participants from condition outset, Weinshenker et al. (1989) were able to provide accurate longitudinal information. This provides some perspective for those diagnosed with MS. Literature indicates that early research reflected findings among participants who were not taking disease modifying treatment; the fluctuating symptoms mean that using mobility aids may be temporary; and the likelihood of being severely disabled is not large.

1.2.4 Health economics: The cost of MS

Evidence on the economics of NHS care and cost-effective perspectives on treatment options are limited but mean total cost of MS per patient was estimated at £17,000 or a total of £1.34 billion per year in England (Kobelt et al., 2000, as cited in NICE, 2004). The overall cost of MS in Europe (including total care, medication and lost productivity) for 2005 was estimated at 12.5 billion Euros; with UK estimates at 45,000 Euros per case, per annum (Sobochi, et al., 2007). Compston and Coles (2002) quoted annual UK expenditure at £1.2 billion.

A comparatively recent study into the economics of MS in the UK, including demographics, disability and quality of life, provided support for the overall NICE estimates (McCrone, Heslin, Knapp, Bull, & Thompson, 2008). This cross-sectional, self-report study of 1,942 members of the MS society in Great Britain and Northern
Ireland estimated mean cost per person over the preceding 6 months at £8,397 (SD £10,404). The majority cost was due to informal care (71.6%), with 8.1% on disease modifying drugs. A mean of £4,240 per person over the six-month period was calculated for lost employment, including days off due to illness or early retirement. Large standard deviations presumably reflect broad condition variation. Comparing service costs across disability and quality of life, the study found that costs increased as quality of life decreased and disease progression and disability increased. The authors noted that their participants were all members of the MS Society, therefore not representative of all people diagnosed, and that studies have demonstrated that quality of life is not necessarily directly related to disability.

These statistics provide some indication of the economic reality of MS. The duration of MS, psychological impact, potential role of poor quality of life and responses to progression support the need for research into psychological understanding. Promoting wellbeing and disease management would benefit individuals and reduce the economic burden of MS.

1.3 Difficulties in Diagnosing MS

Symptom presentation is individual and early signs or strange symptoms (such as tingling, slight numbness, dizziness, clumsiness, minor balance or minor fatigue) may easily go unnoticed. The individual, fluctuating and broad nature of symptom presentation contributes to slow diagnosis. In many cases the condition may develop slowly at first and people comment that diagnosis with MS was a relief in that it explained strange symptoms experienced over many years. Many people with MS may never develop severe impairment.

NICE (2004) guidelines summarise the many symptoms that may be experienced. Problems with vision or optic neuritis are common early signs, including complete loss of vision in one eye. Sight is often restored but in some cases reduced vision or even blindness may occur. Fatigue, bladder or bowel dysfunction, weakness, tremor, spasticity, sensory loss, pain and cognitive impairment may occur. Some patients have speech difficulties. Respiratory and swallowing problems are associated with severe impairment.
1.3.1 Invisible MS
MRI evidence indicates that MS is active even in the absence of symptoms; hence its classification as a progressive disease. This inconspicuous activity highlights the importance of engaging patients with information about the condition during the early stages even though symptoms may be mild or disappear. The potential benefits of early treatment lie in delaying degeneration and the subsequent onset of progressive MS, which is associated with a damage threshold. When the damage has reached this threshold, the phases of remittance disappear and the condition is characterised as secondary progressive, which does not have periods of remission (Compston & Coles, 2002).

1.3.2 Clinical subtypes
The first agreed definitions for MS as relapsing remitting (RR), secondary progressive (SP), primary progressive (PP) and progressing relapsing (PR) were established in 1993 by an international consensus of clinicians. Three main types are now defined by NICE criteria as relapsing remitting, secondary progressive and primary progressive. Although benign is included as one of the main types it is also referred to less widely. Additional categories included in the NICE criteria, but not as widely used as the others, are progressive relapsing and malignant.

i) Relapsing remitting This describes a condition in which there are attacks (the relapsing phase), followed by periods when symptoms subside (remission phase). During remission some symptoms may completely disappear or subside. Relapse may be referred to as exacerbation, when the same or new symptoms may occur. Over time, during relapses the symptoms may gradually worsen with incomplete recovery.

ii) Secondary progressive This type is applied when the remission phases of relapsing remitting cease and the disease progresses. This is a later stage or steady progression, with no reduction or improvement of the symptoms. The condition is not characterised by relapses or exacerbations but gradual degeneration.

iii) Primary progressive This defines the condition when symptoms gradually worsen from diagnosis, without any phases of improvement or remission.
iv) **Benign** This applies when there are few attacks and they are mild. Recovery is complete and the condition does not worsen over time. In some instances, benign may be diagnosed when there are residual mild symptoms that do not deteriorate.

**Additional types (definitions not widely used)**

v) **Progressive relapsing** This denotes the condition as progressive from outset, with clear acute relapses and with progression between relapses. Comparisons of disability progression indicate that this is comparable to primary progressive (Confavreux & Vukusic, 2006).

iv) **Malignant** This defines rapid progression with multiple significant disability or death in short time after disease onset.

From NICE patient information for practitioners, about 45% of patients have relapsing remitting MS and 45% have secondary progressive MS, although up to 90% of patients initially have relapsing remitting before receiving an updated diagnosis. Vukusic and Confavreux (2003) pointed out that all RRMS could be considered to become progressive. Delayed onset of SPMS was associated with good recovery from visible symptoms of first relapse, age at onset, gender (females take longer to progress to SPMS), and the temporal relationship between first and second relapse. About 10% of diagnoses are primary progressive MS.

### 1.3.3 Diagnosis criteria

The lengthy and ambiguous process of diagnosis is explained by medical perspectives. Before the diagnosis of MS can be confirmed, other diseases have to be excluded (Miller et al., 2008). Hurwitz (2009) summarised the history of diagnosis from the first Schumacher clinical criteria in 1965 to the introduction of guidelines by Poser in 1983. The Poser 1983 laboratory criteria were based on paraclinical evidence obtained from cerebrospinal fluid and tissue analysis to identify 'probable' and 'definite' diagnosis. Although originally intended for use in research, these criteria were adopted in clinical practice.

McDonald 2001 criteria included MRI investigations and provided three definitions: 'MS', 'possible MS' and 'no MS'. Guidelines for primary progressive MS were also introduced. Revised McDonald criteria published in 2005 (Polman et al., 2005) reviewed the MRI assessment procedure and other methods of improving
diagnostic speed and accuracy. Eliminating alternative conditions was essential before confirming MS and this was still an unavoidable source of delay. Criteria defining progression were not included in the update.

In the context of poor existing evidence, an international panel recommended a consensus basis for suggesting proposed criteria and future research into the guidelines (Miller et al., 2008). The aim was to provide speedier diagnosis, while maintaining or improving specificity and sensitivity. Another objective was to simplifying the process by using fewer MRI scans where possible. The International Panel on Diagnosis of MS met in 2010 to apply a third revision of the McDonald Criteria (Polman et al., 2011). NICE guidelines follow these criteria, which require, among other information, two separate clinical episodes (typically) and more than one lesion. The first event that suggests MS, known as clinically isolated syndrome (CIS), is the basis, or starting point, from which criteria are applied. In some cases one MRI scan is enough but additional tests are still necessary to confirm diagnosis.

1.3.4 Applying criteria in practice

MS is relatively rare and practical experience of interpreting symptoms may be limited. The importance of eliminating the possibility of alternative conditions is paramount in the guidelines. Accurately interpreting the guidelines contributes to the delay as there is little information available on interpreting and applying them in practice. Fangerau et al. (2004) compared the Poser (1983) and McDonald (2001) criteria by applying them prospectively to previously diagnosed cases. They found that 89% of cases that would have been defined as laboratory definite MS became 'possible MS' in the context of clinical considerations.

A first survey of 97 consultants and 30 trainees from the Association of British Neurologists demonstrated the diversity that exists in the diagnosis and understanding of MS as well as in the use and application of the McDonald criteria (Hawkes & Giovannoni, 2010). For example, although they were understood, terms such as 'attack' and 'objective clinical evidence' used in the criteria could be misinterpreted. While 62% of participants found the McDonald criteria useful, 31% found them confusing and 17% rarely used them. Furthermore, 29.1% were unclear about straightforward content and thought the criteria specified 'MS' and 'not MS' as the only categories. Primary progressive criteria were well understood. There are no criteria for secondary progressive MS (and no specific treatment recommendations).
In spite of the evaluation and improvement to criteria, neurologists still demonstrate ambiguity about diagnosis. When patients encounter delay and ambiguity they are unlikely to be fully aware of the criteria and individual professional perspectives on the technicalities of diagnosis. Thus the professional culture (that is not transparent) contributes additional stress, uncertainty and anxiety to patients' perceptions of MS.

1.4 Treatment Status

Research into the pathophysiology of MS contributes to treatment strategies and development of disease-modifying therapies (Kappos 2004). The European Committee for Treatment and Research in Multiple Sclerosis 2009 lecture highlighted progress into exploration of genetic susceptibility; auto-aggressive T cells in the healthy immune system and how they enter the central nervous system; and the 'excellent safety record' of currently available, moderately effective disease-modifying drugs (Hohlfield, 2010).

Research into orally administered drugs to target inflammatory and degenerative aspects associated with disease progression (Gold and Wolinsky, 2011) could provide an alternative long-term outlook. Currently, treatment is associated with self injecting or hospital-administered infusion options for relapsing-remitting MS and beyond that, on reaching a damage threshold, medics can offer no specific treatment adjustment. Gold and Wolinsky (2011) noted that reluctance to diagnose progressive MS related to the lack of criteria for amending treatment and this, therefore, increased patient anxiety. Sand, Krieger, Farrell and Miller (2012) referred to 'therapeutic futility' expressed by medics in terms of providing patients with updated diagnosis. The absence of guidance on revising treatment as MS progressed meant physicians were ambiguous about the value of updating diagnosis. The avoidance patients encounter in medical consultations represents additional stress, anxiety and uncertainty about the current status and future prognosis of their MS. Research indicates that poor communication and information also leaves patients unhappy with the communication from medics (for example, Forbes, White, & Taylor, 2007; Johnson, 2003; Malcomson, Lowe-Strong, & Dunwoody, 2008; Solari et al., 2007).
This culture of ambiguity influences the early stages from diagnosis. There is no cure for MS but it is now considered to be treatable and with excellent prospects for symptom-management. Educating patients and encouraging a balanced outlook to treatment options and condition management could be beneficial. While unrealistic optimism is inappropriate, neither is the 'go away and get on with your life' approach ideal. Disease modifying drug therapy (DMT) can reduce individual symptom experience and it may delay the progress of the disease. Early treatment and management, even in the absence of visible symptoms, could contribute to long-term wellbeing. Choosing DMT offered in the early stages when symptoms may be mild or in remission means accepting the condition rather than going away and ignoring MS until relapse or progression necessitates treatment. Patients have to accept the existence of the condition and consider the future in a balanced way rather than as catastrophic in order to evaluate the pros and cons of DMT. Engaging with treatment also means taking on at least some aspects of an unwelcome illness identity.

1.4.1 Treatment adherence and complementary therapies

Behavioural challenges accompanying diagnosis with any chronic illness involve finding the motivation and self-management skills to deal with treatment options and lifestyle adjustments in response to the change in health status (Petrie & Moss-Morris, 1997). Considering the MS diagnosis journey and consequent continuation of uncertainty, it is not surprising that non-adherence or refusal of treatment can be a problem. Not only is there an absence of both cure and obvious benefits of early DMT but patients also face long-term self injection over months or years, often on a daily basis; furthermore, flu-like side effects of established drug treatment have negative impact on everyday wellbeing (Klauer & Zettl, 2008). A relatively large US study related poor adherence primarily to injection anxiety, forgetting to inject and not having anyone to administer injections rather than to concerns about side effects or effectiveness (Treadaway et al., 2009); however, the participants were accustomed to drug therapy and demonstrated low levels of depression and high levels of hope.

There is strong evidence for the use of complementary medicine alongside drug treatment (for example, Apel, Greim, Konig, & Zettl, 2006; Apel-Neu & Zettl, 2008; Olsen, 2009; Pucci, Cartechini, Taus, & Giuliani, 2004; Skovgaard et al., 2013; Stoll, Nieves, Tabby, & Schwartzman, 2012). Complementary medicines or complementary and alternative medicine, including diverse methods, are often used
in addition to traditional medical techniques (Vincent, 1996). For example, MS National Therapy Centres (www.msntc.org.uk) may provide oxygen therapy, exercise or music therapy as well as physiotherapy, links with MS nurses and social support as part of their focus on self-management and positive health behaviour.

While Stoll et al. (2012) commented on the use of complementary therapies in the context of the side effects of drugs, particularly the risk of severe side effects (including cancer and death) associated with newly available drug treatments for MS, Skovgaard et al. (2013) pointed out socioeconomic factors and greater use of complementary approaches among younger, better-educated and better-paid females (18 to 40 years old). Taking an holistic approach to diet, exercise and personal control in the absence of available cure also relates to aspects such as low levels of satisfaction with conventional medicine, gaining independence and avoiding treatment side effects (Hussain-Gambles & Tovey, 2004; Olsen, 2009; Schwartz, Knorr, Geiger, & Flachenecker, 2008).

1.4.2 Diet and exercise as complementary therapies

Compared to a frequently negative critical approach to conventional medicine, people look favourably on alternative therapies and demonstrate a positive attitude by seeking out their benefits (Schwartz, Knorr, Geiger & Flachenecker, 2008). This proactive interest, particularly to optimise diet and activity, represents a positive response. Indeed, this current research interest was initiated by anecdotal experience of participants’ uncertainty about how best to behave in response to diagnosis with chronic illness and promoting some positive response to diagnosis through active interest in food and exercise. An interest in diet and exercise for wellbeing seemed potentially beneficial for signposting a long-term route to adaptive coping. In conversation with members of MS centres during the early stages of research, most concurred in principle, saying they had tried diets; however, the majority opinion was that MS-specific diets turned out to be too restrictive, with little benefit outweighed by negative impact and the misery of further-reduced choice signifying yet another shift away from normal life.

Literature on diet and exercise primarily relates to physiological outcomes, emphasising possibilities for reducing relapse as well as weight management to counter reduced mobility and dietary management to improve bladder and bowel control. There is a lack of robust evidence to support the value of diet for reducing
relapse (Payne, 2001) and some of the dietary guidelines are unrealistic. For example, one regime (commonly known as the Swank diet) is based on minimum saturated fat supplemented by polyunsaturated fat alongside extensive food restrictions. Devised in the 1950s and tested over 50 years, the diet is promoted by confident claims of its benefits, including fewer MS-related deaths among high-adherence dieters than among those who ate more fat (Swank & Goodwin, 2003). The researchers also pointed out the excellent mobility and youthful appearance of the fifteen surviving elderly participants who tested the diet. The claims (plus suggestions that saturated fat may cause MS) are inappropriate considering the study was not randomised and there were no control groups. Although the study onset predates modern rigorous standards, the authors' review should present claims in current context; furthermore, hinting at an association between diet and high mobility seems unscrupulous as well as unrealistic.

Research evidence of the benefits of diet and exercise are further discussed under Alternative interventions (see section 1.11.6). An important aspect spotlighted by the literature on current treatment status and associated adherence difficulties is that people diagnosed with MS are confronted with complex individual treatment environments. The situation may be confounded by condition characteristics (as discussed in section 1.2), with the absence of symptoms and uncertainty about the likely timescale of remittance. Thus the contribution of psychological responses to this fluctuating, ambiguous situation and an uncertain future of chronic illness seem crucial in terms of the motivation to engage and implement adaptation choices.

1.4.3 The role of support groups
Charitable organisations contribute to the care and support of people with MS as well as providing information exchange for health professionals, such as MS nurses. Key national organisations that may be recommended by medics following diagnosis include the MS Society, MS Trust and MS Therapy Groups. The MS Society and MS Trust provide print and electronic resources for people diagnosed with MS, including information on research and support for research. There are local representatives and support groups affiliated to the MS Society; however, researchers are asked to promote research via the national body, which reviews protocols prior to advertising studies on the web pages.
MS Therapy Groups are individual charitable trusts operating under the MS National Therapy Centres, which evolved from Action and Research for Multiple Sclerosis in 1980s and the Federation of MS Therapy centres in 1992. There are over 50 centres across the UK working to improve the quality of life for people with MS. While many centres receive some funding locally from the NHS, the majority are individually funded and people pay a membership fee (which varies according to type of group and this may constitute no more than a meeting fee). The national body provides support and training on services and centre management.

Centres offer support for people with MS and their carers, ranging from social activities and group meetings to therapies, such as massage. Levels of support vary according to facilities and some purpose-built premises offer clinical and occupational services, such as physiotherapy, oxygen therapy, massage, exercise classes and gym work. All centres or groups ensure that any therapies are delivered by suitably qualified healthcare professionals. NHS specialist MS nurses may provide appointments or clinics at MS therapy centres. A list of 58 MS Therapy Groups was compiled across England, Wales, Scotland, Northern Ireland and Jersey for the purposes of promoting this research and recruiting participants for the questionnaire study, which was available online or as paper copies. Recruiting from groups means that participants are in touch with suitable sources of support but this does also mean that the sample represents people who have engaged with their diagnosis or condition. People may be in contact with centres when they feel the need for support, which could relate to higher symptom levels. The research was also promoted by the MS Society on its web pages, which provide information on current studies and ways in which people with MS can be involved.

1.5 Psychological Responses to Chronic Illness

Psychological responses to acute illness may be temporary but chronic conditions have greater impact. People identify themselves in terms of their 'normal healthy state' and this concept is challenged by chronic illness. Personal control, self efficacy and confidence in physical ability are integral aspects of identity, or the self, that are disrupted. The body and self are normally identified as a single unit, with the
physical capabilities, responses and limitations taken for granted, but this trust in the body is disrupted by illness (Corbin, 2003).

When physical control is reduced, the person experiences a sense of the body as separate from the self (Kelly & Field, 1996) and therefore certain fundamental aspects of identity are challenged. Such responses are particularly likely in the case of MS because of unexplained and fluctuating symptoms that render parts of the body as alien, for example through numbness, developing a limp, or unusual tickling, itchy or tingling sensations.

In an early review of literature on adaptation to disability due to MS, Antonak (1995) identified reaction phases as shock, anxiety, denial, depression, internalised anger, externalised hostility followed by acknowledgement and adaptation. Depression and anxiety were common. An initial shock response was experienced as feeling of a numbness. This was followed by anxiety that accompanied realisation of the magnitude of the condition and the uncertainty about the future. This reaction to real or potential disability in MS differed from that experienced in relation to a single traumatic event (such as amputation) and some phases, such as shock, were not experienced. Antonak (1995) differentiated between grieving for what was lost as a retrospective evaluation and anxiety about the uncertain future.

Kalb (2007) also highlighted grief for the loss of health, guilt in terms of letting others down, anger and anxiety as typical responses to relapses. These emotions were also experienced by persons close to someone diagnosed with MS. Grief was an important phase that allowed the person to deal with the loss resulting from relapse (or diagnosis) and move on to consider adapting to the way ahead.

When diagnosis explained symptoms, this often resulted in relief, which promoted a positive approach to adjustment in terms of dealing with anxiety, fear, shame and loss of identity. This initial relief was often short lived.

1.5.1 Depression and anxiety
In a review of the prevalence and incidence of disorders resulting from psychological aspects of MS, Sá (2008) highlighted the need to address depression, anxiety and stress on an individual basis. Lifetime prevalence of major depressive disorder following diagnosis with MS is estimated at 50% (Mohr & Cox, 2001; Siegert & Abernethy, 2005). Beiske et al. (2008) found 31.4% of MS patients reported depression and 19.3% reported anxiety in a sample of 140 participants. Fatigue and
diagnosis at a younger age were associated with depression while pain and disability were additionally associated with anxiety.

Janssens et al. (2003, 2006) carried out a longitudinal study of anxiety and distress following diagnosis with MS among 101 patients. Their results indicated that 8 months after diagnosis approximately 50% patients and their partners had clinically high levels of either anxiety or distress. Mean anxiety scores at baseline were found to remain elevated over a two-year follow up and 69% of those with high scores at baseline had high scores at any point of follow up over the two successive years (Janssens et al., 2006). By comparison, among those who had low anxiety at baseline 26% presented high anxiety at any stage during follow up.

1.5.2 Emotional responses: Fear, anger, frustration

Alongside research into general psychological responses and evidence of poor mental wellbeing in terms of comorbidity of depression and anxiety, there are frequent references to emotional responses, such as fear, anger, guilt and resentment. These seem to represent different levels of reaction.

In the context of negative responses to MS, Kehler and Hajistavropoulos (2009) argued that while general anxiety was researched, there was also evidence for specific health anxiety. In a matched case study of 246 participants, the authors found health anxiety to be higher in MS participants compared to a matched group of healthy controls and participants with other medical conditions. Raised health anxiety was associated with higher emotional preoccupation coping, which was defined as a focus on the emotional consequences of the condition, such as anger, frustration and anxiety. This was different from other aspects of emotional coping, such as detachment, wishful thinking or distraction. The authors also noted a link between high levels of health anxiety and social support; and that the high social support was not present with lower levels of health anxiety. The data did not differentiate between the type of support, that is, whether it was emotion or problem focused. The authors pointed to a marginal association between health anxiety and shorter time since diagnosis (they suggest this modest association should be noted but treated with caution).

A relatively recent qualitative study of early stage responses to MS also suggested that responses were potentially more problematic than general anxiety. Thematic analysis of thirty interviews revealed distress, intrusion, threat and low
emotional stability (Dennison, Yardley, Devereux, & Moss-Morris, 2010). Participants' emotional wellbeing was disrupted by fear of progressive MS, particularly visible disability, which represented the stigmatised condition. It was suggested that early positive outlook and adjustment related to the extent of symptoms. Instead of seeking the support of others, participants avoided MS groups where they would see the progressive condition. Peer support is valued by those in groups, yet this study demonstrated that membership of MS communities is unwelcome in early stages while MS is invisible. These participants avoided associations where visible symptoms or mobility aids were evident. Themes defined the threat to identity and participants' reluctance to be associated with 'the cripple club'. The authors highlighted the lack of knowledge on adjustment during early stages, when people encounter information and develop coping strategies; although most people adjust to progression, the process is not well researched or understood.

An interesting additional facet of the Dennison et al. (2010) study is the potential association between the emotional response to living proof of the threat to identity as well as physicality. This would suggest a fear response not only to being disabled but to looking disabled. While mobility aids may facilitate coping they represent stigmatised identity.

1.5.3 What is an emotion?
In the literature on MS, there is noticeable differentiation in the writing on psychological responses, such as depression and anxiety that are presented as measurable aspects of mental health or psychological wellbeing, and anger, resentment, guilt and fear that represent unmeasured emotional responses described in qualitative research or supporting comments. These seem to be aspects that are not measured in their own right yet they are referred to frequently and consistently throughout the literature.

Wundt (1907) differentiated between emotions and feelings. Whereas a feeling represented a single, slow response of no more than medium intensity, an emotion represented a combination of different feelings united in an interconnecting process. This was separate from processes that preceded or followed it and, as such, constituted an entity or 'united whole' with a 'definite temporal course'. This process produced an intensely arousing effect both at the time of expression and thereafter. Rapaport (1942) summarised an emotion as a mechanism of involuntary, instinctive
and unconscious response to a stimulus. An emotion discharges energy that is in conflict with normal pathways for expression. Emotions vary in intensity according to cultural context, from mild to intense, including such responses as rage and fear. These descriptions indicate the concept of emotional responses as processes.

From this fundamental and simplified definition of emotions it would seem that the descriptions of fear, anger and guilt that qualify the measured psychological impact of MS could be worth considering as emotional processes contributing to the measured responses.

1.6 Challenged Identity

Charmaz (1983) explored social implications of identity among those diagnosed with chronic illness and found considerable psychological suffering. Unwanted social constructions were initiated at diagnosis and developed over the course of illness progression. According to Charmaz, the whole experience of being was challenged by chronic illness as it questioned aspects of the self that were taken for granted and introduced new unwanted identities. Gradual loss of identity when illness progressed constituted further psychological suffering, summarised by four aspects: physical restriction, social isolation, discredited identities and becoming a burden. Charmaz's interpretation seems to represent identity as an embodied aspect of the psychological person. The self provided a conceptual overall summary of identity and a tangible concept that can be evaluated in relation to wellbeing.

1.6.1 Defining identity: Identity as processes

The term 'identity' is widely used, fashionable and broadly applied in everyday terms in popular sociological and psychological contexts. It describes lifestyle or aspects of national and cultural origins. Deeper consideration of its meaning and implications is necessary to assess how identity may be relevant for understanding responses to diagnosis with chronic illness, particularly when the condition may relate to long-term physical decline or disability.

Breakwell (1986, 2001) suggested that identity can be understood only in a social and historical context and proposed a model of identity as a dynamic and social product. Arising from psychological processing of social information, this model sought to provide an holistic representation of the person: the biological organism;
the content and value dimensions; and temporal aspects. A further fundamental concept of Breakwell’s interpretation defined identity as two key processes relating to social structures, context, change and the relation of identity to action. The first process was referred to as assimilation and accommodation, and the second process as evaluation. Assimilation and accommodation focussed on taking in, or absorbing identity-relevant content and the changes needed in existing identity structure in order to create a space for this content. The process of evaluation simultaneously considered and interpreted incoming social information in terms of meaning for the self, with the evaluation being shaped by relevant social representations as well as personal and interpersonal considerations. Breakwell proposed that these processes were motivated by principles relating to the required identity outcome or ‘end states that are desirable for identity’ (p. 24). Three main aspects of uniqueness or distinctiveness, continuity and self esteem were initially identified as principles, although self efficacy was added in subsequent work by Breakwell (1992), and others have suggested further principles, some of which are context specific.

While biological aspects represented a fundamental core, Breakwell considered these to be of diminishing importance as the person developed experience and knowledge. Content and value reflected the self as knower and the self as known, the subject 'I' and object 'me'. Temporally, identity processes reflect personal, subjective, inner time; the intersubjective or social-interaction time; and biographical time, which relates to past, present and future narrative of life. Biological identity processes may be relevant when chronic illness represents physical decline, uncertainty or potential disability. Temporal processes complement the way people make sense of their lives as narratives by considering what went before, the current situation and the future.

Defining identity as processes suggests that it constitutes a complex system of interactive evaluation and signalling, which in turn influences response. Breakwell's definition represents processes within the content and value context. In terms of the subject and object positions of the person, identity constructs the self concept through self evaluation. The self as an object is matched by the self as a subject; the social self is countered by the spiritual self; and the real self is compared with the ideal self. When assimilation-accommodation and evaluation processes create
conflict or tension with underlying principles, identity can be said to be threatened. In this context, chronic illness may represent multiple threats.

Breakwell defined strategies for coping with threat at intra-psychic, interpersonal and group (and intergroup) levels. Intra-psychic strategies reflect cognitive and emotional responses, with acceptance or deflection of threatening aspects and/or modification via the two processes of assimilation-accommodation and evaluation. Interpersonal coping focussed on actively changing relationships. Intergroup aspects could relate to coping with potential stigma associated with a particular group.

Simon (2004) proposed a complementary interpretation of identity bridging psychological and sociological perspectives. That identity occupies a social position is generally agreed and the Self-aspect Model of Identity (SAMI) proposed by Simon also defined identity as process-orientated. SAMI represents identity as a social-psychological mediator of the person within the world. Identity represents an underlying process of behaviours and experiences that could be compared to the experimental positions held by both dependent and independent variables. This concept of a dual role for identity defines it as influencing both experience and behaviour. In this sense, identity as a dependent variable is subject to the incoming social experience. As an independent variable identity mediates the projection of the self out into the social situation. Simon represented identity as a multi-faceted process of orientation and definition of the self, reflecting both intrapersonal processes, in terms of human consciousness, and the social conditions or context within which the self is defined.

Simon considered not only micro and macro levels but also a position he defined as meso level of processes. While the micro level represented the individual's cognitive interpretation of social context, the macro level represented processes around social representations or roles fulfilled by the individual. (Breakwell also brought social representations into her theory subsequent to its original exposition as important considerations in shaping the nature and content of the evaluation of identity components.) Identifying the micro and macro as separate and abstract, Simon defined a meso level signifying the ‘concrete’ meeting of the abstract micro and macro. This represented the interaction of abstract processes.
1.6.2 Chronic illness, loss and unwanted identities

Charmaz (1983) considered the self as social, developed and maintained in social context and interaction, emerging over time and throughout life. While organisation of consistent aspects provided the basis for the self, this was not static and the core organisation was adjusted as new definitions of the self evolved with life experience. This seems to represent aspects of ongoing processes but in relation to a core structure such that the underlying self embodies multiple facets of identity that are subject to change. Social processes or interpretations of identity instigated change and when these processes precipitated unwanted identities, the self suffered unwanted loss.

Charmaz identified suffering as problematic and leading to social isolation when the person had to focus inwardly on the self to the detriment of social relationships. Concepts of reserving energy resonate with experiences of fatigue in MS. Visual disability was also associated with the self becoming discredited due to stigmatised or marginalised identities presented when others' expectations differed from the person's own outlook. Encountering unmet expectations of others, or those previously assumed by the self, could result in feeling marginalised. Restricting activity was one way of avoiding unwanted social feedback or facing the reality of unfulfilled personal expectations. Self-selected aspects of social isolation also protected the person from having their hidden, unacknowledged fears validated by the unspoken responses of others.

Charmaz highlighted further suffering from discrediting interactions in close personal relationships, making the person feel they were no longer fulfilling familial roles or obligations. Adopting a stoic position and trying to live as normally as possible constituted suffering and feelings of failure when others' expectations were not met. Altered family (spousal) relationships also imposed identity change when partners (or relatives) become carers. Becoming a burden to a carer was associated with dependency and loss of power.

Charmaz indicated that emotional isolation could occur within a social context as someone felt devalued and powerless when presented with a negative identity. The example cited by Charmaz was of a participant who was patronised, spoken to as a child and spoken of in the third person because he was in a wheelchair.
1.6.3 Protecting identity

Implications of identity challenge on everyday life are so broad that they can have adverse effects on health behaviours. Finlay (2003) described the changed existential, physical and social factors that influenced identity and resulted in unhelpful behaviours and cognitions. The researcher provided in-depth analysis of one case study that demonstrated vividly the ways in which it is possible to refuse fully to accept MS because of the identity implications. The behaviour and consequences interacted in a dynamic combination of concealment, trauma and a desperate need to cling to some aspects of previous identity while simultaneously urgently searching for a current identity and being frightened of future identities. By withdrawing from social contact others' responses to the first minor visual symptoms of MS could be ignored and this also meant there was no need to comply with any presented disabled role. To preserve her maternal role, the participant employed a process of compartmentalising illness, protecting family and forfeiting work or other aspects of life that were previously important on a personal level. This facilitated short-term coping but it also produced huge grief and rage, particularly as the strategy became increasingly less successful. Not being able to create a new identity meant that the participant experienced (and described) periods of trauma related to conflicting identity and fear.

1.6.4 Constructing new identity

Using grounded theory to analyse interview data from participants with various disabilities (spinal cord injuries, visual impairments and amputations), Salick and Auerbach (2006) defined a process of resilience and growth of the self in response to medical trauma. However, the participants were not exclusively diagnosed with MS and the unpredictable nature of MS meant that constructing new identity was not easy (Kralik et al., 2003). Kralik's research into sexual identity emphasised the 'extraordinariness' of the experience of MS. It was only through a process of accepting changes that 'ordinariness' could be reinstated. Such adjustment involved more than a one-off stage of acceptance, especially with constant change in MS.

The nature of symptoms means that MS has also been conceptualised as violating dignity by a sample of mature women aged 43-59 years (Olsson et al., 2008). Olsson summarised the power challenges to the socially constructed self when obvious physical changes meant the women were treated differently. The body
was experienced as an unfamiliar 'burden' attacked by MS as an enemy. The women had to adopt a different social position. They had to become strong and controlling to protect their dignity. Maintaining power and a consistently positive perspective on the future enabled them to counter the illness.

Charmaz (1983) conceptualised chronic illness as gradually diminishing or reducing the self. Loss of ability and independence made the person with chronic illness aware of their former self disintegrating. Experiences of the patients in the Olsson et al. study illustrate Charmaz's description of traumatic loss of self as an embodied intrinsic aspect of identity. The sense of indignity resulting from embarrassing physical symptoms relates to loss of what could be considered as 'self dignity' or an aspect of self esteem. In response to the perceived potential loss, the ladies had to adopt a new identity position, embodied in a strong and controlling countenance that protected their dignity in social context.

1.6.5 Identity transition: Adjusting to chronic illness

Successful coping with chronic illness involves acceptance and adjustment to the reality of the condition. The process of adjusting is also termed 'transition' (Morse, 2009) as it involves internal change and on-going adjustment of the self in concordance with the illness. Kralik, Visentin and van Loon (2005) explored the use of the term 'transition' in a review of 23 qualitative studies. Transition was defined in terms of a psychological process as 'the way people change over time ... to adapt to a new event in their lives'. Self identity, biographical disruption, restructuring meaning and reshaping the self were associated with transition, with 'reconstruction of valued self identity as central'.

It would seem that coping with inconsistent MS would mean constructing an identity that is both extremely resilient and flexible. Broad but strong boundaries could accommodate fluctuation. This, it would seem, could provide a stable foundation for understanding and building a resilient identity.

1.7 Illness Beliefs or Cognitions

Diagnosis with serious illness involves dealing with new life circumstances and understanding the illness or condition. The concept that a person's beliefs, based on individual evaluation and interpretation of the diagnosed condition, would contribute
to their response and behaviour was proposed by Leventhal and colleagues in a commonsense model of illness representations (Leventhal, Meyer, & Nerenz, 1980; Leventhal, & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984; Meyer, Leventhal, & Guttman, 1985). Data from interviews with patients diagnosed with different illnesses were analysed to explore their understanding. Patients' interpretations were used to define a framework of constructs that they used to evaluate and build up their beliefs about the conditions. Making sense of illness involved processing existing information and symptom experience in the context of previous personal experience (or schemata) alongside opinions from important others (familial, social and professional). This represented abstract interpretation of concrete information using the following five constructs or cognitions to cover illness characteristics.

i) **Identity** This refers to the diagnosis or label and the symptoms defining the condition.

ii) **Cause** This relates to the biological or physical causes, such as infection or accident, and relevant psychosocial or behavioural contributors, including being vulnerable and stressed.

iii) **Time line** This is the interpretation of the expected duration of the illness.

iv) **Consequences** The implications of the illness, including physical, social and emotional outcomes.

v) **Curability and controllability** The treatment options and implications for personal control or professional control (medication or treatment).

A later review and meta analysis of research using illness representations provided supporting evidence for the relevance of the above characteristic, with data from 45 studies covering 23 conditions (including two studies of MS) indicating both construct and discriminant validity of the framework (Hagger & Orbell, 2003).

1.7.1 **Leventhal's self-regulatory model**

The illness cognitions contributed to Leventhal's (1980) cognitive self-regulatory model which is summarised in Figure 1. Three-stages make up a dynamic model of coping in which interpretation of symptoms and social messages lead to coping. The coping strategy is then subject to appraisal and revision, if necessary. A key concept in the model is the individual's assessment of their status with illness diagnosis in
terms of their preceding normal healthy state. The model proposes a process for regaining equilibrium following acute illness and for optimising equilibrium, as far as possible, based the individual's normally healthy concept.

The stages can be summarised as follows.

i) Interpretation The personal beliefs covered by the constructs as well as professional advice and opinion. Social context, understanding and implications of the illness also contribute. Moving from interpretation to coping involves dynamic assessment of multiple factors, based on objective and subjective interpretations and emotional responses. Consideration of interacting factors contributes to re-evaluation of interpretations and approaches to coping.

![Leventhal's (1980) self-regulatory model](image)

ii) Coping Coping strategies can be summarised as approach or avoidance. Realistic interpretation involves complementary use of both. Approach coping could include adherence to medical regimes, seeking and following information, and adopting health-promoting behaviour. Avoidance can be used to minimise anxiety, for example not focussing on potential negative illness aspects; denial can also be useful for short-term coping.

iii) Appraisal Appraisal is the process of evaluating coping strategies. Successful strategies can be maintained and problematic approaches reconsidered. This may mean reassessing coping and/or illness representations. This accommodates illness or circumstance changes.
The model allows for multiple responses to be categorised and linked to coping. Emotional experiences can be considered as well as subjective, objective and practical considerations. Self regulation represents willingness to engage, awareness of responses and acceptance to some extent. In terms of the characteristics of MS, the diagnosis process and responses as discussed in sections 1.2 to 1.6, the self-regulatory model seems realistic in that it accommodates the possibility of maladaptive coping and appraising the adopted strategy as a post-coping stage. It would seem possible that the uncertainty of MS could make building a coherent or consistent set of beliefs difficult and thus arriving at a coping strategy may be more complex. The option for appraisal and revision is appropriate, for example to accommodate fluctuating or progressive symptoms; however, if uncertainty is unresolved, or recurring, it would seem possible that a loop of unsuccessful interpretation and ad hoc coping could result without appraisal. While the model represents logical and commonsense approaches, it is reasonable to consider that they could be hindered by confusion arising from unresolved uncertainty, persistent fluctuation and difficulty in making an appropriate appraisal.

1.7.2 Measuring beliefs: Illness perception questionnaire

A succinct measure was needed for quantitatively evaluating the illness perception structure and the self-regulatory model. Weinman, Petrie, Moss-Morris and Horne (1996) developed the illness perception questionnaire. This was intended as a tool for understanding coping and also for developing interventions to promote self management of chronic conditions. The authors cited limitations of previous questionnaires as their suitability for evaluating only specific patient groups and not complying with (and therefore not accurately measuring) the self-regulatory model and related theory. Some previous questionnaires collated beliefs of professionals and carers in addition to those of patients.

The illness perception questionnaire was designed to assess the five constructs in the self regulatory model (illness identity, cause, time line, consequences and control/cure). The first section rated a core symptom list for frequency of occurrence. Subsequent sections involved rating agreement with series of statements. Lists of symptoms and causes could be changed to suit the condition. Weinman et al. (1996) tested the questionnaire on seven illness groups: people experiencing or who had experienced myocardial infarction (hospitalised and discharged at two time points),
chronic fatigue syndrome, rheumatoid arthritis, diabetes, pain, renal illness and asthma. Different symptom, cause and consequence options were evaluated. A revised shorter version was tested for assessing the perceptions of carers and spouse.

1.7.3 Illness perception questionnaire – revised
The questionnaire was revised and extended to investigate both personal and treatment control; cognitive and emotional representations; and a cyclical timeline dimension (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). The cognitive section retained the five constructs from the self-regulatory model. The treatment line was sub-divided to allow for acute, chronic or cyclical factors. Additionally, the scale explored patient coherence of their illness.

1.7.4 Brief illness perception questionnaire
Broadbent, Petrie, Main and Weinman (2006) critiqued the length and time necessary for completing the revised questionnaire as prohibitive for patients with severe illness or restricted writing capacity. Combining a long set of scales with outcome measures made questionnaires detrimentally long for repeated use in before-and-after research. Broadbent et al. evaluated a brief illness perception questionnaire providing single-item measures of the same constructs. The questionnaire was tested on patients with myocardial infarction, renal disease, type 2 diabetes, asthma, pre-diagnosis stress and minor illnesses (allergies, colds, headache). Test-retest reliability was good and items on the brief scale correlated well with corresponding items on the longer revised version. The brief scale also showed good discriminant validity in comparisons of mean scores across the different illnesses. The brief version was also easier to understand and complete.

The adaptability and clarity of the brief illness perception questionnaire was recently challenged by van Oort, Schroder and French (2011). In a think-aloud study of forty five participants' interpretations of the Dutch version, the authors identified 88 problems with clarity, and considered eleven misinterpretations and six queries on content to be important. Participants (recruited from preoperative exercise and primary care physiotherapy for musculoskeletal complaints programmes) ranged in age from 18 to 87 years old. The researchers did amend the questionnaire to include specific conditions but asked participants to 'replace the word "illness" with the health problem you need treatment for'. This was potentially confusing and ambiguous. Participants provided think-aloud commentary while completing the
questionnaire. Think-aloud method reveals the approach to providing descriptive detail and interpretation but it is not clear in this study whether the commentary revealed participants' ambiguities about the questions or their conditions. The internal validity is questionable as well as the ambiguity of the method.

1.7.5 Illness perception and outcome

Weinman et al. (1996) found that beliefs were not only associated with coping (as predicted by self-regulatory theory) but that they could also be directly predictive of outcome. Associations with coping were found in both myocardial infarction and chronic fatigue syndrome. In chronic fatigue syndrome illness perceptions were predictive of outcome aside from the mediatory influence of coping. The questionnaire elicited findings similar to those from qualitative methods and with no order effects according to whether participants completed the questionnaire before or after the intervention interview. There was a priming effect and participants who were interviewed first completed the questionnaire more easily. The authors suggested that being interviewed before filling in the questionnaire helped patients to access schemata they had developed about their illness.

It would seem possible that the priming effect could influence evaluation of an intervention by providing patients with an opportunity to reconsider and update or revise their beliefs independently of an intervention. Particularly with reference to emotional responses, when reviewing a complex list of symptoms and consequences could exacerbate anxiety and distress.

1.8 MS and Illness Perceptions

A number of studies have demonstrated that the illness perceptions questionnaire is a useful measure of patients' beliefs about MS. The following studies support findings of Weinman et al. (1996) that beliefs could be directly predictive of outcome.

Jopson and Moss-Morris (2003) found that illness representations were associated with adjustment. In differentiating between physical and mental fatigue, the authors found that while physical fatigue was associated with reduced control, increased mental fatigue was associated with increased personal control and perceptions of lower treatment control. Although personal control related to mental fatigue, it was positively related to psychological wellbeing, including less distress.
and depression. Perceptions of serious consequences were related to participants' own greater disability ratings and poor psychological wellbeing as were the uncertainty and lack of clear understanding of MS. In this study, the revised illness perceptions questionnaire provided insight into patients' perceptions of MS and associations with measures of physical and mental outcome.

Vaughan, Morrison and Miller (2003) demonstrated associations between MS illness perceptions and outcomes based on the Weinman et al. (1996) scale (with symptoms adapted to MS). Their results indicated that participants beliefs (n = 99) were consistent with medical understanding of chronicity and no specific cause or cure. Control was considered to be low and consequences serious. The illness intrusiveness ratings scale; activities of daily living scale; hospital anxiety and depression scale; and the Rosenberg self-esteem scale were outcome measures. Serious consequences were associated with intrusiveness, physical impairment, anxiety and depression; however, perceptions of greater control, despite there being no cure, related to lower intrusiveness and physical impairment, and higher levels of self esteem.

Illness perceptions were also found to contribute to health-related quality of life outcome in a cross-sectional study of 580 Australian MS patients (Spain, Tubridy, Kilpatrick, Adams & Holmes, 2007). Increased identity related to decreased physical function and wellbeing independently of measured disability levels, and negative consequences were associated with reduced social activity.

1.9 Alternative Theories and Models

While evidence supports the applicability of health beliefs and the illness perception questionnaire to MS, and research indicates associations with outcomes, the process of adaptation appears to be too complex to map on to one model. A number of longstanding theories contribute to understanding the social, physical and psychological aspects of responses to MS.

1.9.1 Social aspects of identity threat
Section 1.6 considered the threat to identity posed by chronic illness. As well as the physical aspects of identity and the fear of becoming a burden, the concept of having existing aspects of the self discredited contributes to the suffering (Charmaz, 1983).
Being discredited implies rejection through evaluation by others. Constructivist theories suggest that the self is played out according to the views of important others. An extreme view would suggest that others' persistent opinions, impressions and responses are so vital to identity that the self, therefore, becomes a shifting representation that alters to suit situations.

An alternative interpretation would suggest that instead of being in a constant state of flux, opinions of important others are internalised, accepted or rejected as identities and they contribute to a multi-faceted self (Harré, 1995; Burr, 2003). Chronic illness, and MS in particular, threatens the self with unwanted identities, involving reduced physicality or disability, different social interactions and dependency. Breakwell (1986) proposed that coping strategies, such as denial or acceptance, were used in situations of identity threat and that identity was reassessed. Different strategies were adopted to deal with identity threat and they were repeated for successful coping.

1.9.2 Disrupting and restorying narrative of identity
Crossley (2000) proposed that identity represented a temporal storyline of unity and expectation based on past, present and expected future contexts. People make sense of their lives in terms of stories or narratives that link and interact. Multiple narratives contribute to the global or overall story and this represents an underlying personal understanding of the self. This phenomenological or experiential and subjective understanding provides a coherent identity. Events are evaluated in this context, in terms of previous experience, current circumstances and implications for the future.

Chronic illness represents a threat that disrupts the narrative of identity. Seeking causes may bring the past into question; current plans become unstable or destroyed and assumptions about the future change. Crossley suggested that narrative becomes important for reconstructing identity following trauma. When all taken-for-granted aspects are thrown into doubt, narrative becomes important for reconstructing a new identity. A process of narrative reconfiguration facilitates coping with the disruption and demonstrates the process of constructing or revising identity.

1.9.3 Illness perceptions and the narrative of illness
The idea of the narrative of identity appears to interact well with the concept of illness perceptions. Leventhal's self-regulatory model and the corresponding
constructs or schema represent a simplified narrative of illness. Crossley (2000) proposed that people's narratives of illness reveal the processes involved in personal meaning making. A narrative of illness implies a process of acceptance.

The concept of constructing a new narrative of identity suggests that the resulting, revised coherent self represents the equilibrium objective of the self-regulatory model. By establishing a new coherent, flexible foundation for identity, an equilibrium is achieved. It is against this that forthcoming events and future challenges can be appraised.

The new narrative of identity allows the narrative of illness to interact with the temporal narrative of past and future in order to redefine equilibrium. New self-regulatory boundaries incorporate the narrative of illness and all its implications for acknowledging the need for coping and appraising strategies.

1.9.4 Crisis theory

Being diagnosed with serious chronic illness with uncertain prognosis represents a major life crisis with multiple implications. Crisis theory represents the way people react to major threat that imposes a turning point in life by threatening established identity. Moos and Shaefer (1984) proposed that illness crisis involves a process of appraisal, adjustment and adaptive tasks with the aim of reinstating a balance. Figure 2 summarises the process of coping with chronic illness. Three key aspects of short-term crisis approach involve appraising the threat to identity, physical and social circumstances, role and the future; employing adaptive tasks to deal with the illness itself and its impact on everyday life; and deciding on coping approach.

![Figure 2: Moos and Shaefer (1984) proposed coping with illness crisis theory](image)

The crisis approach to coping strategies can influence future outcome, through adaptation or maladaptive responses. According to this model, adaptation to a new identity involves dealing with the condition, understood as three means of coping.
i) Appraisal-focused coping This method focusses on understanding, finding meaning, then using avoidance or denial to minimise the threat.

ii) Problem-focused coping This method is expressed as confronting, restructuring and resolving problems.

iii) Emotion-focused coping Dealing with responses is aimed at maintaining emotional stability in this approach. This could involve affective expression and finding hope and support, venting feelings in anger or despair, or resigned acceptance.

This process of dealing with the crisis provides time to mediate change from pre- to post-illness self. The objective is to regain balance through self regulation and to gain a new balanced identity capable of accommodating the illness.

The fluctuating, unexpected, disappearing or invisible symptoms and lengthy diagnosis process represent a complex MS crisis for which a linear progression from crisis through to potential coping would seem difficult. Fear of the unknown and potential relapses represent the uncertainty of continuing fluctuating crises.

1.9.5 Meaning, mastery and enhancing life

Taylor (1983) suggested that adjustment is based on a more complex interactive process of cognitive adaptation, involving searching for meaning, mastery and enhancing the self to restore esteem. Taylor proposed that these adaptive cognitions were not necessarily completely separate processes but they overlapped. Enhancing self esteem by downward comparison with others who were worse off but coping also provided motivating role models for gaining control. Enhancing the self relates to benefit finding, which Packenham (2005, 2007) highlighted as useful for adjusting along with meaning making in relapsing remitting MS. However, the value of benefit finding in MS is not supported by a strong body of literature.

Taylor's theory involves optimism as a set of illusions of control that have to be constructed and nurtured for successful cognitive adaptation. This would seem appropriate for dealing with uncertainty and the potentially uncontrollable aspects of MS but also potentially problematic if coping illusions were disconfirmed. Taylor found that failure did not result in reactance or learned helplessness if the expected control could not be achieved. People learn resilience through everyday experiences and they apply this to coping with chronic illness. As long as there is hope and alternative means of achieving a goal, people will try repeatedly rather than concede.
Bogle, Percy and Morrison (1999) proposed that coping methods could not be
generalised but were individual. Not adapting could result in being overwhelmed by
illness, giving up work, requiring greater professional resources and resulting in
lower quality of life. This would seem to be a danger with MS because of the
individuality of symptom presentation and unpredictable relapses hindering stability.

1.10 Call for Revised Models

suggested that being realistic was important to avoid disconfirmation or failure of
plans for controlling illness. They noted that the complexity of chronic illness, its
context and consequences, mean that personal interpretation and reality do not
necessarily equate. Existing theories of adjustment based on evaluation of illness
beliefs and perceptions, meaning making and planning coping strategies do not
consider interactions and processes that are hierarchical rather than linear. The
authors proposed the revised model shown in Figure 3, based on earlier 1997 work
of Park and Folkman. This model of adjustment includes hierarchical processes of
attributing situational meanings and interpretations of illness. When illness
perceptions, intermediary and pre-existing beliefs cannot be matched to facilitate
coping, hierarchical stages of adjustment are used in order to achieve equilibrium.
Pre-existing beliefs or schema are evaluated and amended, and intermediary beliefs
are formed relating to the illness or illness perceptions.

The Sharpe and Curran model magnifies the stages of linear theory, such as those
in Leventhal's self-regulatory model. While this represents a more realistic
interpretation of complex responses, it could be argued that hierarchical
interpretations do not adequately represent the processes involved in responding to
the uniquely complex uncertainty of MS. Fluctuating, interacting, unexplained and
often unexpected symptoms characterise the condition, particularly during the early
stages. As some symptoms become familiar, new ones may appear; others may
subside or disappear. The culture of medical ambiguity; health-specific anxieties; potential unknown future threat; perceptions of stigma; and social messages do not necessarily occur sequentially or with hierarchical links.

At its worst, MS poses multiple, unpredictable and concurrent demands. While interpreting, understanding and engaging in short-term decision making to facilitate crisis coping, simultaneous aspects of mid- to long-term prospects have to be manipulated. As existing appropriate illness perceptions progress successfully through phases of processing and coping, changing circumstances or new aspects
may present alternative, additional or even novel challenges. Negotiating such interacting demands would suggest multiple layers of adjustment, involving continuous – possibly linear – processes in parallel to hierarchical responses.

1.10.1 Models of interactive perceptions, emotions and processes

The following two working models shown in Figures 4 and 5 propose revised theories of adjustment to MS in particular and chronic illness in general. The first model developed by Dennison, Moss-Morris and Chalder (2009) is specific to MS. Based on this, Moss-Morris (2013) proposed a model of adjustment to chronic illness, summarising complex interacting aspects of cognitive evaluation and emotional responses. The model of adjustment to MS indicates influences of personality, early experiences and social aspects relating to identity. Critical events at the core of the model include diagnosis, symptom presentation, relapse or progression. These factors lead to emotional disruption and successful adjustment includes, among other aspects, problem-focused coping and social support. Control over generic life situations also feature in the model. Illness perceptions are absent in the early stages of the model and they do not feature prominently among cognitive factors influencing adjustment, other than in the context of MS as threatening.

By comparison, in the model representing adjustment to general chronic conditions, illness perceptions, including prognosis, treatment and symptoms are represented as early contributors alongside personal background, social and environment factors. In both models, emotional disruption and quality of life are represented as pivotal aspects.

Moss-Morris (2013) points to ambiguity over the definition of adjustment, currently viewed in mental health terms as measurable depression or anxiety, and argues that these mental comorbidities may not be a consequence of the illness. Therefore they are not necessarily indicators of adjustment. Instead, poor adjustment may be reflected in poor health behaviour or aspects of impact on life roles. Depending on the condition or the individual, Moss-Morris highlights the fact that adaptive processes and outcomes vary and that they should be considered separately. In chronic illness, adjustment is not a one-off change but it represents an on-going process that matches the condition. Negative emotional responses are not necessarily indicative of poor adjustment but they are part of a process and are likely to be problematic only when unresolved and prolonged.
At the top of the figures, both models include contributing factors but do not identify more specific contributors that are evidenced as being important in existing research. For example, the personal factors include personality and early experiences.

![Diagram of adjustment model to MS]

**SUCCESSFUL ADJUSTMENT**
(text distress and interference/impact of MS on life)

Factors helpful for adjustment:

- Cognitive Factors
  - Coping by using positive reappraisal
  - Perceived control over generic life situations
  - Self-efficacy regarding MS management
  - Optimism
  - Hope
  - Benefit finding
  - Self-efficacy regarding generic life situations
  - Acceptance of Illness
  - Spirituality

- Behavioral Factors
  - Coping by using problem-focused strategies or seeking social support
  - Health behaviors

- Social/environmental Factors
  - High perceived social support
  - Positive relationships/interactions with family/spouse

**ADJUSTMENT DIFFICULTIES**
(disproportionate distress and impact of MS on life)

Factors unhelpful for adjustment:

- Cognitive Factors
  - High perceived stress
  - Coping through wishful thinking or avoidance
  - Uncertainty about Illness
  - Appraisal of MS as threatening
  - Dysfunctional cognitions/cognitive errors & biases
  - Helplessness
  - Perceived barriers to health behaviors
  - Unhelpful Illness/Symptom representations
  - Unhelpful beliefs about pain

- Behavioral Factors
  - Coping through avoidance
  - Unhelpful responses to symptoms (avoidance/resting)

**Figure 4:** A working model of adjustment to MS (Dennison, Moss-Morris, & Chalder, 2009)
in the MS model plus goals and values in the general model. In the first, (MS) model, linear links are represented between personality and experiences, beliefs about self and others, leading to values goals and behaviours. It would seem possible

**PERSONAL BACKGROUND FACTORS**
- Early life experiences; Personality
  (e.g., optimism, neuroticism)
- Values and life goals
- Demographics (e.g., age)

**ILLNESS-SPECIFIC FACTORS**
- Nature of symptoms
- Degree of disability/disfigurement
- Degree of uncertainty
- Prognosis
- Treatment regime and side effects

**BACKGROUND SOCIAL AND ENVIRONMENTAL FACTORS**
- SES; Physical environment
- Availability of health & social care
- Social support
- Relationships with others

**POSSIBLE KEY CRITICAL EVENTS**
- Development of initial symptoms of illness
- Diagnosis of chronic condition
- Relapse and/or disease progression
- Threat to mortality
- Change in identity/life roles

**POSSIBLE ONGOING ILLNESS STRESSORS**
- Managing social relationships and relations with health professionals/social services
- Uncertain future
- Preserving autonomy
- Acknowledging limits
- Managing stressful/ongoing treatments, lifestyle changes, disability, disfigurement, and symptoms

Disrupts emotional equilibrium and current quality of life

**SUCCESSFUL ADJUSTMENT (return to equilibrium)**
- Examples of factors helpful for adjustment (need to examine empirically within context of illness and related adaptive tasks and critical events)
  - **Cognitive Factors**
    - Self-efficacy/sense of control regarding disease management
    - Self-efficacy regarding generic life situations
    - Benefit finding (positive reinterpretation)
    - Acceptance of illness
    - High perceived social support
  - **Behavioural Factors**
    - Coping by using problem-focused strategies, planning and/or seeking social support
    - Engagement in good health behaviours
    - Adherence to medical and self-management regimes
    - Maintaining activity levels in the face of illness
    - Appropriate expression of emotion

**ADJUSTMENT DIFFICULTIES (ongoing disequilibrium)**
- Examples of factors unhelpful for adjustment (need to examine empirically within context of illness and related adaptive tasks and critical events)
  - **Cognitive Factors**
    - High perceived stress
    - Coping through wishful thinking
    - Negative illness/symptom representations
    - Dysfunctional cognitions/cognitive errors & biases, e.g., catastrophizing
    - Helplessness
    - Suppression of negative affect
  - **Behavioural Factors**
    - Coping through avoidance
    - Unhelpful responses to symptoms (consistently reducing activity/resting, focusing on symptoms)
    - Venting or denying/repressing emotions

**Good Psychological, Physical and Social Adjustment**
- (e.g., less distress and interference/impact of illness on life roles and relationships; good illness management, high positive affect)

**Poor Psychological, Physical and Social Adjustment**
- (e.g., disproportionate distress and interference/impact of illness on life roles and relationships; poor illness management, low positive affect)

Figure 5: A working model of adjustment to chronic illness (Moss-Morris, 2013)
that personality and experiences could be defined as separate constructs, the first possibly related to intrinsic factors and the second to external events. The same applies to the top line of the general model, in which multiple factors are covered.

Both the MS-specific model and general chronic illness model consider emotional responses as pivotal and Moss-Morris proposed that the absence of distress should not be considered to be a core indicator of positive outcome. Interactions leading from diagnosis to emotional disruption stage are not clearly represented. The problem with the models is that they both include examples of any and all aspects that influence adjustment and in both cases the central focus on emotions is the simplest aspect. Yet the significance, role and processes of emotional disruption are not identified. While top level contributors in the model could be re-defined with relative ease, the step from emotional disruption to successful adjustment or difficulties is unexplained.

Even though both are presented as working models, the links between early contributing aspects and the outcomes are not convincing and coherent. The models present blocks of information without attempting to define the vital processes or pathways. Both models demonstrate that multiple factors are potentially important but there is an absence of analytic consideration of action processes. Testable pathways provide opportunity for building evidence to support the processes or indications for how they should be adjusted.

Models based on evidence of processes indicate points at which interventions may be introduced to amend or adjust the pathways. Interventions redirect responses off adverse pathways and through positive steps towards improving outcome.

1.11 Addressing Implications in Interventions

Considering the large volume of research into patient representations and psychological implications of being diagnosed with MS, there is a comparative dearth of corresponding robust, well-focused research into psychological interventions. It is useful to consider this area of research in terms of the overall limitations that signpost ways in which future research into psychological
interventions could progress. Therefore, the following information summarises recent reviews and provides examples of studies and trials.

1.11.1 Published reviews

The findings of two systematic reviews and one scoping review demonstrate the need for further research into psychological interventions primarily because existing work does not represent a credible body of well planned and documented research. The overall impression from the following papers is that the area is characterised by imprecise and unwieldy design with often optimistic interpretation and/or inconclusive findings.

Thomas, Thomas, Hillier, Galvin and Baker (2006) conducted a systematic review to assess the effectiveness of psychological interventions addressing cognitive functions, thought, mood and behaviour among people diagnosed with MS. Examples of the types of interventions evaluated for the review included psychoanalytical, behavioural and cognitive therapy; educational interventions; counselling; and cognitive rehabilitation. Papers published up to December 2004 were covered and authors who had previously conducted research in this area were contacted in June 2004 to access newly complete work. The follow-up times of the studies included in the final review ranged from five weeks to four years.

The review evaluated effectiveness outcomes in terms of quality of life, cognitive function and disability as well as pain, fatigue and use of health-related services. Among the sixteen studies that met their research standards criteria, the authors found a broad range of interventions with different objectives and they grouped papers into four mini reviews according to participant groups. Therefore they could not apply overall meta analysis to published results or disseminate decisive evidence of the effectiveness of specific methods; however, cognitive behavioural therapy (CBT) was deemed to assist with depression, adjustment and coping.

The authors' general critique provides useful insight into the status of this field of research. Although it was apparent that there was broad scope for potentially helpful interventions, there was little supporting evidence from randomised controlled research. The authors criticised small sample sizes (from 15 to 240) in studies that did not acknowledge their contributions as pilot studies (and the usefulness of such work). Methodological shortfalls included using large numbers of outcome measures without a priori definition of primary objectives and inadequate
application of statistical analysis and interpretation. Seven studies were published in the 1980s and 1990s, and research standards had improved since then. Noting advancing research into multiple aspects of MS, Thomas et al. defined implications of their review in terms of suggested objectives for future intervention studies.

i) The need for interventions on adjustment and coping following diagnosis.
ii) Research comparisons of group therapies versus one-to-one interventions.
iii) Evaluate the possibility for training nurses or occupational therapists in intervention delivery.
iv) Explore the optimum stage in the condition for delivering interventions targeting adjustment.
v) Research MS subgroups for whom interventions would be most beneficial.

While there was a need for large-scale randomised control trials in this area, Thomas et al. considered that this may not always be the most suitable method.

A systematic review collating published papers up to 2006 supported the Thomas et al. opinion, with comment on the wide variation in content, delivery and measurement of psychosocial interventions for MS (Malcomson, Dunwoody, & Lowe-Strong, 2007). Potential benefits of interventions were not adequately supported by consistent evidence due to poor methodology. The authors found only three studies that met their quality criteria from thirty three interventions retrieved in searches. The authors concluded that while there was some evidence of the benefits of multi-disciplinary approaches to providing education and support interventions for patients, further research into interventions is needed.

In a scoping review of studies focused on self-management interventions between 1980 and 2008, Plow, Finlayson and Rezac (2011) further contributed to the general view that inconsistency is a problem. From twenty seven interventions the authors highlighted the heterogeneity of interventions for addressing the same outcomes, including studies into fatigue, coping, depression, stress and medication. Clearer definition and transparency was needing in research testing of interventions.

1.11.2 Reviewing CBT interventions
The need for sound research that could deliver robust evidence was also relevant to cognitive behavioural therapy (CBT) for MS (Dennison & Moss-Morris, 2010). This
review highlighted the need for high-quality research into the potential benefits of
CBT for improving psychological distress and behavioural responses to MS. The
authors proposed that CBT could suitably address the unpredictability, potential
severity and anxiety related to MS as well as physical symptom management and
broad adjustment. The authors decided that further research should assess the
potential for telephone and on-line interventions as well as face-to-face delivery.

1.11.3 Reviewing group therapy

It is logical to consider group therapy as a seemingly cost-effective format, yet research
in this area was also weak. For example, limited evidence on outcomes was found in
a review of group interventions from 1984 to 2012 (Firth, 2013). Firth identified
fourteen studies (including three preceding 2000) meeting the review’s criteria,
which included quantitative evaluation and use of control group or comparative
intervention. Overall findings indicated that group interventions were effective for
reducing depression but with only moderate improvement of self efficacy and quality
of life. There was little change in anxiety and group therapy was less effective for
short-term improvement in depression compared to CBT but equivalent in the long-
term. However, the broad range of methods used diluted the evidence, for example
CBT, coping skills, mindfulness, supportive expressive methods, psycho drama
methods and mixed-method interventions (CBT, exercise and relaxation) were all
included. Different, multiple, broad or general outcomes were also a limitation of the
area of research, further spreading the body of evidence such that the overall
conclusion was that psychological group interventions were deemed effective for
improving some outcomes.

1.11.4 Examples of randomised controlled trials (RCTs)

The following examples demonstrate some of the difficulties and strengths
associated with RCTs to improve psychological responses to MS.

Group Therapy

Schwartz (1999) ran a two-year RCT comparing coping skills training with peer
telephone support with a trial group of 64 participants selected according to clinical
criteria, disability status and treatment preferences. Sessions lasting two hours each
were provided over a period of eight weeks, members were provided with
information packs and they were also partnered up to provide continued telephone
contact in pairs over ten months. Outcome measures were taken at two, twelve,
eighteen and twenty four months. Peer support was found to increase an external locus of control while group therapy improved psychosocial outcomes, wellbeing and coping approaches. These findings are unsurprising since they reflect the context of the different social approaches in the trial and control groups. Following up the group session by partnering members into long-term peer-support relationships meant that the trial group method overlapped with the control peer support group. The intervention was long with questionable value for practice.

The following, far more concise, study of group CBT with an education intervention by Rigby, Thornton and Young (2008) indicated that there was no difference between CBT or social discussion groups but that both were better than providing written information (bibliotherapy). Objectives were to encourage participants to address condition appraisal and support, resources, coping, social support, uncertainty, relationships, invisible symptoms and disability. Outcome measures taken at five time points over one year included anxiety and depression, self-efficacy and resilience. Ninety participants were assigned to small groups (2 to 5, mode = 3) with the trial and social discussion group receiving three 90-minute sessions. Members of the trial group were provided with the written information that was also used for the bibliotherapy control. The immediate advantage of this trial would seem to be its conciseness and the relevance of the control group to the trial in terms of assessing the value of the information provision; however, the extensive objectives were broad for the time frame allowed.

The following study indicates the difficulties around defining precisely what an intervention aims to do and the potential disparity of outcome measures in published research. Tesar, Baumhackl, Kopp and Gunther (2003) conducted a pilot study of group CBT. Over a seven-week course, comprising weekly 90-minute sessions, mixed objectives were covered in strategies with multiple aims for improving behavioural, cognitive, relaxation and exercise outlook; outcome measures included scales for depression, anxiety, coping and body image. Measurements were taken at baseline, at the end of the course and two-months after completion. Short-term improvements were found for 'vitality and body dynamics' and the trial group showed long-term improvement in terms of coping style with a reduction of anxious-depressive approach, reduced helplessness and resignation. Depression was lower at long term among the trial group but there was no difference between levels for trial
and control groups. As in some other interventions, the expectations of what can be achieved seem to challenge a commonsense outlook on time frame, the likelihood of adhering to sessions and the complexity of personal situations people face when diagnosed with chronic illness. Even over a period of seven weeks (not as long as some trials) the objectives represent attempts to introduce major changes to lifestyle.

The following study demonstrates how complex and demanding interventions can be. A more recent pilot RCT of group therapy for adjustment to illness, depression and anxiety focussed on six two-hour group sessions (Forman & Lincoln, 2010). Based on CBT and psycho-educational principles, the objective was to enable participants to identify and use skills to reduce current and future distress. The intervention aimed to increase awareness of emotions, mood and behaviours. Topics were identified from an adjustment group for people with brain injury and the manual for the intervention was based on one used for therapy for stroke patients. Microsoft PowerPoint presentations at each session including information on MS, exercise, problem solving, realistic target setting, worry (anxiety), gloom (depression), relationships, the future and relaxation. Sessions also included discussion and exercises, and participants were given homework to encourage further practice of the exercises and discussion with families.

Screening for eligibility included low mood and of 219 suitable patients identified with appropriate low mood only 26% agreed to take part. Further screening identified forty suitable patients, twenty were assigned to the trial group in which six were currently taking antidepressants (compared to five in the control group). Depression among the trial group was higher than among the controls (7 to 10, median = 10; compared with 6 to 10, median = 8). Anxiety, however, was higher among controls (10 to 15, median = 12; compared to 7 to 14, median 10). Although all participants completed the final questionnaire, seven did not attend the group sessions and one person did not complete the questionnaire due to bereavement. Although results demonstrated reduced depressive symptoms among the trial group compared to the control group, anxiety, self efficacy and quality of life were unchanged. The researchers acknowledged that the one significant finding could have been due to chance because of the small sample size and higher than usual levels of depression at baseline. Analysis of qualitative feedback from eleven
participants was reported as demonstrating responses as 75% positive, 25% neutral and 8% negative.

This pilot RCT resembles an academic teaching module in terms of delivery, extent and complexity of content. PowerPoint presentations may have the advantage of being easy to standardise but they are intrinsically formal, impersonal and minimally interactive. Instead of being strongly representative of those diagnosed with MS, the content was based on information from a brain-injury group and the study design was adapted from a stroke intervention. This suggests that there is a need for focus on MS-specific designs. The intervention is also striking in terms of requiring a high level of commitment, including significant amounts of regular time each week for attendance and extra-group practice.

Using telephone-administered therapy

The importance of aims and objectives is demonstrated in the following two studies by Mohr and colleagues. In spite of length of time, the focus on specific symptoms could have contributed to participant retention. Mohr et al. (2000) tested an eight-week course of CBT delivered by telephone to address depression. Participants (N=32) were consigned to trial or control groups, with the control group following normal treatment. A patient workbook was provided as support for the telephone CBT. Although depression decreased, attrition was 28%, higher than for the 'usual care' control group, and the researchers decided that the telephone delivery was of limited value partly due to difficulties in arranging and honouring telephone appointments. In 2007, Mohr, Hart and Vella conducted a further evaluation of telephone-administered therapies. This RCT compared CBT with supportive emotion-focus therapy in a sixteen-week evaluation aimed at reducing disability via fatigue management. Attrition across both conditions was 5.5%, with three lost from telephone and four from supportive emotion-focus therapy. Reductions in fatigue and disability were related to the reduction in depression and CBT was found to be more beneficial than supportive emotion-focus therapy. The study differed from others in that it had clear focus on chronic fatigue and a hypothesised link between fatigue and disability; and the results demonstrated particular reduction in physical fatigue. The researchers pointed out the value of CBT for identifying behavioural as well as cognitive solutions. In spite of longer time, attrition was lower than in the preceding study.
Moss-Morris, Dennison, Landau, Yardley, Silber and Chalder (2013) provided evidence for the benefits of CBT from a RCT comparing CBT with supportive listening. The intervention included eight sessions, based on two with face-to-face delivery and the remainder conducted by telephone. Participants in the CBT group showed less distress than the control group post treatment and at 12-month follow up. CBT was more effective for reducing unhelpful negative emotions and dysfunctional beliefs. The participants were recruited within 10 years of diagnosis, with a median time of 3 years (0.8 to 10 year range). This trial showcased a practical intervention with a comprehensive delivery manual that could (following training) be used by a range of professionals via remote methods as well as personal contact. However, the aims were global in terms of responses to MS, with a primary aim being to evaluate whether participants demonstrate better adjustment (defined as psychological wellbeing and social and role adjustment) and five paragraphs of secondary aims.

A combination of in-person and telephone-delivered therapy was used in another trial comparing CBT with relaxation training, this time with a more concise primary focus of addressing chronic fatigue in MS (van Kessel, Moss-Morris, Willoughby, Chalder, Johnson, & Robinson, 2008). As well as the primary outcome focus on fatigue, there were secondary measures for stress, mood and fatigue-related impairment. Over eight weeks, three face-to-face and five telephone sessions were delivered. Outcome measures were taken at three and six months. Both CBT and relaxation were found to be effective for up to six months after delivery but CBT was more effective. Further analysis of specific fatigue symptom data from the 2008 study by Knoop, Kessel and Moss-Morris (2011) suggested that CBT was more effective than relaxation training for fatigue in that the method changed beliefs about fatigue. The marked difference between the 2008 study and others was the definition of primary outcomes and a clear focus on one aspect of MS. By exploring the trial results in greater depth, it seems that the secondary analysis also suggests that concentrating on tight objectives and precise aspects that can be improved would be the way to progress interventions.

From the literature, evaluating the likely acceptability of different types of interventions in pilot studies would be sensible. For example, Finkelstein (2008) evaluated the feasibility of providing an exercise rehabilitation intervention by
telephone over twelve weeks and found that a sample of 12 participants were highly satisfied and that the intervention improved function outcome. Again, this study was concise, well focussed and patient centred.

**Multi-disciplinary education intervention**

One trial summarised in the Thomas et al. (2006) review demonstrated the success of a multi-disciplinary approach in an education intervention for people with MS. In the context of uncertainty and prevalence of negative perspectives around MS, developing an education intervention to provide a flexible strategy for long-term implementation across a team of health professionals would seem to support good practice. Ennis, Thain, Boggild, Baker and Young (2006) tested an eight-week health promotion education programme with the aim of improving knowledge and skills to improve self-efficacy among people with MS for engaging in positive health behaviour, including exercise and physical activity, lifestyle, fatigue and stress management. Results demonstrated improved physical activity and self-efficacy for health management and stress reduction, and these benefits were maintained at three-month follow up; furthermore, mental health was demonstrated as improved three months after the programme.

The programme was complex and demanded high levels of commitment but the education was tailored to individual needs. It took two years to inform eighty six suitable participants and sixty four of these agreed to take part. Medical assessment at the outset indicated nineteen cases requiring (and receiving) treatment for conditions including raised cholesterol, hypertension, anaemia and abnormal thyroid function. Being diagnosed with one of these conditions could have influenced adherence, which was high in this study, with thirty two of thirty four participants completing in the treatment group. The participants were also self selecting and it could be presumed they felt they needed information.

**1.11.5 Internet trials**

Two recent protocols for research into on-line or software-based problem-solving treatment and CBT indicate another possible direction for future research. A pilot study of the first CBT trial aimed at addressing depression as the primary outcome (Cooper et al., 2011) found recruitment to be slow and universal preference for home participation (rather than at a centre). Participants were critical of face validity of the depression measure (Beck Depression Inventory II for self report) and a specific
measure of multiple sclerosis impact was considered more appropriate. Adherence to the intervention schedule was poor from both patients and NHS centre perspectives (responsible for reminders and follow-up appointments). In order that an intervention be considered for trial, the authors recommended revision of measures and recruitment from MS centres or multidisciplinary secondary care neurology teams. Therapist support would improve the intervention but the practicalities of this in the current NHS environment would have to be evaluated.

Boeschoten et al. (2012) published a protocol for problem solving treatment to be delivered in a five-week internet trial focussed on depression as the primary outcome measure. A multidisciplinary team of MS experts was involved in developing the intervention. The authors intend to include MS patients with only medium or high depressive complaints.

The internet provides those diagnosed with MS with ready access to information that can exacerbate unrealistic opinions. While an internet intervention could support in-person sessions, on its own it could exacerbate isolation, particularly for people with impaired mobility or fatigue. While telephone contact limits interpersonal contact and the opportunity for deeper understanding of patients' reactions as well as for unspoken empathy, it does allow interpretation and understanding according to how people speak. The internet minimises interaction and offers the opportunity for limiting the extent of participation and screening responses.

1.11.6 Alternative interventions

Diet

A recent Cochrane review highlighted the fact that research still does not support robust conclusions on dietary interventions (Farinotti, Vacchi, Simi, Pietrantonj, Brait, & Filippini, 2012). Of six studies meeting inclusion criteria, four were published in the 1970s, one in the 1980s and one in 2005. The authors suggested further research is required to support existing indications on the value of supplements. Diet advice for condition management mirrors general principles of healthy eating, including balanced consumption of fat and carbohydrates, plus the benefits of vitamin D and fish-oil supplements; and the particular need for attention to individual requirements relating both to weight management and potential malnutrition relating to specific symptoms (Cunningham, 2013; Payne, 2001; Schwartz & Lewling, 2005; Yadav & Bourdette, 2006).
Exercise
Evidence for benefits of exercise therapy is stronger, with improved psychosocial constructs, self efficacy and quality of life associated with physical activity (Motl & McAuley, 2009; Plow, Mathiowetz, & Resnik, 2008; & Sung, Chiu, Lee, Bezyak, Chan, & Muller, 2012). In a Cochrane review pointing at improved muscle function, exercise tolerance and mobility; mood was improved, but there was no effect on fatigue or mobility perceptions; and no specific programme was more successful (Rietberg, Brooks, Uitdehaag, & Kwakkel, 2009). Reviewing research with the objective of devising an exercise prescription resulted in the unsurprising recommendation that further research is needed (Asano, Dawes, Arafah, Moriello, & Mayo, 2009): activity (also diet) are individual and psychosocial activities, involving more than fulfilling physiological needs. Commonsense suggests that the nature of MS adds to the need for interventions based on a simple concept that can be adapted easily to meet individual requirements.

Findings in a study by Dettmers, Sulzmann, Ruchay-Plossl, Cutler and Vieten (2009) demonstrate that functional and perceived fatigue differ, with the former improved followed endurance exercise (intervention group) even though perceptions remained the same. Depression and quality of life improved among the control group (who participated in stretching, balance, relaxation and other non-cardio activities) but not in the intervention group. The male physical education student running both groups devised 'games and playful elements' (p. 252) for the intervention, including throwing balls into cans and collecting cards from the corners of the room. The average age of participants was 45.8 (± 7.9) years (intervention) and 39.7 (± 9.1) years (control); the student's age was unknown. The contrasting format of activities for experimental versus control groups and the potential psychosocial implications were not evaluated. Social factors, including encouraging leaders or group activity, contributed to outcome according to findings of a qualitative study by Dodd, Taylor, Denisenko and Prasad (2006), who reported positive physical and psychological benefits, including perceptions of reduced fatigue. Research into barriers to activity returns predicable results: fatigue, physical impairment, lack of motivation and cost (Vanner, Block, Christodoulou, Horowitz & Krupp, 2008); and disease severity, receiving disability pension and caring for children (Beckermann, de Groot, Scholten, Kempen, & Lankhorst, 2010).
Music therapy

Music therapy represents an activity that is used in MS therapy centres to promote physical wellbeing. Singing exercises thoracic muscles to improve breathing and it can be particularly helpful for those with limited mobility. Ostermann and Schmid (2006) reviewed studies into the use of music therapy and found that much of the research reports qualitative data from uncontrolled studies. From seven studies and seven case reports, singing, song writing, listening to music, active music making and discussing music were evaluated in one-to-one or group studies. The benefits included socialisation and reduced isolation as well as respiratory improvement, especially among wheelchair users. Music interventions were demonstrated as useful for improving mood and enabling people to express and cope with their emotions.

Music therapy highlights the fact that alternative approaches can be utilised to access and exercise emotional responses. Anecdotal evidence from members, organisers and professional staff at MS therapy centres suggest that involvement in activity that bridges the divide between occupational and clinical therapy can be useful. For example, some people reject counselling because they prefer not to talk about their MS, yet when they are engrossed in a craft-based activity, they freely talk about their condition and problem. They also engage with suggestions and solutions. This represents a potential way of breaching barriers to engaging, possibilities for overcoming isolation and opportunity for alternative outlook, or restructuring.

Self hypnosis

Self hypnosis has been compared with progressive muscle relaxation for enabling coping with pain in MS (Jensen et al., 2009) and a further study compared four methods: education (control); self-hypnosis training; cognitive restructuring; and combined hypnosis-cognitive restructuring (Jensen et al, 2011). Hypnotic analgesic methods were proposed as helpful for reducing pain, while cognitive restructuring would also address catastrophizing cognitions associated with chronic pain. The hypnotic technique in the fourth condition of this study was intended to provide an automatic restructuring approach. Results suggested that the combination of cognitive restructuring and hypnotic techniques was more beneficial than the individual effect and the researchers suggested that further research be conducted.

The interesting aspect of this study, apart from the progression from earlier work and clear criteria, aims and method, was the concept of combining elements of
automatic and learned or rehearsed response. Automatic response resonates with heuristics or the schema we unconsciously access; cognitive restructuring suggests amending an unhelpful outlook; therefore combining the two in this study could represent the replacement of existing, quick-reference unhelpful heuristics with an alternative, modified version. Considering the method used in this study, it would seem possible that a parallel method for accessing unconscious images, such as using visual techniques, could access heuristics rather than self-hypnosis linking with automatic responses; if so, then the same process of enabling access could facilitate reducing and redirecting or restructuring.

1.11.7 Overall evaluation of interventions for MS
Published reviews have criticised research into interventions for poor focus and study design. As well as highlighting the same problem, the examples reviewed here demonstrate the major omission of a patient-centred outlook. Interventions running from six to sixteen weeks demand commitment, resource and energy, particularly when the session content is complex and extensive. Design seems to be based on psychological theory without consideration of symptom presentation and the fluctuating character of MS. For example, consistently intermittent symptoms are highly disruptive. Fatigue is common, presenting as both mental and physical, and other physically distressing but invisible symptoms include urinary infections and incontinence. Long interventions seem particularly inappropriate for addressing maladaptive responses, such as avoidance. Cost-benefit evaluation would suggest that the possibility of attrition could render the trial more damaging in terms of disengagement for lost participants than beneficial for those completing the course.

People with MS try to avoid talking about the condition and want to get away from it, making commitment a problem. Broad, lengthy and ambiguous interventions fail to acknowledge the relevance of natural fluctuation in MS and patients' responses to it as a potential influence on measures. The individuality of the condition requires an intervention that can easily be adapted to specific needs; however, this has to be embodied in a clear-cut, simple method that can be standardised and delivered with consistency. Long group sessions with multiple parts and related activities do allow for separate aspects to be tailored to individual needs but participants also have to engage in general information that they may find inapplicable to their situation or understanding.
There seems to be a lack of coherent, well-defined focus in terms of objectives; stage, phase or other MS-specific group; and purpose of outcome measures in many interventions. Breadth of content, sometimes addressing global adjustment, suggests interventions try to do too much rather than identify pivotal aspects and address them with realistic applications. Mixed methods of approach create complexity associated with attempting to be everything for everyone.

To summarise, the driving principles of interventions seem problematic in terms of three major omissions. Firstly, few interventions reflect a robust patient-centred perspective, if the intervention is not acceptable or too physically or mentally demanding it is not practical. Secondly, condition characteristics are not accommodated in many intervention strategies and approaches are not appropriately flexible. Thirdly, interventions seem to address the consequences rather than specific causes. Identifying and addressing causes would seem more logical than aiming to improve depression, coping, adjustment or even bigger issues.

Clear patient-centred research questions need to be posed, operationalised and evaluated in pilot studies. These should inform coherent hypotheses that can be tested in interventions focused on bridging any potential research-practice divide.

1.12 Expressive Methods and Rescripting

The literature reviewed indicates that, from research to date, CBT is a potentially successful method for delivering interventions in MS, particularly for addressing depression, but there is also general agreement that further research is needed.

In a practice-based guide to CBT for chronic illness, Sage, Sowden, Chorlton and Edelenau (2008) considered CBT useful for improving quality of life in relation to MS. It is widely used to treat depression, often in conjunction with antidepressants (Sage et al., 2008), but research has yet to provide robust evidence of its effectiveness in promoting adjustment to MS. The complexity of the interventions reviewed here reflect the overall approach of CBT in terms of working with the patient to establish commitment and goals, agreeing a formulation and then working through step-by-step weekly sessions to address unhelpful cognitions and behaviours (Sage et al.). From assessment through stages of engagement with the concept of CBT, identifying problems and responses, the intervention can take up to fifteen
weeks, including sessions focused on expressing emotions through techniques such as expressive writing as an adjunct to core CBT (Sage et al.).

Thus CBT represents a long, in-depth and complex process that demands commitment and engagement. Telephone methods of delivering some sessions may reduce practical problems of mobility, disability and fatigue that hinder compliance with sessions at centres over many weeks. The fact that CBT accesses and interprets responses verbally means that the immediately available information represents the processed responses. Using Socratic questioning provides a way for the therapist to encourage the patient to delve deeper into their understanding and thereby uncover the aspects that may not have been previously processed or evaluated. This may be a long, slow process, and there may be resistance to exploring unacceptable aspects. Gradually engaging the person over a number of weeks may be necessary to reach the crux of a problem and this provides opportunity for discontinuing, particularly when the sessions involve evaluating difficult, stressful or unacceptable areas.

Potentially faster and more concise techniques for encouraging expression of responses to stressful events include expressive writing, which has been extensively researched among student populations as well as for some health issues and bereavement, or visual methods that have been studied in relation to illness perceptions and, in terms of art therapy, as a means of expressing and restructuring unhelpful responses. The potential advantage of visual methods is providing access to heuristics with relative speed. Visual techniques do not necessarily demand artistic talent or ability as diagrams work equally well.

1.12.1 Expressive writing

Research by Pennebaker and colleagues over two decades indicates that writing about trauma can be beneficial for health. The concept involves brief but intensive writing sessions (15 to 20 minute) on three to four consecutive days without feedback. Studying undergraduate students' responses to starting university, Pennebaker and Beall (1986) found that writing about traumatic experiences increased stress in the short term but was beneficial to long-term health. The concept of catharsis potentially explained the effect in terms of venting by expressing hidden emotional responses. Writing facilitated understanding, assimilation and a different perspective on events (Pennebaker, Kiecolt-Glaser, & Glaser, 1988).
In timed sessions of talking rather than writing, recorded sessions were more successful than having a live person listening anonymously (Pennebaker, Hughes, & O'Heeron, 1987) suggesting that expression was inhibited by social contact. Analysis of language indicated a tendency to construct coherent narratives with beneficial aspects included causal and insightful words and positive emotional expressions (Pennebaker & Francis, 1996). Narrative formation was considered critical for organising and meaning; for integrating thought and feeling to facilitate dealing with emotions and bringing completion to traumatic events (Pennebaker & Seagal, 1999). The authors considered that words encapsulated the essential coherent act of expression, which could not be achieved non-verbally through dance or movement.

Two reviews provide meta analyses of evidence for the benefits of expressive writing. From nineteen articles, Smyth (1988) found benefits for health but not health behaviour with no effect according to length of task but benefits from a longer period for completing sessions. A review of 146 studies included twenty seven studies of non-student patient populations with a range of illnesses, including diabetes, cancer and rheumatoid arthritis; MS was not covered (Frattaroli, 2006). Findings of health benefits but not health behaviour were supported; however, length of disclosure was a moderator (at least three sessions of 20 minutes) but there was no effect of time between sessions. Greatest benefits were found among participants with health problems and when the tasks were provided early on before stressful events had not been processed.

There are no coherent explanations of processes involved in expressive writing. Whereas processing stress is traditionally explained by either personality factors or stages of coping over time, the concept of inhibition confrontation in expressive writing research suggests that following a structured timescale of stages is not implicit (Pennebaker, Colder, & Sharp, 1990). Making sense of unexpected trauma involves inhibiting responses to complicated information that could not be assimilated. Controlling behavioural expressions and thoughts to inhibit emotions promotes denial; therefore it would seem possible to short-circuit stages and speed up the process through expressive writing.

Providing booster sessions in a five-week follow up produced no effect (Gortner, Rude, & Pennebaker, 2006) and completing three sessions in quick succession was as effective as running them on consecutive days (Chung &
Pennebaker, 2008). Linguistic analysis indicates that insight and changes in perspective may explain the results (Pennebaker, 2004; Pennebaker & Chung, 2006; Pennebaker, Mayne, & Francis, 1997). Cresswell et al. (2007) found that using self-affirming language related to long-term benefits among cancer patients, indicating a process of protecting self integrity when threatened with illness. While benefit finding may be as beneficial as expressing trauma (King & Miner, 2000), allowing freedom of expression is important (Chung & Pennebaker, 2006). Unlike the problem-orientation approach of CBT, expressive writing is participant centred, with benefits evidenced by biomarkers and self report, thus multiple theoretical perspectives may contribute, including cognitive, emotional, social and biological factors (Pennebaker, 2004).

Among the above papers, the frequent use of university student samples is likely to influence results as students are accustomed to providing evaluative written information in a short time frame. It is also worth noting that verbal expression is not necessarily an indicator of complete awareness of responses. Reflection and interpretation during interviewing and counselling facilitates access to deeper meaning but expressive writing does not include such interaction or feedback. Therefore it would seem logical to assume that if unwanted, unacknowledged sensory impressions are not readily available to verbal interpretation, they may not be accessed by writing. Pennebaker and Seagal (1999) found that movement did not facilitate interpretation without translation into language. It could be argued that visual signs and symbols convey powerful non-verbal messages with speed, therefore familiarity with form may be necessary for narrative interpretation and insight. Familiar movement, such as waving or clapping, are readily interpreted, therefore fluency and familiarity with the medium of movement would presumably allow narrative construction, interpretation and insight.

1.12.2 Visual versus verbal

While art therapy may be used for psychotherapy, it is not a method for diagnosing mental state and interpretation is not objective but subject to relationships between the person, image and therapist (Shaverien, 1992). Shaverien outlined the basis of trust and confidentiality necessary for successful engagement in art therapy and an understanding that artistic ability is not required. In fact, experience in visual
expression may introduce developed ability to think through and control expression rather than spontaneously represent unconscious responses (Shaverien, 1992).

In research context, visual methods have been used for understanding patient experiences of both physical and psychological disorders. For example, physiological-based drawings of illnesses have been shown to provide insight into patients' perceptions of heart attack and these have been linked with recovery (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). The physical drawing size related to illness anxiety and recovery rate following heart attack: the bigger the drawing the greater the concern and slower recovery (Broadbent, Ellis, Gamble, & Petri, 2006).

Moving away from physiological definitions on a body outline or representations of familiar heart shapes, free-form drawings of headache have provided rich insight into holistic experiences of illness (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009). Participants' perceptions were evident in terms of severity, control and time; and the relationship with, along with reactions to, pain. Preliminary analysis of images provided by MS participants in Study Three indicate that the content reflects that found by Broadbent et al. (2009).

Philips (2011) found that people could be unaware of avoiding existing mental images that had powerful influence on emotions, cognitions and behaviour in relation to pain. Such intrusive or involuntary images are associated with adult psychological disorders, including post traumatic stress and anxiety disorders (Brewin, Gregory, Lipton, & Burgess, 2010).

The opportunity to access the full depth and breadth of responses, including those subconscious interpretations and impressions of which the participants may be unaware could be beneficial for people diagnosed with MS. Revealing retained, unspoken, adverse responses to MS could provide a first step to evaluating their relevance and providing a means of adopting a different perspective.

1.12.3 Important influence of images

Knowledge (information) and emotions influence response to risks, such as threat resulting from diagnosis. Perceptions of likelihood of contracting an illness are increased with knowledge about the illness and, conversely, decreased with ignorance (Sherman, Cialdini, Shwartzmann, & Reynolds, 1985), suggesting that heuristics are more influential than rational evaluation. Decisions on how to respond to future threat are influenced by emotional responses, which are subject to the
vividness and extent of exposure to the potential outcome (Loewenstein, Hsee, Weber, & Welch, 2001). Results of rational evaluation of the threat – weighing up the chances of risk coming to fruition – based on realistic probability are different from those based on emotional response, and, when faced with making decisions based on risk, emotions influence cognitions (Loewenstein et al.). Thus, vivid images of disability and MS are likely to elicit a powerful emotional response to diagnosis and its uncertain consequences. In a study of imagery related to pain, Philips (2011) noted that people were often unaware of mental images that demonstrated powerful influence on their emotions, cognitions and behaviour: negative emotions and cognitive interpretations of threat were accompanied by distraction tactics to avoid the images.

1.12.4 Identifying and rescripting images

Rescripting as cognitive therapy to redefine adverse images and introduce more positive aspects has been successfully tested as a treatment for depression (Brewin et al., 2009) and this method has been as effective as image exposure in treating phobias and intrusive memories in depression (Hagenaars & Arntz, 2012).

Hagenaars and Arntz summarised image restructuring as a way of introducing alternative responses and outcomes by proposing an amended image. The meaning of the source stress may be reinterpreted and additional concepts may be introduced, such as support, power and mastery over an underlying stressor. Suggested changes work at a sensory, emotional level rather than at a verbal, cognitive and rational level, thus providing amended heuristic references.

Metaphorical images can help evoke, manipulate and transform negative aspects that are difficult to access verbally (Hackmann, Bennett-Levy, & Holmes, 2011). Drawing can symbolise problems and reflecting on what is drawn can provide step-by-step stages of re-thinking barriers and considering support or strategies for coping (Johles, 2005, as cited in Hackmann, Bennett-Levy, & Holmes, 2011, p163). Restructuring, or transforming, metaphorical images may involve several stages of drawing and building emotional bridges to the past, which could be useful for overcoming subconscious associated fears about the future that promote avoidance.

With MS, rescripting could relate to anxiety and early fears around severe disability. Members of MS groups suggest that some non-verbal method of expression would be helpful due to physical restrictions that include speech
difficulties and fatigue. The latter applies to mental fatigue for processing ideas into coherent written form even when using a computer provides a means of overcoming deterioration in physical dexterity. Drawing pictures or diagrams also provides a relatively quick way of capturing substantial amounts of information.

1.13 Summary

Published literature demonstrates a focus on exploring patients' experiences of living with MS. A strong body of research defines the individuality, uncertainty and threat of MS and presents robust evidence of adverse psychological implications and potentially broad impact.

Simultaneously, biological and pathophysiology research, particularly focussed on disease modifying therapies, is fast evolving to the extent that the definition of MS now includes treatment options aimed at reducing relapse impact and delaying progression. Professional perspectives and diagnosis guidelines are continuously under review. However, the process of diagnosis is inevitably lengthy to ensure that alternative conditions are not mistaken for MS. The question of how early to deliver diagnosis and criteria for updating diagnosis are under debate. This is an area that is slow to change due to the process of research, dissemination of evidence and provision of follow-on education.

Meanwhile, there is evidence of psychological and emotional distress, and behavioural responses that do not map on to existing theories. There is no coherent, unified model explaining processes of adjustment to MS and the direction of current research suggests that this problem is not necessarily limited to MS. MS may epitomize ambiguity about how to treat patient uncertainty and distress, but chronic illnesses in general are not well served by existing models of responses. Therefore research providing evidence of processes of response to MS could contribute to the broader understanding of adjustment to chronic illness in general.
1.14 Research Aims

Published literature on psychological responses to MS indicates that there is strong evidence of comorbid depression and anxiety, negative emotional responses and potentially maladaptive coping responses. Long-accepted theories of coping and adaptation suggest that initial adverse responses to the shock of being diagnosed with chronic illness represent part of a natural process of transition or adjustment that is necessary for long-term coping. Not only do such models fall short of explaining evidenced responses to the fluctuating, uncertain and threatening characteristics of MS but published literature also indicates that poor psychological health can be a persistent, if not continuous, problem. Among existing papers there are frequent general references to the need for further research into the psychological implications of diagnosis with MS and their influence on adjustment and coping. There is also particular signposting towards early stage responses and adjustment as potentially under-researched aspects of the condition.

Thus the review highlights a gap in the research into emotional responses to MS. While emotional responses are referred to in much of the literature and feature prominently in newly proposed working models of coping with MS (as well as chronic illness in general), there is little work focussed on understanding their contribution. The aetiology and influence of emotional responses are generally attributed taken-for-granted status as temporary aspects of standard processes of response stages. Specifically, therefore, deeper understanding of the type and timeline of adverse responses is required. Information on negative emotions needs to be dissected so that their dynamic involvement in short-term coping and long-term adjustment or transition can be investigated more extensively. This area of research requires attention in order that current proposals for potential models of adaptation to MS can be appropriately developed and tested.

This thesis proposes that early maladaptive responses to diagnosis are not necessarily a temporary phase and unresolved adverse reactions may persistently hinder adjustment, coping and long-term wellbeing. This thesis is addressed by research aims that are summarised in terms of three main approaches to study.
i) The research aims to explore emotional responses to being diagnosed with MS using in-depth narrative analysis to define emotions and their influence.

ii) The second key aim is to quantitatively evaluate evidence relating to the qualitative findings from the first stage of research: the focus is on generalisability of data around emotional responses; their contribution to coping and adaptation; and predictive links with long-term wellbeing.

iii) A third aim is to draw on findings and results from the first stages to investigate a patient-centred intervention to promote adjustment and coping. This stage will draw on research relating to expressive writing as a basis for designing and piloting a brief intervention using visual methods.

1.14.1 Summary of thesis and research aims

This thesis proposes that early maladaptive responses to diagnosis are not necessarily a temporary phase and unresolved adverse reactions may persistently hinder adjustment, coping and long-term wellbeing. Key aims can be summarised as follows.

i) Qualitative exploration of emotional responses to being diagnosed with MS.

ii) Quantitative evaluation of evidence around qualitative findings: their generalisability and contribution to coping, adaptation and wellbeing.

iii) Preliminary investigation of a potential intervention to promote adjustment.
Chapter 2

Study One

Emotional responses to multiple sclerosis:
A narrative study of pivotal idiographic experiences and processes

2.1 Chapter Overview

An initial interpretative phenomenological analysis (IPA) study into the lived experience of MS highlighted the importance of emotional responses for their potential influence on adaptation. This chapter presents a narrative analysis of the many stories participants related, providing in-depth evaluation of emotional processes and responses. The introduction (section 2) includes background information on narrative analysis and section 3 summarises aims and objectives. Section 4 outlines the method; section 5 presents findings; section 6 provides a brief discussion; section 7 is a reflective account; and section 8 offers brief conclusions.
2.2 Introduction

Research indicates wide-ranging emotional responses to MS, sometimes resulting in long-term intermittent trauma in coping. Diagnosis may bring relief, as it explains unusual symptoms but, while this may aid initial coping with anxiety, fear, shame and loss of identity (Sá, 2007), such responses are temporary and often replaced by fear associated with the uncertainty and worst-possible MS outcomes. If symptoms subside significantly, then conscious anxieties may be allayed and the concept of MS may be ignored and not be dealt with. Relapse and sudden physical deterioration can produce dramatic threat and future-oriented fear (Sharpe & Curran, 2006).

Compartmentalising illness, protecting family and forfeiting valued identities to facilitate short-term coping results in loss, "grief and rage" (Finlay, 2003).

A preceding MSc dissertation study using interpretative phenomenological analysis (IPA) to explore identity transition in multiple sclerosis (MS) identified emotional responses among three superordinate themes: 1) 'Emotional Responses: interactions and outcomes' indicated that fear, changed emotional identity, guilt or disgust could hinder cognitive engagement; 2) 'Cognitive Engagement: acknowledge, accept, adapt, control' was neither one off and 'global' nor linear but achieving overall equilibrium could facilitate control to optimise the relationship with MS; and 3) 'Identity Implications: social construction of the self' summarised lives split by altered identity (Jones, 2010). Rejecting identity challenges diminished self esteem while ignoring them promoted avoidance. Transition was identified as an on-going process within which a framework for engagement was possible and engagement at diagnosis seemed crucial. In particular, findings suggested that greater understanding of the impact of emotional responses to diagnosis on cognitive engagement could signpost ways forward that may facilitate engagement, adaptation and transition.

IPA examined the data as a whole, analysing across all interviews to attribute themes based on participants' spoken reality and the researcher's interpretations of these. However, data from the relatively unstructured interviews, exploring individual experiences of living with MS, were both extensive and storied in nature. Participants related multiple accounts of pivotal events, their meaning making and social impact. Many narratives demonstrated critical emotional significance.
Such separate stories seemed vital not only for the information and perspectives they provided on subjective reality, and thus the way in which constructing stories added to the reality, but also for the way they were told and, in some instances, their continuing broad impact on the teller. Therefore narrative analysis was selected to fulfil two analytic objectives.

i) To identify and isolate narratives with critical emotional significance.

ii) To analyse the spoken meaning making and explore the influence and impact as demonstrated by how stories were narrated.

2.2.1 Narrative and psychology
It was not until the 1980s and 1990s that the psychological relevance of narrative was highlighted and understood for its role in ontological representation and contribution to the construction of personal reality (Murray, 2008). People do not deal mechanically with life reality and events by listing and responding to them in isolation but they account for them: they evaluate, understand, reveal and explain them as stories (Sarbin, 1986). Gergen and Gergen (1986) considered that narratives were created through everyday social interaction and reflected not only understanding and interpretation but also future outlook. Murray (1999) summarised people as narrative oriented from birth into a world where multiple influences, identities, events and agencies are organised and understood in a storied way.

Therefore narrative can be defined as an account of some event, progressing from one point towards another. Incidental comments or reflections are not in themselves narratives; therefore information on isolated aspects does not necessarily constitute a unified story or narrative. Narratives are characterised by structure, with a beginning, middle and end; they have purpose in terms of making meaning and having a causal effect; and they are social accounts. People use stories to make sense of events, especially unexpected or inexplicable incidents that challenge identity or life context (Frost, 2009). Narrative represents the choice of attention to an event: what is meaningful and selected as part of the story that is expressed in a clear and coherent account for others' information (Reissman, 1993).

Murray (2008) outlines the function, construction and context of narrative as a means of understanding the world in terms of stories. Constructing narrative brings
order to changing events and social circumstances, and attributes meaning (Murray, 2008). Emplotment, an on-going process of ordering, involves sequencing and bringing in the personal perspective of the narrator's role in the events. By relating the story, the owner expresses interpretation of their agency and position. Narratives demonstrate the teller's identity and they may confirm or express the ways in which identity is challenged or changed by the topic or its social context. Stories are both constructed and told in social context, with social and personal perspectives possibly integrating or overlapping.

2.2.2 Narrative and health

Constructing narratives to make sense of life events also provides a basis for ranking them in terms of their importance or impact (Murray, 1999). Health and illness do not necessarily feature in everyday narratives; however, diagnosis with illness represents a life-changing event and one of the natural responses is to construct an account of illness (Murray, 2000). Narratives constructed around diagnosis with chronic illness, such as cancer or MS, involve temporal perspectives, reflecting on the past, dealing with the present and considering the future. Social representations also contribute to the storied comprehension of illness (Murray, 2000), which deals with social circumstances as well as personal contexts, aspects of experience and cultural outlook. A diagnosis of progressive chronic illness at a relatively young age presents an otherwise healthy person with threat to fit and able identity that has been taken for granted. Implications and options can be considered by re-storying the personal situation and such narratives represent how a person deals with illness. The multiple stories individuals narrate open windows on to more than experiences and responses: potentially, they reveal processes, both considered and unconscious, of dealing with illness.

2.2.3 Narrative analysis

Crossley (2007) summarised the theoretical position of narrative analysis compared to other qualitative methods in the context of realist and constructionist perspectives. The realist position views reality as objective, material or action based; in this stance, although social context may shape the phenomenon of reality it does not create the reality. In IPA, the individual's spoken experience represents a stable reality, representing a relatively realist epistemological stance. Conversely, social constructionist approaches consider the only reality to be the interpretation within
any one social context, based on language and discourse (explored through discourse analysis). From the constructionist perspective, there is no essentialism but reality is socially constructed, that is according to the shared knowledge, interactions and negotiated social positions of those involved. In this sense, individual reality is created entirely within each situational social context and subject to definition through social and discursive understanding or negotiation. Note that there is no sense of the individual crafting their meaning outside social context, so much so that debates have been noted concerning whether social constructionism sees the person speaking discourse or discourse speaking the person (that is, crafting the subject). Social constructivism differs from social constructionism (or the constructionist stance) in that, while it too reflects the idea of reality being subject to social influence, it allows for individual cognitive interpretation and construction of the social influence (Young & Collin, 2003). In this sense, 'constructivist' seemingly positions reality representing social influence as the basis but subject to cognitive construction by the individual.

Bhaskar (1975) proposed an epistemological compromise when he also challenged the absolute position of realism with the concept of social influence. Starting from the realist basis, Bhaskar proposed that all scientific fact or reality was subject to human evaluation and interpretation. In material or functional (action) terms, although subject to boundaries, reality was not absolute but it was subject to critical evaluation in terms of human and social understanding. One person's evaluation may differ from another's, both would be based on circumstances and context, and both individually relevant. This represents a critical realist epistemological approach.

The concept and relevance of narrative is that it represents a human temporal, reflexive and storied existence in which people retain a consistent underlying and subjective understanding of their identity and 'self' as their individual reality. This foundational reality, or identity, is not completely fluid and constructed only to fit every social context; neither is it static. Stories are constructed to make sense of events and their impact on priorities, aspirations and social interactions that challenge or alter aspects of identity (Crossley, 2007).

While narrative analysis explores individual lived experiences and acknowledges the existence of reality, it affords critical evaluation from a constructivist
perspective. By exploring not only what is said but also how the story is told, narrative analysis critically evaluates the individual's evolving construction of reality. From this critical realist position, narrative analysis explores the implications of unexpected and emotionally charged life events on identity.

2.2.4 Doing narrative analysis: Approaches and models

Narrative analysis is a term applied to a genre of methods used to explore stories derived from conversations or written accounts, that is naturally constructed rather than answers formed in response to, and guided by, tightly structured questions. Reissman (1993) pointed out that when participants talk freely in interviews, uninterrupted by frequent questions, they may provide rich storied data that is suitable for narrative analysis. Whereas other qualitative methods often focus on fragmenting rich accounts for interpretative purposes, narrative analysis also draws on the structural and sequential features (Reissman, 1993). Narrative analysis may consider the 'what' and 'how' of the story, including the order in which it is told (this may differ from the chronological order in which events actually occurred); the type of language (paralinguistic features); and the way in which it is told (discursive features). Murray (2008) summarised the analytic process as phases of description and interpretation, acknowledging that the analyst also contributes to the interpretation and perspective.

Mishler (1999) summarised methods of different approaches to narrative analysis as identifying the temporal order of an account; considering the linguistic and discursive structure; and analysing the context or consequences, meaning the purpose or function of the narrative for the teller. Identifying temporal order refers to arranging the story according to the order in which events occurred as opposed to the order in which they were told. Stories are current accounts of past happenings that are not necessarily related chronologically but according to the importance of aspects for the teller as well as impressions and interactions that occur during telling (Mishler, 1999). Temporal ordering reflects the meaning of events for the teller while language is manipulated to convey an image in which chronology evolves from narration rather than providing the basis for it (White, 1987). Considering the temporal aspects of narrative may provide insight into the narrator's position with the topic, particularly in terms of the 'so what' or 'what happened next' aspect. The narrator's current interpretation of past account may or may not be related. In terms
of chronic illness, aspects of narrative may reflect the present and future as well as
the past; with aspects of MS it is possible that uncertainty could blur the condition or
symptom boundaries between past, present and future as closure on past, temporal
context for present and prognosis for future are not easily assessed or defined.

Gee (1991) proposed deeper exploration of feeling and reasoning as expressed in
spoken narratives, where paralinguistic features of tone and rhythm are important as
well as the type of language used in terms of content, meaning making and
communicative function. Using the concept of poetic structure (lines, verses and so
on), Gee mapped the natural flow and form of spoken narrative. Spoken expression,
discursive tactics and content can be evaluated, representing different perspectives
and responses, both stated and performed in recorded interviews.

defined practical approaches to analysis as focusing on structure; content (including
attributing themes to content); and contextual features of how the story is told
(interactional or performative evaluation). These methods explore not only
individual experiences but also illuminate the "social processes that shape these
experiences" (Esin, 2008, p. 95). Esin suggested that using a combination of methods
in a pluralist approach could facilitate analysis of different aspects of the data. Using
more than one approach would seem appropriate when approaching rich data from
lengthy interviews, in which multiple stories are narrated separately, with unrelated
information and asides. In order to conduct in-depth analysis on specific accounts of
responses or experiences, structural analysis first facilitates definition of different
narratives within lengthy transcripts.

2.2.5 Structural analysis
Labov and Waletsky's (1967) and Labov's (1972) models are recognised approaches
to structural analysis. Labov (1972) identified six components of fully developed
narrative: abstract, orientation, complicating action, evaluation, result or resolution
and coda. The evaluation is the narrator's comment or perspective on the story,
conveying the importance and prioritisation of events. This evaluation may also be
relevant to the narrator's social construction, in terms of roles, action and positions of
those involved. The narrator may be negotiating his or her status or identity in the
context of an event. Analysis does not set out to question the story's accuracy: what
is told, and the way in which it is told, reflects the narrator's reality. In other words,
the telling is considered to be true to the told and the researcher accepts the content of the descriptive account as accurate.

Stories are not necessarily narrated according to the logical sequence of components; the content (what happened) is not necessarily told chronologically according to how it happened. The researcher reconstructs the order of events from the account (as one would when listening to someone telling a complex story.) The order may differ as people digress or rearrange stories, for example, and the account may be shaped by the presence of and dialogue with the interviewer. The evaluation is also retrospective and the meaning or significance of events alters according to present perspective on the past; the perspective on the past is not what might have been relevant at the time and the narrator may reflect on the difference during narration. Such aspects are included in analysis.

Accounts can be selective and incomplete as information may be repeated or forgotten. The telling may be influenced by motive, for example to project a personal image and the context also influences what is told. In analysing the data, it is important to acknowledge that it is the 'telling of the told' that is interpreted. While accepting that the account reflects the truth, this is not static but subject to on-going influence during narration. From this critical realist perspective, using complementary methods of analysis, for example to consider linguistic and discursive features, helps to reveal different perspectives and influences.

2.2.6 Linguistic analysis

Linguistic and discursive analysis de-construct narratives at a relatively micro level to explore textual content, tone and emotional representations. Gee (1991) emphasised the important contribution language made to interpretation of narrative and proposed that story telling was naturally poetic in terms of pace, rhythm and tone. Changes in tone, pace, pauses and emphasis related to the narrative content.

Breaking down narratives according to these paralinguistic features de-constructs phrases and sentences such that they - literally - take on poetic form or structure, shaped not only by what is said but by emotional expressions and values. The poetic structure, in terms of line length and sections, represents the spoken narrative as defined by the way in which ideas and different aspects of the narrative are expressed. This de-construction of linguistic and discursive characteristics, such as tense, person and repetition, also reveal the narrator's processes of understanding and
interpretation. This micro analysis indicates functional aspects of the narration intended for the teller's personal evaluation of the plot and for conveying meaning to the listener.

2.3 Aims and Objectives

As discussed in section 2.2.4, narrative analysis tends to be used for naturally occurring accounts rather than structured interview data; however, the long interviews recorded and used for this study included multiple storied accounts. The current study aims to interrogate semi-structured interview data for emotional responses and expressions (stated, evident in the spoken narrative and non-verbal features) by participants diagnosed with MS. The following research question provided the focus for analysis:

How are emotional responses to MS expressed in participants' narratives?

Key objectives were to:

i) define the relevant narratives that focused on, or provoked, emotional responses

ii) explore the different perspectives and processes involved.

Findings were intended to provide an informed basis for a quantitative study of specific emotional responses and their influence on participants' transition with MS.

2.4 Method

2.4.1 Participants
For a preceding MSc dissertation study using IPA to explore identity transition in multiple sclerosis (MS), a heterogeneous sample of eleven volunteers were recruited from an MS therapy group in south-east England. Recorded interviews of over 140,000 words were transcribed verbatim. The original ethical considerations for the IPA study were observed, including data use, storage, anonymity and confidentiality. Seven transcripts were selected for their extensively storied nature. Participants included five females and two males, ranging in age from 31 to 66 years and
Table 2: Participant details

<table>
<thead>
<tr>
<th>Data set</th>
<th>Male / Female</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Diagnosis time</th>
<th>Type</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>Val</td>
<td>49*</td>
<td>24 yr</td>
<td>SP</td>
<td>Uses sticks. Married; no children. * Older than stated.</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>Brenda</td>
<td>47</td>
<td>10 yr</td>
<td>benign</td>
<td>Slight limp. Married; 2 children.</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>Marie</td>
<td>31</td>
<td>11-12 yr</td>
<td>SP</td>
<td>Uses stick. Boyfriend; no children.</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>Paul</td>
<td>53</td>
<td>3 yr</td>
<td>PP</td>
<td>Uses sticks. Widowed; 2 children.</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>David</td>
<td>67</td>
<td>20 yr</td>
<td>benign</td>
<td>Uses sticks. Married; adult children.</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>Wendy</td>
<td>66</td>
<td>10 yr</td>
<td>&quot;mild&quot;</td>
<td>No visible impairment. Married; adult children.</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>Alex</td>
<td>50</td>
<td>24 yr</td>
<td>RR</td>
<td>Limp no stick. Married; 2 children.</td>
</tr>
</tbody>
</table>

Note
RR = relapsing remitting  PP = primary progressive  SP = secondary progressive.

diagnosed from 3 to 24 years (Table 2). Mobility varied and cognitive ability in terms of recall and concentration was unimpaired.

2.4.2 Analytic method

The analytic approach is positioned within a critical realist framework. Bhaskar (1975) proposed that the realist stance of scientific investigation could not be isolated from human interpretation and understanding, and reality, therefore, was also based on critical evaluation within social reality.

This study analyses participants' narratives from the position of acknowledging that their consistent individual reality exists but it is interpreted and understood in a social context. Narratives include statements of existing reality and a construction of its understanding in the teller's socially influenced context. The narrator may contextualise understanding in past, general present and anticipated future impact. The interview situation and researcher presence contribute to the narration. The researcher's listening to, reading and interpretation of the data are also acknowledged as contributing to the analysis.

Two complementary steps in narrative analysis were used to identify and evaluate relevant narratives and the way in which they were narrated.

i) The transcripts were read and recordings reviewed to identify coherent narratives disclosing critical aspects in participants' emotional responses to
MS (that is, different from incidental 'in-passing' references or expressions). For example, these included descriptions of emotionally significant events; pivotal aspects relating to emotional reactions; and events that evoked emotional responses.

ii) Gee’s (1991) linguistic model was used to analyse each narrative aspect separately.

2.4.3 Identifying relevant narratives

Labov’s (1972) structural model of analysis was used to define accounts that constituted coherent narratives as distinct from isolated comments, incidental phrases or expressions of emotion. Labov defined narratives as coherent stories according to their structure or parts: abstract, orientation, complicating action, evaluation, result or resolution and coda.

The parts were not necessarily narrated in sequence. The narrator could fluctuate or repeat and qualify aspects of the story. Digression or interaction with the listener are normal characteristics of narration. Assembling the parts exposed the story and clarified the narrator’s evaluation or articulated outcome. Figure 6 shows the parts and how a narrative may flow. Labov (1972) defined evaluation as being concentrated in a separate structure but integrated throughout the telling forming "waves of evaluation that penetrate the narrative" (p. 369).

Relevant text extracts were cut and pasted in the order in which they were narrated (order of telling). They were then reorganised according to Labov’s structure to show the narrative order (order of told). Titles or topics were attributed to reflect the focus of each narrative. Narratives were identified by participant and topic or title. Examples of an extracted narrative in 'order of telling' and 'order of told' are provided in Appendix I.
1 Abstract: provides an overview while the other sections contribute to a narrative flow.
2 Orientation: who, what, when, where. Free clauses, not linked to core narrative but providing background information
3 Complicating action: then what happened?
4 Evaluation: so what? Not all narratives include evaluation. It is not necessarily a personal experience but may be a vicarious account.
5 Result or resolution: and finally ... What happened finally?
6 Coda: the tail end, bringing the story up to date. The current relevance of the story.

Figure 6: Labov’s (1972) structural narrative analysis

2.4.4 Linguistic analysis of separate narratives
Gee (1991) considered the syntax and cohesion of what was said, the order of words, logic and connections. Aspects of stress and emphasis in normal speech, such as subtle rises and falls in voice (pitch glides), contribute to the fundamental sense of spoken narrative and direct the listener's focus towards key points in a story. In other words, speech is not a flat monotone of unrelated words but expressed as groups of words, or units of ideas (referred to as tone groups). These units are linked and organised syntactically, or according to grammar, as well as by the way in which they are spoken. In Gee's analytic structure, linked units form lines, which are then successively grouped according to meaning, ideas or focus into stanzas (similar to verses in poetry), strophes (groups of related verses) and parts. Figure 7 outlines how the analytic stages were used to reorganise and analyse the text. Appendix I provides
Narrative de-construction

1. phrases = idea units

Reconstruction: grouping ideas

2. lines = idea or argument

3. stanzas = idea focus

4. strophes: key parts made up of related ideas

5. parts: sub-stories or plots within narrative

Micro analysis

structure  syntax cohesion  idea priorities  focus  psychological subject

Note

Steps 1-5 de-construct the narrative transcript and reconstruct it according to narration and content. Micro analysis explores the way ideas are prioritised in the narrative and the detailed use of language. Gee (1991) suggested five levels of analysis, including comparison of lines (ideas and arguments) and structure for priorities. The psychological use of language was important in the current study.

Figure 7: Key steps in Gee’s (1991) linguistic analysis

a diagrammatic summary of this method and sample narrative demonstrating deconstruction from typescript and revised formatting.

Analysis involved de-constructing entire narratives, into small groups of words that formed idea units. The units were then reconstructed successively into lines, stanzas, strophes and parts showing how ideas and concepts built up the meaning of the story. The text was annotated with the focus of ideas, topics, titles or concepts. The resulting text looked like poetry and the appearance suggested how the text was
narrated, for example short units and stanzas indicated greater pace and brevity than more extensive units and longer stanzas. Transcript extracts demonstrating the key stages and process of analysis are provided in Appendix I.

Adhering to the research aims and emotional focus, further analysis specifically explored tense (past, present or future; active or passive), metaphor and psychological implications of language, such as the use of first person as an indication of ownership or distancing by using collective nouns, generic or impersonal language. Each stage of analysis involved reading and listening to recordings to check understandings and interpretations.

2.5 Findings

Appendix I provides a tabulated overview of case-wise findings in terms of emotional responses revealed by Gee's (1991) model of analysis, within narratives identified by Labov's (1971) method. Summary findings from both stages of analysis are presented in Table 3.

2.5.1 Summary overview of findings

The study aimed to explore emotional responses as expressed in personal experiences of diagnosis and living with MS. Narratives were defined and extracted from semi-structured interview transcripts based on the pivotal emotional responses they described, emotional influences and demonstrations of experiences. Expressions of negative emotions were common. While counterbalancing, such as benefit finding, was evident in many narratives, only one participant expressed broader positive emotional responses. The complexity of emotional responses was such that emotional interactions, context and processes were as much part of the responses as the types of emotions described. For example, emotions could focus on past, present or anticipated future events; they could be active or passive; and while some were described semantically, others were evident in latent expressions.

Fear and a sense of threat were common responses often accompanied by a sense of loss and sadness that was sufficiently intense to represent an emotional package. Anger, frustration and irritation were expressed at different levels: active and passive, latent and semantic in the context of past, present and future prospects.
Participants demonstrated distress at different levels of pain, hurt and sadness. There were representations of emotional burden resulting from concern for important others, including parental responsibility and emotional duty. Perceived failure in fulfilling roles of emotional protection led to sadness, guilt and regret.

Emotional responses to aspects of the MS could arouse further reactions in terms of embarrassment, guilt, sometimes in the context of disbelief. Loss of confidence and fear of threat was seen to evoke feelings of inadequacy, a sense of being pathetic and suffering humiliation. Embarrassment degenerated to humiliation and helplessness. Emotional isolation with such responses was a problem and, in many narratives, instances of emotional turmoil, terror and catastrophe were played out.

While relief was a short-lived emotion for many participants after diagnosis, one person demonstrated long-term resolution and relief from a life-time of questioned credibility; however, the positive emotions or relief and a sense of calmness and belonging were set against withdrawal and numbness. While some narratives represented levels of long-term resolution and others highlighted how fluctuating MS could result in an ebb and flow of resolution and disruption, there were also clear indications of damage and distress resulting from chronic emotional disruption.
<table>
<thead>
<tr>
<th>Labov's analysis: narratives</th>
<th>Gee's analysis: emotion perspective/response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Val (DATA SET 1: Interview 2)</td>
<td></td>
</tr>
<tr>
<td>1 Enemy threat</td>
<td>• Emotional isolation with MS</td>
</tr>
<tr>
<td></td>
<td>• MS isolated from her</td>
</tr>
<tr>
<td></td>
<td>• Self labelling</td>
</tr>
<tr>
<td>2 Learned discrimination threat</td>
<td>• People threaten: fear of social threat</td>
</tr>
<tr>
<td></td>
<td>• Isolated with threat: social and physical</td>
</tr>
<tr>
<td>3 Future-oriented fear at diagnosis</td>
<td>• Isolated with multiple sources of fluctuating fear</td>
</tr>
<tr>
<td></td>
<td>• Active fear and passive threat</td>
</tr>
<tr>
<td>4 Social isolation: people don't help</td>
<td>• Inferiority and stigma since childhood</td>
</tr>
<tr>
<td></td>
<td>• Emotionally strengthened for destity</td>
</tr>
<tr>
<td>5 Control trait: shaped from childhood</td>
<td>• Isolated + enforced responsibility since childhood</td>
</tr>
<tr>
<td></td>
<td>• Control driven by negative emotions</td>
</tr>
<tr>
<td>6 Age-focused fear</td>
<td>• Future-oriented fear related to age</td>
</tr>
<tr>
<td>Brenda (DATA SET 2: Interview 3)</td>
<td></td>
</tr>
<tr>
<td>1 Diagnosis delivery: anger and fear</td>
<td>• Active distress and anger mutates to current, active, stress and urgency</td>
</tr>
<tr>
<td></td>
<td>• Frustration / desperation, fear / intense distress</td>
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<tr>
<td></td>
<td>• Disbelief and disgust</td>
</tr>
<tr>
<td></td>
<td>• Concern, guilt and retained embarrassment</td>
</tr>
<tr>
<td>2 Motherhood choice withdrawn; violated rights</td>
<td>• Vividly recounts fury</td>
</tr>
<tr>
<td></td>
<td>• Marital discord, anger, disbelief = frustration</td>
</tr>
<tr>
<td></td>
<td>• Still angry: but resolved / Resolution in plural/past</td>
</tr>
<tr>
<td></td>
<td>• Understanding in singular/present</td>
</tr>
<tr>
<td>3 Diminished fear</td>
<td>• Discussed/copied with fears to diminish threat</td>
</tr>
<tr>
<td></td>
<td>• Reduced future-oriented fear and personal threat</td>
</tr>
<tr>
<td></td>
<td>• Now: regret, unfairness, concern</td>
</tr>
<tr>
<td>4 Coping with threat: MS as alien</td>
<td>• Uncertainty distanced from her identity</td>
</tr>
<tr>
<td></td>
<td>• Insecurity, uncertainty and ignorance</td>
</tr>
<tr>
<td></td>
<td>• Lack of understanding = inability to explain</td>
</tr>
<tr>
<td>5 MS identity downgrades fear</td>
<td>• Accepting does not mean labelling</td>
</tr>
<tr>
<td></td>
<td>• Irritated and annoyed but no longer traumatic</td>
</tr>
<tr>
<td>6 Faith process for coping</td>
<td>• More inward looking</td>
</tr>
<tr>
<td></td>
<td>• Process to go through but hurt not necessarily reduced</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Labov's analysis: narratives</th>
<th>Gee's analysis: emotion perspective/response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paul (DATA SET 4: Interview 5)</td>
<td></td>
</tr>
<tr>
<td>1 Nursing wife: frustration and concern</td>
<td>• Unresolved regret, frustration, conflict</td>
</tr>
<tr>
<td></td>
<td>• Intermittently passive and active</td>
</tr>
<tr>
<td></td>
<td>• Loneliness and isolation</td>
</tr>
<tr>
<td></td>
<td>• Fear of future relationships</td>
</tr>
<tr>
<td></td>
<td>• Lack of confidence and uncertainty</td>
</tr>
<tr>
<td>2 Diagnosis process: uncertainty</td>
<td>• Frustration and desperation</td>
</tr>
<tr>
<td></td>
<td>• Uncertainty and lack of support</td>
</tr>
<tr>
<td></td>
<td>• Coping persona hides desperation</td>
</tr>
<tr>
<td></td>
<td>• Avoids distressing others</td>
</tr>
<tr>
<td>3 Paternal concern</td>
<td>• Addresses/resolves daughters' concerns</td>
</tr>
<tr>
<td>4 Reassuring his father</td>
<td>• Minimises stress to father</td>
</tr>
<tr>
<td>5 Personal isolation: Needs hugs</td>
<td>• Isolation, loneliness and need affection</td>
</tr>
<tr>
<td></td>
<td>• Lacks emotional support</td>
</tr>
</tbody>
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<thead>
<tr>
<th>Labov's analysis: narratives</th>
<th>Gee's analysis: emotion perspective/response</th>
</tr>
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<tbody>
<tr>
<td>David (DATA SET 5: Interview 6)</td>
<td></td>
</tr>
<tr>
<td>1 Blindness threat</td>
<td>• Relief resolved initial fear</td>
</tr>
<tr>
<td></td>
<td>• Assertive, confident: no uncertainty</td>
</tr>
<tr>
<td>2 Denial: self blame and responsibility</td>
<td>• Threat to fit and attractive identity</td>
</tr>
<tr>
<td></td>
<td>• Vulnerability / visible disability threat</td>
</tr>
<tr>
<td></td>
<td>• Ashamed of previous pride and arrogance</td>
</tr>
<tr>
<td>3 Business social: identity issues and isolation</td>
<td>• Intense sadness</td>
</tr>
<tr>
<td></td>
<td>• Humiliated and humbled</td>
</tr>
<tr>
<td></td>
<td>• Frustrations resolved to sadness</td>
</tr>
<tr>
<td>4 Challenged sexual identity/attractiveness</td>
<td>• Invasive sense of loss at reduced status</td>
</tr>
<tr>
<td></td>
<td>• Social isolation and inadequacy</td>
</tr>
<tr>
<td>5 Read, thinking and uncertainty</td>
<td>• Emotionally unsettling search for identity</td>
</tr>
<tr>
<td></td>
<td>• Expanding mental capacity = uncertainty</td>
</tr>
<tr>
<td>6 Existential threat</td>
<td>• Disturbing emotions: guilt / retention</td>
</tr>
<tr>
<td></td>
<td>• Punishment for past hubris or excessive pride</td>
</tr>
</tbody>
</table>

76
<table>
<thead>
<tr>
<th>Labov’s analysis: narratives</th>
<th>Gee’s analysis: emotion perspective/response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marie (DATA SET 3: Interview 4)</strong></td>
<td></td>
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| 1 Prescribing error resentment | • Active negative emotions: resentment, contempt, disgust and blame = vengeful  
                          • Unresolved anger and lost control |
| 2 Physical rejection: unattractive disability | • Injustice, resentment and blame  
                          • Physical rejection  
                          • Riddled with ambiguity |
| 3 Rejecting invisible MS | • Unresolved anger  
                          • Fight against identity with MS |
| 4 Negative family interactions | • Negative emotions / actively negative interactions  
                          • Patronises mother |
| 5 Resentment and maternal friction | • Active irritation and resentment at mother  
                          • Loss of control: resentful and intensely negative  
                          • Egotistic, impatient, selfish and self isolating |
| 6 Ambiguous social capital | • Pride in manipulative skills/flirting  
                          • Indirect but effective in articulating self esteem |
| 7 Colleague interaction intolerance | • Contempt, intolerance and disapproval  
                          • Anger: shouted resentment and frustration  
                          • Frustration that negative MS dominates |
| 8 Beautiful boyfriend: emotional void | • Confidence-boosting exercise  
                          • Self reassurance of attractiveness |
| 9 Resents reduced attractiveness | • Rejection and lost physical attractiveness due to walking stick  
                          • Confused and unconvincing ambiguous language  
                          • Rejection leads to irritation and anger |
| 10 Resents perfectionist mother | • Anger and resentment at perceived maternal threat  
                          • Self isolating |
| 11 Maternal connection: lost control | • Lost independence / control  
                          • Resentment / exasperation at her mother  
                          • Isolating / independence seeking  
                          • Intense frustration |
| **Wendy (DATA SET 6: Interview 8)** |                                           |
| 1 Relief and inferiority | • Relief resolution to life-long inferiority  
                          • Resilience and emotion suppression  
                          • Isolating with coping |
| 2 Lifelong questioned credibility | • Lack of empathy / emotional support  
                          • Lack of confidence / sense of inferiority  
                          • Calms her inner panic in isolation |
| 3 Relief and resolution | • Chronic inferiority has evolved into unfairness  
                          • Lacks close emotional connections: isolation from family  
                          • Grateful for any help |
| 4 Sense of belonging | • Shared experiences = emotional support  
                          • Acceptance enabling = isolation relief |
| 5 Inferior MS and questioned credibility | • Invisible MS renews credibility challenge  
                          • Rejection and unfairness  
                          • Dismissal of / distancing from MS |
| 6 Failure and disappointment | • Childhood + lifelong shaping  
                          • Ability to cope in spite of criticism |
| **Alex (DATA SET 7: Interview 9)** |                                           |
| 1 Diagnosis fear | • Subconscious threat  
                          • Self isolating past and present  
                          • Threat/shock contextualised, retained  
                          • Unresolved shock = anger |
| 2 Relapse horror and humiliation | • Unresolved active control of pent-up, unresolved emotional responses  
                          • Isolation with future-oriented fear  
                          • Continuation of negative emotions  
                          • Retrospective horror |
| 3 Maternal response: turmoil and regret | • Sense of rejection  
                          • Regret and maternal loss  
                          • Distress, loss, helplessness and isolation |
| 4 Fear of future | • Catastrophizes situations  
                          • Extends future fear and unrealistic terror  
                          • Isolates herself from (and with) MS |
2.5.2 Cross-case summary

The influence of previous experience contributed to responses in some cases but this was not universal. Three overarching concepts or themes focusing on emotional responses and related processes influenced identity transition: Emotional Isolation; Future-oriented Fear; and Resentment at 'eroded/reduced/violated' rights.

2.5.2.1 Emotional Isolation

Emotional isolation referred to being isolated with emotions (responses and emotional processes related to MS). While it could be imposed through others' responses or behaviour, this was not a defining characteristic; emotional isolation could be actively self selected in either a conscious way or unintentionally as a result of related behaviour. Although emotional isolation was different from social isolation and the two could be unrelated, these different aspects could interact. The data suggested that while acute phases of emotional isolation were not uncommon and were resolved by expressing or discussing concerns, less-usual interactions of social isolation arising from circumstances or through others' behaviour could initiate emotional isolation or induce a chronic problem.

Motivated by the urge to protect identity from perceived, anticipated or actual challenges, an active emotionally isolating approach could relate to denial. Denial served to protect an existing identity as a healthy person from that of someone with MS. At the same time, trying to suppress rather than share concerns and emotional responses did not prevent subconscious awareness from becoming threatening. For example, one participant (Alex) described her condition as "lurking in the background". Denial was demonstrated by several participants and described explicitly by Alex, whose immediate response to images of people disabled with MS was, 'I used to ... block it ... block it out. / And thinking, "Not me. I'm fine."' Faced with the anticipated threat, she actively avoided further information and, in her
account, laid claim to a continuous position as ‘alright...okay’, perhaps emphasising her ‘not disabled’ position or offering reassurance about any potential adverse implications of strategy. For example:

(Stanza 3/13) And you can r...
I didn't read any books or anything
I didn't want to know.
I didn't want to know.

(Stanza 3/14) I was alright.
I'm okay.

Isolating specific aspects of identity from MS could involve integrating denial of its impact with a sense of control. While privately acknowledging and exercising control over physical symptoms in order to conceal the condition from others created a sense of power over the condition, it also increased isolation with problems. Val demonstrated the extent to which she kept her diagnosis to herself:

(Stanza 1/1) I never talked to people – in fact very few people where I worked
(and I was very high up) –
only three people knew I had MS
and that didn’t include the management.

(Stanza 1/4) I had holidays.
I was perfectly normal.

Her emotional isolation was intense, as she 'never talked to people'; felt that 'nobody needed to know'; and strove to appear 'perfectly normal'. However, using this approach to minimise the personal impact of the condition on her career, involved isolation with complex emotional responses and physical consequences, as she described:

(Stanza 1/5) Except, I used to get very stressed
and the trouble was
I'd get hot spots on my leg, my bladder gave up twice ...

(Stanza 1/6) lots of things happened to me.
But I never told anybody.

Val qualified being 'perfectly normal' with getting 'very stressed' related to physical difficulties. Her intense emphasis on 'never' telling anyone highlighted her isolation with the 'stress' and 'trouble' of physical symptoms.

In common with Val, David had minimal visible symptoms so he adjusted behaviour to avoid them rather than confronting and challenging them. This way, he was also able to conceal them from others but, in doing so, David isolated himself
with his condition. David said he was 'very conscious' of how, at first, rather than adjust his busy workload in response to diagnosis, he decided instead to focus on family commitments:

(Stanza 1/1) I now realise because of that
I made a number of dec[isions] ... since then I managed to come through that period and um ... now we're okay and they all wo[rk]...

(Stanza 1/2) and I had to get them through university
... I keep saying 'I had to'
but, you know, y, y ... you did that,
and um you rushed around and, um, doing whatever. Eer ... The temporal construction of stanza 1 constitutes a well-formed retrospective analysis. The recent realisation ('now' and 'because') seems to be working out that lack of visible disability facilitated decisions about avoiding MS. In the past tense, 'since then', indicates reflection and definition of 'that period', which he 'managed to come through'. This well-formed continuous statement suggests that, rather than being interview generated, it represents something he has thought about and considered. In stanza 2, when he qualified what he (in the first person 'I') 'had' to do by justifying it as the general rule (in 'you did that'), he seemed, in relatively confident discourse, to be seeking empathy in lines 3 and 4, with 'you know' directed at the interviewer. He was more tentative in expressing awareness that avoiding activity became 'self-fulfilling':

(Stanza 2/7) Er and then, of course, it becomes self-fulfilling
... you don't walk any distance,
you walk less distance and blah di blah di blah.
All of which,

(Stanza 2/12) [I So, 'I'm not coming along until I get to that stage'?] That's right.
That's right.
Maybe if I'd gone to class one (...) or whatever
I may be I would have... [I Maybe you would have been involved a bit sooner] Yes. So there you are.
[I So, it's, so basically you just get on with life.] Sure

The language became hesitant and less direct in stanza 7; for example, with reluctance to be specific and reliance on generalising in 'of course' and 'blah di blah di blah'. Digression into unspecific comments, such as 'you'd hear this stuff', and comparing his symptoms with information on MS, for example, "tick box four, five and six", intervened before, in stanza 12, the interviewer sought qualification of what he was saying. David responded promptly. The sense of finality in the curt, 'Yes. So
there you are' suggests he was unhappy voicing self-critical thoughts and was bringing the topic to a close. It seemed like a confession of private reflection on what he could have done ('if I'd gone') and how that could have influenced his circumstances, possibly indicating some sense of responsibility for the self-fulfilling consequences of his approach. This reluctant admission of some sense of responsibility, or failure in terms of outcomes, overlapped with expressions by other participants. Wendy's comment (below) that she was "a bit irresponsible, really, aren't I?" indicated reluctance when posed as a question. Similarly, whereas Val consistently described MS as 'an enemy' or 'the enemy' that she would beat, she made the following (one of only two) curt, unqualified, admissions to failure:

(Stanza 1/2) And it was always an enemy.
And I would beat it. I never did.

As with David, a similar straightforward parental need to carry on was common among participants and it could lead to emotional isolation as a result of subconscious, less-active avoidance coping. This was demonstrated particularly by Wendy, whose avoidance process was evident in repeated minimising of MS; for example, referring to symptoms as 'peculiarities' and 'trivial things', and dismissing their impact, including speaking of repeated blindness in terms of, 'I still had the other eye' and 'I don't think they ever go, both at the same time.' She seemed to distance herself by talking of 'the other eye' or 'the feet' in an objectifying way and frequently generalised her approach in terms of 'you', while rarely expressing ownership through 'I' or 'my'. While objectifying body parts when describing their malfunction is not uncommon, and other participants referred to 'the leg' that was not flexible or 'playing up', Wendy's language was also consistently characterised by broader remoteness. She took the advice of the consultant who advised her to, ' "get on and lead your life"':

(Stanza 5/32) ... which is how I, I went on.
And, as I say, I had a good doctor,
who I consider was a pal
and er he was a good diagnostic one,

(Stanza 5/33) so he'd set me in the right position.
I then actually knew what was wrong with me
and just cope with it as bits and bobs came along.
So I'm a bit irresponsible, really, aren't I? When you think about it.
[laughs]
Wendy indicated close reliance on her GP's professional ability and personal support as 'a pal' but distanced herself from treatment details. For example she referred to being 'set in the right position' and, in later narrative, having the doctor 'bung me on the tablets'. Similarly, rather than describing personal recovery, she spoke of improvements as 'magic' and 'like magic'. In contrast to reinforcing her position as 'a bit of a coper' who dealt with 'bits and bobs', she seemed aware of some avoidance in being 'a bit irresponsible'. Laughing after saying this could be associated with discomfort rather than humour. Had Wendy been older, her outlook could have related to a culture for downplaying illness to strangers, yet she had associated with the interviewer early in the interview and commented on mutual youthful attitudes.  

Focusing on external professional medical support for controlling physical symptoms while creating personal distance from the condition (rather than exercising control) could represent a positive short-term approach to coping and getting on with life rather than focusing on a potentially negative prognosis. Wendy was relieved to have 'just a handle' on unexplained symptoms and with effective medication "that was absolutely fine". In the longer term, subconscious disengagement could facilitate subsequent emotional isolation and withdrawal from dealing with negative feelings in the absence of an emotionally supportive environment. Unlike other participants' narratives, Wendy's account was devoid of conscious attempts to isolate herself with her feelings but it lacked indications of reported empathy from family and friends. Wendy also experienced frequent rebuffs, including lack of emotional support from friends, who told her not to be silly because '"You look so well."' In such circumstances, she withdrew, thinking, 'Alright, well you're the one that's got the problem, not me'. Twenty years after diagnosis, she recently found she could share her feelings with others in a support group:

(Stanza 1/1)  
Um. So, yes, you know, I have little silly patches and this place has been a godsend because you realise you're not the only person who's got something wrong with you.

(Stanza 1/11)  
I don't, I'm not, I don't think it's particularly changed me, but, er ... you know I am in a group of people that I can relate to. Not that I haven't related to other people in my life, but it's just like you're accepted as you are.

Dismissing times when she was not coping as 'little silly patches' contrasted with her description of the group as a godsend. Wendy's detached status from, and isolation
with, MS seems to have shifted as her emotional isolation was relieved and she realised she was not alone. In part three, the comment that belonging to the group had not changed her was qualified with 'not particularly'; in fact, she said it, 'made me do more exercise', possibly indicating a changed outlook on responsibility. The highlighted emphasis was on being accepted 'as you are' rather than being different from her social group and isolated with feelings and unspoken responses to friends.

The data indicated that Wendy's avoidance approach was probably a learned response to childhood dyslexia, classed "as being stupid" through which she "just learned to cope" and "bumbled along". Interpreting her continuous self-analytic approach in terms of the way she felt she was perceived by others and her qualification of her own reality as learned from childhood does not diminish the influence on her relationship with MS. Wendy may have been conditioned to 'just cope' with the fact that her norm was 'not everyone else's norm' but, ultimately, she questioned her ability to cope with MS when she said '... but on the whole I'm a pretty positive person, / I think' and admitted that sharing concerns with others was 'beneficial, really'.

Alternatively, intentional emotional isolation could result from avoiding negative responses by shutting them out rather than confronting and concealing them. Multiple motivations, such as prioritising maternal responsibility (focusing on looking after the family first) and personal fear for the future, could fuel the intention to avoid expressing concerns. Unlike Wendy's sub-conscious avoidance, Alex was conscientious in attempting to isolate herself from MS but, in common with Val, this meant she was initially isolated with it. Turning away from information, as demonstrated earlier, she focused on the relief of being diagnosed rather than seeking support:

(Stanza 4/11) Could be worse.
Mum thought I had a brain tumour.

(Stanza 4/12) There's all these things going on.
And just to find out
I had MS was a relief
because I knew I was alright.

Her language was consistently singular, suggesting a personal ownership ('I') and her own interpretation, rather than a shared (in the plural) or general perspective. Not only did Alex avoid formal information about MS but, also, she did not tell her
parents that the diagnosis was MS for eight years, saying 'There was no need. No need. Don't want to scare the living daylights out of them.' This suggested that her relief was not so overwhelming and consistent that she wanted to share it with her parents, but she herself was scared. In fact, Alex said it was a family friend who (on her behalf) eventually told her parents. Her statements were definite and unquestioning, without indicating any process of consideration or evaluation. Instead of sharing, evaluating and dealing with negative responses at diagnosis, avoiding them could lead to instigation and long-term perpetuation of emotional isolation.

Whereas other participants included some critique of their own position (for example, Val briefly evaluated her interpretation of MS as 'an enemy' that she would beat by admitting 'I never did') or indicated some comparison by generalising (as David did in justifying his decision to focus on family commitments in terms of 'you did that'), Alex's account was consistently singular, emotional and with an unqualified perspective that suggested she was isolated with unresolved, actively disturbing, fears. Alex's experience of traumatic exacerbation and her relationship with her husband may have shaped her position with MS.

The combination of both avoiding expressing and attempting to suppress unwanted emotional responses could also provide a basis for disturbing rumination. For example, Alex contemplated the fate of deceased group members as 'really frightening', citing the suffering of someone who opted for assisted suicide and 'actually went to digitas... Dignitas ... digitas? Dignits?' and unrealistically compared herself with others:

(Stanza 1/99) And then ... Marion died.  
She drowned in the bath. Absolutely horrific.

(Stanza 1/100) 1 ... I've had a bath.  
1 ... got so frightened because I couldn't get out.

Instead of enhancing her position as relatively disability free by downward comparison, she used another worst-case scenario as a basis for catastrophizing her future when she focused on an extreme accident (and its horror) to make unrealistic comparison with an occasion when she had to 'scream loud enough during a Chelsea match to get my husband to get me out.' Her repeated 'That was frightening', with emphasis on 'that' and without any evaluation or qualification, suggested her fear was unresolved. She did not indicate that she had contextualised her fear at the time and
retrospectively re-assessed the likelihood of drowning in the bath (or ways in which she could avoid doing so) while her husband was near.

Similarly, being alone with a need to understand the reasons for having an unpredictable and poorly defined condition such as MS could motivate uncomfortable exploration of, and challenge to, existential beliefs. David revealed that he kept extensive thoughts on 'well not mysticism exactly' to himself because otherwise he said, 'I'll be locked up as mad.' Repeated references to 'mad', 'madness' and later to having to 'put that back into its box'. Otherwise 'Mr Madness' creeps in' suggested discomfort and emotional disruption. He indicated that he was ruminating on some individual interpretation rather than a standard religious concept:

(Stanza 1/6) I'm not talking about anything that could be painted or anything that could be 'what's its named'... just you feel that there's a ... there's, there's an object lesson [David] you must learn.

This was not something that he could represent by icons, such as paintings, or definitions in terms of 'anything that could be 'what's its named' but it was something he felt was a personal message and a specific 'object lesson'. David seemed to interpret MS as a lesson in response to the fact that he was a fit athlete and 'at the same time, arrogant.'

(Stanza 1/9) [laughs] But unfortunately, you're not God's gift. You've actually got a few, you're almost as though, um, hubris and um ... [I ... you're vulnerable ... ]. That's right.

He felt MS was sent to teach him that he was not 'God's gift', a common metaphor for superiority; that he had flaws perhaps, and that his 'hubris', or extreme pride, was inappropriate. It seemed that examining the conscience and re-tracing personal moral values and motivations without having an outlet for discussing and evaluating them could create a threatening isolation with unwanted personal spiritual feelings. It was for this reason that he said he had to put such feelings 'back into the box' or avoid thinking about them.

It was common for participants to demonstrate characteristic resilience (as in Wendy's case) and role-related responsibility (particularly paternal or maternal from David, Wendy and Alex) that meant prioritising the responses of close family at diagnosis. This could lead to a level of self-imposed emotional isolation in terms of
looking to rather than for support. Paul responded when his daughters asked if MS was hereditary by reassuring them that 'you're not going to catch nothing off me':

(Stanza 1/3) So with the booklets
and, like, with me pacifying them,
it was enough to put their minds at rest.
So, sort of, thank heavens for that.

His first focus was to find the necessary information to reassure them. Relieved that he can 'put their minds at rest', saying 'thank heavens for that' suggests that he shares their relief.

(Stanza 1/4) And again, they were happy,
"Oh, you know what's wrong with you now, Dad,
you can get on with your life as such.
How are you going to cope?"

(Stanza 1/5) Well, like everything, you know,
brush meself down and get on with it.

Paul recounted how they reciprocate with their understanding of him as someone who has always got on with life, qualified by 'as such' suggesting that they were concerned and want to know how he would cope. In stanza 5 he seemed to rely on his standard position of resilience. He coped with his father in a similar way:

(Stanza 1/4) He was very shocked, very shocked ...
but he was happy, I think,
that I knew what the end result was.
What was giving me all this problem as, just ... well ...

(Stanza 1/5) "How are you coping."
"I'm coping quite well."

(Stanza 1/6) Now I know what it is
I can get on with life and ...

He wanted to reassure his father and presented his response in terms of relief at diagnosis and reasons for the problems. Again, he positions himself as someone who copes. From the descriptions of his daughters' and father's responses, he sought to reassure them based on his own perceived need to protect them from distress. Adopting his familiar position of resilience meant he did not begin to explore other aspects of his reaction with them. Paul's position exemplified the concept of emotional isolation evolving against a backdrop of good social and familial contact. Just as Wendy found that invisible symptoms did not secure emotional support, so Paul felt he could not contradict friends who would 'always say, "Oh, you're looking well." "Well, I feel quite well." But, but ... I think, I'd like to say, "Look, No. I feel
absolute crap today.' This reaction may reflect others' denial as a coping method instead of dealing with a friend's situation. In the context of both family and friends, even though he would 'get a hug from my kids', Paul repeatedly expressed the need for closeness and support:

(Stanza 2/11) but it's odd ...
doyou say to someone, oh I feel crap
I need a hug
to someone you don't know?

In this way, self isolating with emotions was not necessarily a conscious and continuous process: it could be gradual and relate to negative social perceptions of sharing emotions.

An interesting aspect of emotional isolation was the interaction between a self-selected, but possibly unintentional, emotionally isolating approach and emotional isolation through external pressure and others' responses in terms of socially imposed emotional isolation. The fear of being socially inappropriate could provide motivation for creating an outwardly coping persona while becoming emotionally isolated. Thus emotional isolation could exist in the context of existence of broad general support but lack of an appropriate close or supportive relationship.

2.5.2.1.1 Emotional isolation: Analytic insight

In the context of the research question as to how emotional responses to MS are expressed, the concept of emotional isolation demonstrates the processes involved in dealing with responses.

Applying complementary methods of narrative analysis in a simultaneous stepped way approached the enquiry of data from complementary stances. There was the danger that two methods could either perform little more than validation or produce contradictory reading and clashing perspectives. Such outcomes could not have been deemed unacceptable but could reflect more on method than data. However, the concept of emotional isolation was revealed only as the layers of analysis uncovered parallel aspects of response and processing.

Both methods were vital. While Labov's method could be seen as functioning here only for mechanically defining areas of narrative text, this would undermine the status of this stage of analysis. Extraction by Labov's method demonstrated the existence of essential processes. Without this instrumental analysis, the critical
emotional responses could not have been credibly defined and extracted from overall interview narrative. Questioning the entire body of data using Labov's structure differentiated incidental sub-plots from independent contributory narratives. The event or emotion was more than 'in passing' as it had been designated pivotal significance by the narrator within the overarching story. This analysis provided credible criteria for distinguishing relevant and important responses. Text that was set aside did not meet the criteria of emplotment that defined pivotal emotional responses.

Instead of continuing with descriptive comparison of the relative and temporal importance of responses, Gee's model provided insight into narrative processes and reasons for their enactment. As these narrators' personal perspectives and performances, both current and reflexive, unfolded they disclosed not only the construction of narrative but also purpose and impact, unconscious aspects and spoken interpretations. This evaluation of emotional isolation provides an underlying focus against which all other responses can be mapped.

2.5.2.2 Future-oriented fear

Future-oriented fear represented an emotional response to potential adversity or suffering. Although possible physical decline and disability were common fears, the interpretation of related adversity was individual, with indications of focus on social identity challenge as well as loss of control or diminished independence. Future-oriented fear could be a conscious reaction, semantically described or defined in narratives, or a latent aspect, suggested not only from what was said but the way in which some aspects were expressed.

It seemed that fear could originate from the diagnosis experience and, importantly, it was not necessarily based on realistic appraisal of the situation. Persistent future-oriented fear could be indicative of some inappropriate interpretation, lacking personal perspective on the diagnosis, the individual's condition or symptoms. An unwelcome focus on worst-case scenario would seem to be a normal response to being diagnosed with an unpredictable and incurable chronic illness. One participant, Alex, focused on images of disability in advertisements she saw on her journey home after being diagnosed. She blocked the negative images, that she found 'really scary' and 'horrible', and the fear of disability they aroused.
It would also seem reasonable to assume that, over time, such shock would translate into a better-balanced approach to coping. However, Alex's reaction to the adverts that frightened her over twenty years ago was still expressed in the present tense ('you get all these adverts', 'they do these' and 'they are people in wheelchairs') and with emphasis, in an actively angry way. For example:

(Stanza 4/17) And I think that's wrong. Because a lot of people aren't like that with MS. Okay, a lot of people are ... [assertive and cross] but it's a very mixed bag.

Her narrative was current, real-life and ambiguous about disability, suggesting that her perspective at diagnosis was unresolved. Her account was neither tearful nor raging, yet consistently intense and emotional. She spoke in short sentences, with an occasional hint of a breathless, nervous laugh. Repeating her experience of 'going up on the tube' she eventually trailed off, lowering her tone and becoming speechless as she recalled the shock.

(Stanza 4/20) But to start with it was quite a shock I always remember going down the tube at Waterloo, thinking, [slight pause to breathe in]"God ..."] [Speechless, part-laugh, part-tutting noise]

There was no indication in what she said above (or later in her narrative) that she had reconsidered her reaction. The emotional account, ending in speechless disbelief, suggested her memory of the shock had not been resolved. However, there were indications that continued attempts to suppress unwanted fears meant they could become a sub-conscious threat, an aspect suggested when Alex talked about how she kept fit 'because I knew it was in the background' and repeated this in a more threatening image:

(Stanza 3/9) Because I knew that this was lurking in the background but that's all really.

Alex referred to MS in the sub-conscious term, 'background', not as a constant in the life-long sense but with some negative potential for which she had to be 'sensible' and 'boring'. In stanza 9 she qualified the preceding statements with 'lurking', indicated the status as active, unpleasant and threatening. Contradictions and uncertainty characterised the constant turmoil in her narrative. She fluctuated among frequent dramatic references to the horror of one relapse (eight years ago), for
example as 'Bang. Hell.' and 'it was terrifying'; assurances, such as 'But I'm alright.);
and expressions of active fear, including 'So I'm terrified of Christmas' and 'I dare not look to the future.'

The possibility of arresting active fear, anger and frustration by evaluating and contextualising the diagnosis situation was represented in Brenda's account. Although Brenda was equally as vivid and passionate as Alex in narrating her traumatic diagnosis experience, her description was definitely positioned in the past tense. Using reported speech to emphasise her frustration, Brenda recalled asking "Will anybody, please, explain to me, before I leave, what this actually says?" She vividly replayed her shouted response to nurses offering tea as ' "NO. I WANT TO KNOW. / And THAT doctor can't tell me ... " ' Her unhesitant account included reference to 'seeing a newly qualified doctor' and she contextualised the situation, for example:

(Stanza 1/5) And I was in the hospital.
It's probably on their, it was at the time, on their CCTV footage
of me having a tantrum,
going, "Will somebody ... "

(Stanza 1/4) I was in tears.
Absolute tears.

She shouted as she referred again to her angry comment, then reverted to a normal, but emphatic, tone to describe the experience. Without pausing, retrospective evaluation was interwoven with her account of events, for example referring to being on the CCTV and to her behaviour as a 'tantrum'. The complexity of the narrative and its setting in the past tense, suggests it is a familiar interpretation that Brenda had constructed in order to make sense of the situation. Her narrative concentrated first on the trauma of the situation and only then did she go on to explain her fear at the time:

(Stanza 2/22) And as I say, I ... er ... I really didn't want it to be the worst news
and muscular dystrophy, that would have been three years.
You know, MS by that point, was not, sadly, the worst ...

(Stanza 2/23) I just wanted to know.

Brenda's coherent account was constructed around the trauma of the diagnosis event. She vividly enacted her anger before indicating that the cause of the emotional response was her fear of muscular dystrophy and death. The retrospective description of her fear was calm, matter of fact and embedded within retrospective sense
making. Brenda explained how her fear for herself had diminished. She did have fears until "probably even three / or four years ago". Any current fear was for her children, not herself.

(Stanza 1/1) I have a fear. A fear that - if it is something that is something that is genetic - that my children might get it. [Very strong and positive - no doubt about this comment]

(Stanza 1/2) Do I fear for myself? No. [very, very quiet]

(Stanza 1/10) Yes, I think I was more fearful for the future. More fearful on all fronts, I think.

The above brief statement of having fear was unambiguous, in the present tense and direct; however, when identifying what it was her language became comparatively remote and ambiguous ('if it is something'), suggesting that although this fear was real it was neither precise nor a strong focus. She emphasised that the fear was not for herself and added that, although her body was 'definitely getting worse', by accepting MS it seemed that many aspects of fear were reduced. Being able to deal with fear seemed to alter the control status quo so that the threat was 'not a proper fear'. For example, discussing the fear of having to stop driving meant she and her husband agreed to move house for better transport. She said:

(Stanza 3/23) That's how you deal with it. So ... it's not fearful

(Stanza 3/24) in a 'I don't, I can't handle it' or 'I don't know what to do with it';

Fear for the future seemed to be associated with not being able to cope. Dealing with potential problems provided a sense of control. The potential fear of not being able to manage in their home was subject to potential solution: '... we sell it. / It goes. / End of story.' Speaking in the first person and present tense emphasised ownership and individual control but this was also something she and her husband had discussed; this was unequivocal. Brenda also seemed to be getting her fears for her children into perspective, when she said:

(Stanza 4/29) So, but if I have a real fear, it's for my children and that ... and why should I fear them having this? Because, as I say, the proverbial bus could come along and get either of them.
Real fear was repositioned as dislike, related to something considered as unfair. This was seemingly still an active emotion, being dealt with and under evaluation. The positive statement in lines 1 and 2 was questioned as she spoke and, to an extent, the fear was justified in stanza 30 (rather than resolved). In this perspective on the threat to her children, as well as potential disability, there was a marked difference between Brenda's ability to speak openly and calmly about her future-oriented fears in terms of solutions and Alex's disturbed and apparently fearful position with MS.

As well as adjusting the status of the threat from active to passive, the individual perception of the nature or source of potential adversity could change. Val, a participant who experienced more physically intrusive symptoms than either Alex or Brenda, revealed chronic fear of threat to her professional identity. Unlike Alex's consistently broad fear of disability, Val had adopted a similarly practical approach to problem solving as Brenda. Val described periods of acute fear, including her interpretation of MS as life threatening when she was first diagnosed:

(Stanza 1/1) Because, at first when I first heard about the MS, I went to pieces. I was, I really was bad.

(Stanza 1/4) but I thought, "Oh dear, I've got a disease,"

(Stanza 1/5) and I thought "it's life threatening because it's there forever ..."

(Stanza 1/7) And so at first, I sort of thought, "Oh, this is terrible." And then I wasn't so bad.

Val's description in the past tense was vivid with reported speech but, as for Brenda, this was a coherent account. She constructed MS as personal, something that she had, and a 'disease', which seemed a particularly threatening and unpleasant term (more so than 'condition' or even 'illness'). The way she constructed her diagnosis as life threatening was difficult to challenge: the MS would not get 'better next year'. However, her fear subsided when the MS 'wasn't so bad'. The temporally well-organised narrative ran through her initial reaction, temporary loss of eyesight and an evaluation of how she got used to dealing with problems. Physical threat subsided as 'every time something went wrong ... it used to disappear'. Thus, it seems her fear of the future in terms of physical problems fluctuated. Even though she coped, she
admitted 'I used to get very stressed' and this related to Val's consistent fear from her construction of herself as a target for discrimination:

(Stanza 1/2) Because I was a very high positioned person ...
... and I used to think
if people found out about the MS,
they would use that against me.

(Stanza 1/3) And I wanted to maintain my position.
And nobody needed to know.

As with Alex, Val expressed an intense individual focus in the repeated use of the first person singular 'I' as she described her perceived threat to her identity as a 'very high positioned person'. This personal insecurity was more than a general concern that physical disability would jeopardise her ability to work but a specific fear that other people would usurp her from her career position. There seemed to be something of a siege mentally in Val's account, with 'they would use that against me' representing some fear of attack.

Therefore, altering the perception of the future was seemingly not necessarily a single, one-off solution for promoting coping with an uncertain prognosis, particularly in the context of unpredictable and fluctuating symptom presentation. For example, David was another participant whose fear related to perceived identity threat and, as for Val, the threat was future oriented in terms of anticipated degeneration. David encountered the potential physical consequences when, on being diagnosed, he went to a support group and this aroused his fear of future disability in a similar, but less dramatic, way to the posters that horrified Alex. Although David interpreted others' physical disability as 'a pretty advanced condition', he avoided the group 'for two to three years because I thought, "okay, I've got MS but I haven't ... you know ..." '. He went on actively to avoid situations that potentially threatened his physically strong identity. For example, he said:

(Stanza 1/1) So, but then I conditioned myself
by taking on projects that involved short distances and (...) whatever
and half convincing myself I didn't really have a problem.
Except the car went everywhere.

However, he commented that he was only 'half convincing' himself, indicating that, in hindsight, it is possible that he was aware at the time that his strategy was not completely successful. David comments that he does 'not walk any distance' and 'I've got slower', but later reflects that he tends 'to read a lot more' and 'in a way my
mind's become more ... it's like the attic's even bigger'. He observes that this 'has all
got a down side', saying:

(Stanza 1/5) I'm generalising. Unfortunately, and you mentioned the word caveat well,
or perhaps I did,
the fact that, er, certainties ... actually, the number of certainties ...
they, they're qualified certainties.
And er, the more you read, the more, you know ... [...] you realise that there
is no certainty... No, that's right.

Focusing on mental capabilities, reading, being more analytical and philosophical
highlights uncertainty, which seems problematic for David, not only as a negative
'downside' but as he seems ambiguous, unready to take ownership of the 'caveat' he
had mentioned. Uncertainty relates not only to MS but also to existential aspects:
'mysticism', being on 'a journey' and being taught a lesson. Ruminating on spiritual
aspects leads him to construct MS as a punishment and this threatens his mental
wellbeing. He comments:

(Stanza 1/2) because I've got to be careful
otherwise I'll be locked up as mad.

(Stanza 2/10) And I must er, ... I must put that back into its box,
Otherwise 'Mr Madness' creeps in [laugh] ... you know ...
delusions, you know ...

When David set out to improve his mind to allay fear of potential loss of cognitive
capacity, he encountered a different threat. The possibility of MS as punishment
represented a spiritual threat and one he seemed unable to deal with but, instead, he
had to lock it away, 'put that back into its box'. Thinking about it threatened his
mental health, emphasised by repeated reference to madness.

Suppressing fear without evaluating it could result in subconscious threat. This
could remain unresolved in the long term. There were indications that persistence of
such threat was not consistent but characterised by occasional relief that could relate
to control. Alex reacted to her fear at diagnosis with fairly extreme measures, such as
planning for future disability and building a wheelchair-accessible house. MS relapse
re-ignited her extreme fear that was unresolved and focused around loss of physical
control. Conversely, Brenda's fear was allayed by gradual realistic acceptance, allied
with discussion around taking control. David also dealt with his fear by exercising
control but the shift of focus from physical and personal identity to spiritual aspects
seemed beyond his control.
Val demonstrated that the threat of losing control as a result of disability, possibly unconscious, could fuel a need to fight. Fighting could become the default response to a nagging chronic threat based on an established perception of the inevitability of decline and disability. The paradox of fighting, based on the constant urge to prevent MS from controlling life, was that the fight could evolve into a controlling concept. It was possible for fighting the enemy to become the controlling principle for life. Val's ultimate expression of her need for control was expressed as determination to commit suicide, when she said:

(Stanza 5/21) I will take charge
because I know one day
I will decide I've had enough
and commit suicide.

(Stanza 5/22) Because I know what the death is going to be –
no, MS is not going to kill me,
but everything else will.
And I can see that,

(Stanza 5/23) so I would choose to die
when I want to.
Because I don't want to be so ill
that everybody else has to look after me.

Val delivers her suicide statement after summarising her intention to fight MS as the enemy, determination to beat it and final acknowledgment that she did not win. The controlled, strong and even delivery of stanza 21 seems to encapsulate her resentment and defiance. Explaining why in stanza 22 reveals not only future-oriented determination but also the persistence of intrusive negative evaluation. Her conviction that she knows 'what the death is going to be' seems to be an evaluated construction of an event in the future. In stanza 23 this translates into an underlying fear for the future, a fear of a situation she envisages, of being very ill, with no control and unable to look after herself. It could be argued that many people are aware of the ultimate potential for being totally dependent on others without focusing on suicide. When Val acknowledges that 'MS is not going to kill me' she seems to be referring to the physical cause of death but she may be referring to the fact that she cannot accept loss of control. Her determination to commit suicide represents a statement of retaliation as much as defiance: it seems she can beat MS by killing herself. This seems to epitomise the poignant resentment and anger that underpin and punctuate Val's narratives.
2.5.2.2.1 Future-oriented fear: Analytic insight

Considering the research question of how emotional responses to MS are expressed, the insight into processes provided by the emotional isolation cannot be disregarded in the evaluation of future-oriented fear.

Future-oriented fear shows active and passive emotional processes, how they can be resolved or disrupted. Murray (1999) described emplotment as continuous and this is particularly relevant in the fluctuating construction through which participants demonstrate fear responses.

The descriptive analysis – or definition and extraction – by Labov’s method provides essential insight into past and current responses here. Their evaluation in social context and implications for identity related responses are revealed by analytic insight into the extent of description provided and narration delivery.

2.5.2.3 Resentment at eroded rights

Resentment at eroded rights referred to a potentially long-term response to perceived loss, reduction or violation of normal personal rights. There were indications that experiencing challenges to rights, for example in terms of expected levels of choice, control, independence and role fulfilment, could result in acute negative emotional responses. Anger or frustration could focus on, or relate to, MS and if such negative emotions were not addressed or evaluated, and resolved to some extent, they could create underlying resentment. Persistent resentment could become sufficiently pervasive to fuel chronic negative emotional responses with adverse effects on adaptation and coping.

It would seem quite natural that recalling or relating a story could arouse previously experienced negative emotions and some retained resentment, especially in the context of life-changing events such as diagnosis with MS. This could produce limited or relatively controlled expressions of frustration, irritation or anger as a result of disrupting some particular previously resolved response. Alex’s fear of future disability was initiated by advertisements she saw on the day she was diagnosed. She recalled the experience with anger, saying ‘And I think that’s wrong’, and was cross and assertive about the relevance of the images to real life.
Her resentment seemed to relate to fear, which was the dominant emotion, and her expression of current anger was short-lived:

(Stanza 4/18) And I think to advertise ...
I know it's advertising
and all the rest,
I mean it's really...

Moving away from specific 'horrible' images, she generalised in stanza 18 and felt their use could not be justified but her anger subsided. Anger seemed to be an automatic reaction rather than a rehearsed response. She generalised with 'all the rest' and left her sentence unfinished before moving on to her memory of the fear.

By comparison, her account of being unable to care for her baby was filled with horror, an intense sense of maternal loss, regret and disbelief at being deprived of ability to fulfil her expected role. Alex repeatedly used 'I couldn't': 'I couldn't even pick up my baby', 'I couldn't walk', 'I couldn't do anything', 'I couldn't, I couldn't bath her' and 'I couldn't pick her up'. Eventually she screeched:

(Stanza 2/82) I know she was tiny. [screeching]
She was tiny.

(Stanza 2/83) I couldn't pick her up,
I wasn't strong enough to pick her up.

(Stanza 2/84) That was awful, absolutely awful

Alex was not tearful but angry and resentful; although relating a past experience, her emotions were current. Unlike earlier ambiguous anger about advertising, in stanzas 82-84 her assertive and emphatic comments seemed resentful. There was no attempt at an equivalent of the part-justification or consideration she included in her reference to advertising. Short statements and concise stanzas provided ideas without evaluation. This focus was on her loss; her children were 'absolutely fine' and 'brilliant actually'.

Alex went on to point out that her husband had taken 'a week off work to start with. / Then he went back to work' and '... didn't want to bath the baby. / So ...'. Her unfinished comments suggested Alex resented the lack of support and elsewhere she indicated that her husband did his own laundry while her mother washed the children's and her clothes. Although she did not make direct negative comments about him, and she did acknowledge that it was difficult for him (working and
cooking), there was no indication of understanding her husband's response to the
baby and her relapse. Her focus was on what she, individually, could not do and she
spoke in the singular ('I') rather than referring to 'we', for example as a couple or
family dealing with practicalities. She relied on 'er ... getting volunteers in'; she was
' lucky', her 'mum ... came in a lot' and she ' had quite good friends coming in'. The
only positive comments were about 'a girl' from the Home Start organisation, who
helped and was 'lovely' and 'very sweet'. Alex's expressions of continued resentment
were specific to this narrative, to her loss of maternal rights. While fear persisted
rather than anger, the resentment, although controlled, was not resolved. Alex gave
no indication of having made sense of what happened and it was possible that
resentment and some fear of being alone again, coping in the singular, contributed to
poor adaptation.

A similar restricted sense of resentment and anger was evident in relation to
another participant's maternal situation. Brenda's account of her violated right to
decide whether to have another baby epitomised active anger and resentment
invoked through narrating an experience. When the doctor suggested she should
avoid further pregnancy she recalled unequivocally stating their right (her husband
was present) to that choice:

(Stanza 1/4) And I said to him,
"Look, that's not your decision,
that's our decision, really.
I think that's our decision." And, um...

(Stanza 1/5) And, um, he just said, "No, absolutely,
But you do need to be aware
that you are likely to have a really bad something
if you have another child."

(Stanza 1/21) And I really,
really wanted another child

She in the singular ('I') expressed their joint decision, emphasising 'our'. She easily
reconstructed the conversation and what was said, suggesting familiarity with
replaying the scenario, possibly by going over it and making sense of what happened
and why. The report of the doctor's comment is precisely worded and retold with
control; stanzas 4 and 5 are assertive and controlled. As she moved from what
happened, orientating the event, to her evaluation, she quickened her pace slightly in
stanza 6, making succinct statements. Short stanzas reflect brevity and lack of doubt
about the point she makes emphatically. She spoke more quickly as she recalled what happened next:

(Stanza 1/7) but my husband went and had a vasectomy because he didn't want to put me through it again.

(Stanza 2/8) And I was furious. I couldn't speak to him.

Unlike Alex's account, including the reason for her husband's decision in stanza 7, even though she is speaking quickly, indicates that Brenda has evaluated this business. The reasoning seems automatically linked to his action. The precise, short statements in stanza 8 were spoken more quickly and in a raised voice. However, she regained control and continued over a further three, two-lined stanzas to state her anger with control, placing huge emphasis on the fact that it '... again was my choice. / It was not for him to take the choice away from me'. She related quietly and calmly how she had insisted that she would have another child. Then she unexpectedly erupted, shouting:

(Stanza 2/12) I was so angry ... ha, ha, ha ...[laughing and shouting] ... I said "I'M TRYING. A CHILD.

(Stanza 2/13) I'LL FIND SOMEONE THAT CAN GIVE ME A CHILD." HA. HA. HA.

Mock humour represented a current and continued expression of the resentment and retaliation in her reported speech. She was actively, alarmingly cross. Calming slightly, but still in a raised voice, she seemed to retreat from active anger into reasoned anger.

(Stanza 2/14) But it was MY choice. It was not for other people to make that decision: that's how I felt about it.

Although speaking fast and emphatically, Brenda seemed in control of her emotions again. She was still cross but she contextualised her evaluation in the past tense above. By comparison, Alex's anger and resentment were also controlled and bounded but not qualified by indications of altered state. Dealing with, rather than understanding, what happened seemed to contribute to Alex's resentment. Interestingly, in stanza 14 (above) Brenda also referred to 'other people' rather than continuing to direct her anger at her husband and she separately confirmed that she no longer blamed him. Furthermore, she justified her intense past anger, in current
terms because she was still coping with diagnosis '... doing it ... when the news was so new ... that, sort of, big decision ...'. Thus it seems Brenda's intense resentment was resolved to the extent that she felt some retrospective remorse. In spite of this, she could not quell her emotions and she seemed vitriolic as she said:

(Stanza 2/18) And I said, "No but you DIDN'T allow me to talk about it." [pause]
(Stanza 2/19) And I thought that was a big one for me. I always wanted three children.

At the end of stanza 18 she sounded different from elsewhere: nasty as she spat out the reported speech. Although she was not shouting, she seemed to impart active considered resentment and anger. This seemed more than purely retrospective because she continued resentfully, expressing anger over twelve stanzas, including some residual disbelief or inability to assimilate her husband's reasoning, saying that even though she could 'understand the fear' it seemed inadequate justification ('but that was still not...') for depriving her of the opportunity to chose.

The extent to which her anger was current was highlighted by the way she seemed to burn herself out. She subsided, quietly responding when asked if her husband had ever done anything of that type before, saying, "No. No, no ... / No. No, it was completely out of character.' She shouted again recalling her lack of sympathy for his infection following the vasectomy ('YOUR FAULT. / YOU CHOSE TO DO IT. / DON'T COMPLAIN.'); however, she laughed briefly with genuine humour. She said they had eventually discussed and resolved the situation: 'it's gone, it's in the past. / It's nothing to be worried about now.' The sense of resolution was supported by the way Brenda contextualised herself as part of a couple with her husband; conversely Alex generally positioned herself in the singular even though she and her husband were still together.

Even though Alex's reaction to her lost maternal role was not fully evaluated and Brenda's response to her violated rights could be vitriolic, both participants demonstrated boundaries for the influence of resentment. This was not the case with Marie, who displayed an almost subconsciously negative outlook and intrusive sense of resentment. This seemed to stem from when she was wrongly prescribed with insufficient drugs to treat a relapse. Her understandably angry response was unresolved and she was resentful when she said:
but, I shall tell you
— because you're recording this —

Marie started by emphasising that she was relating this information because the interview was being recorded: it represented a complaint and a record of the error made by her 'inexperienced doctor'. She described how at first sign of relapse doctors would 'hit it hard with steroids ... a hundred grammes a day' and continued:

And my silly inexperienced doctor, prescribed me steroids
but he prescribed me one gramme
rather than one ... you know ... [I ... one hundred...] You know.

She knew and, it seemed, her knowledge was pitted against that of her ('my') doctor. She was contemptuous, emphasising 'silly', and spoke with disgust. The doctor's error seemed to be interpreted as a personal attack by Marie as she repeated 'he prescribed me' in line 3. 'My' and 'me' suggested a very personal interpretation of wrong doing against her. By pausing and asking 'you know' she seemed to be seeking empathy and confirmation of understanding the enormity of the error. She repeated 'you know' to confirm that the interviewer's reference to 'one hundred' grammes was correct.

The notion that Marie was seeking to lay blame, wanting retribution or revenge by having this recorded in stanza 3 could be supported by considering the way she generalised when talking about a decision not to sue:

... Well there was a lot of, talk about suing
and all of that kind of thing,
but you know ... when you've been so ill and, and ...
all of that ... you begin to, sort of, think, well ...

... like, you know. I suppose you start to see that what ...
I don't know.
After you've fought, and fought, and fought for your life,
essentially, the last thing you want to do
is go into another battle...

Whereas she took ownership in stanza 7 and earlier of 'the kind of relapse/that I was having', she spoke of suing in general terms and with little detail. For example, the lack of detail in stanza 10 contrasted to the way she quoted the neurologist who first validated her opinion of the error as saying he was "... going to write him a letter" (referring to the inexperienced doctor) but this seemed to be aimed at preventing further error (not suing). She used ambiguous language when referring to the 'talk about suing', including phrases, such as 'that kind of thing' and 'a lot of talk about' in
contrast to her confident and articulate style elsewhere. The ambiguity may have been over how the decision not to take action came about. Marie took pride in owning her decisions and expressing her own mind, yet there was no sense of ownership of the decision in stanza 11. It is possible that her physical circumstances prevented her from proceeding as she would have wished or that she was reflecting advice from others who persuaded her not to sue. Although she spoke in the present tense about not wanting to fight, her general outlook was to focus on 'pushing' for independence and to regain control.

When she was discharged from hospital but still using a wheelchair, Marie confronted the doctor. She provided a vivid description of the context and exchange:

(Stanza 2/12) ... so essentially all I did
was go in there with my wheelchair

(Stanza 2/13) ... and said ... "Just thought I'd mention ...
  it's a gramme you know ...
  it's a gramme of steroids,
  not a milligramme." Sort of thing.

(Stanza 2/14) And he went... got his book out
  and looked through and looked through and looked through
  and looked to the page that
  he, obviously, had looked through previously ...

(Stanza 2/15) and looked along
  and saw, "NO, one...."

(Stanza 2/16) and he was like, "oh, one gramme."
  Because, obviously, he'd given me one milligramme.
  And it was like, "O-oh, yes, sorry."
  You know. So obviously, he felt a bit ...

It seems that Marie set out to humiliate the doctor. There is a sense of personal revenge, with ownership of 'all I did' and sarcasm by suggesting presumed minimal impact of her personal confrontation. She clearly reconstructs the context and her sarcastic and contemptuous message in stanzas 14 and 15. She was smirking and unrushed as she described the doctor's response, the image of him searching his book and her evaluation of this being the book he had originally consulted. However, the sense of satisfaction culminates in an anti-climax in stanza 16. The phrase 'it was like' does not indicate clearly what was said. The topic remained unfinished and her personal vindication or resolution seemed incomplete. It seemed, as could be expected, that the doctor made no response. Instead of demonstrating some
resolution, Marie returned to recount the ineffective telephone call to check his prescription. Her account suggests that he dismissed her:

(Stanza 2/20) But he was being 'doctor-ish' and saying 'NO, I'm right'... and I'm like, 'No you're not.' [contempt] You know.

Her disgust and contempt for his response was justified by her retrospective knowledge that she was right. In lines 1 and 2 he was assertive and superior. Line 3 suggests that, instead of arguing her point, Marie may have been intimidated. The phrase 'and I'm like' possibly indicated her thoughts and not what she said.

The harboured resentment could have stemmed from an unresolved sense of blame for the damage caused by the prescribing error and injustice. She contextualised the damage not only as 'three months in hospital' but also 'the way I am now' and the 'amount of damage that was done in that relapse / ... obviously ... couldn't be fixed.' One focus that influenced multiple other aspects was Marie's perception of her reduced physical attractiveness. References throughout her narratives were underpinned with an active resentfulness, giving an impression of her as vengeful, blaming and seeking retaliation.

One example was her pride in the fact that she could be 'considered quite a looker' but once she was seen to have a walking stick attracting the attention of the opposite sex was 'out of the question'. She blamed the breakdown of her long-term relationship on her perception of disability as unattractive, saying 'I can see it. / Especially when [ex-boyfriend] left me'. Her interpretation of her poor relationship with her mother also included references to 'Because she can't accept me / as not being perfect'. Conversely, Marie then talked about her new boyfriend, who was 'beautiful', 'he's a millionaire' and 'He could get any girl – because he's beautiful'. She talked at length about his appearance and lifestyle, and that her disability had not 'put him off at all', with no reference to affection. This seemed to represent retaliation, including getting back at her mother, whom she distanced from her boyfriend.

Encounters she cited to support her misplaced perception that she had 'lost that initial attractiveness', extended beyond social interactions and included blame for losing her job. She described her (male) boss as prejudiced against anyone who 'would not meet his, his perfect' standards of physical attractiveness as 'he employed ...fairly beautiful, you know, / fairly pretty young women'. Her resentment centred
around prejudice against appearance, yet her description also suggested that she had not ensured her boss was fully aware that she had MS before employing her; and she admitted finding the work too stressful.

Brenda and Alex demonstrated that it was possible to express awareness not only of retrospective anger, frustration and resentment, along with, in Brenda's case, understanding of the conscientious means by which the feelings were addressed, but also of the consequences for coping. Conversely, it seemed that the extent of active resentment or negative emotions could go unnoticed, as in Marie's case. Marie was not unattractive because of her physical characteristics but her resentment influenced her expression and stance: she imparted an air of unappealing contempt. She seemed unaware of her resentment and negative attitude, instead presenting herself as accepting, positive, with an ability to flirt and exercise her 'social capital'. She contradicted herself when, referring to a colleague whom she felt was negative, she stressed the importance of accepting MS:

(Stanza 2/11) I don't wanna live miserable all the time ... so ...

(Stanza 2/12) I suppose it's your choice:
to either just accept it
and ... and move forward,
or live in that, "I'm gutted, it's shit"

(Stanza 2/13) Nothing can stop it from being shit but ...
Just like ... which is, forget don't want ...don't ...
it being shit shouldn't constantly be on my mind.
It should always be, "What am I going to achieve? What's ... you know"

Her reference to not wanting to be miserable suggested that she was aware of her negative emotions. She brought this topic up when describing her perception of a colleague's response to disability. Whereas her conscious references were always to positive abilities, this represented many of the contradictory messages throughout her narratives. While her negative responses were not necessarily subconscious, it was possible that they were suppressed. While Marie was not necessarily ignorant of potential negative influences, there were indications of ambiguity about their impact. Her language was different in stanza 11, 'wanna' seemed throw away and different from the speech elsewhere. She generalised about choice in stanza 12 and minimized the options, then suddenly reacted angrily in line 4. Stanzas 12 and 13 were among limited examples of significant active anger, shouting 'I'm gutted, it's shit'. Stanza 13 also highlighted her resentment and indicated Marie's awareness of negative
responses that she shut out. Moving forward did not seem to include any opportunity for resolution but did involve pushing for what she wanted.

It is interesting to compare Marie's outlook with that of Val because both participants demonstrated a pervasive influence of a negative response. Preceding experience underpinned Val's fear of stigmatisation and fight to control MS as an enemy; however, she differed from Marie on two key points. Firstly, she was aware of her need for control and its origins, saying 'It's everything about me / is from that childhood'. Secondly, whereas control was a common objective, Val's was a life-long trait rather than a reaction to specific negative responses to MS. Marie's equivalent urge to control was frequently underpinned by her resentful response, for example she acknowledged that her determination to walk without using a stick was fuelled by her perception of disability as unattractive and she was resentful of her lost attractiveness. Her specific push for lifestyle independence seemed to be associated with resentment of her mother's intrusion. Ultimately, it seemed that Marie was unconsciously caught up in a cycle of resentment related to unresolved issues and this hindered her adaptation.

2.5.2.3.1 Resentment at eroded rights: Analytic insight

Considering the research question of how emotional responses to MS are expressed, the way in which narrative reveals the long-term impact of negative emotions is powerfully demonstrated in both the descriptive text and deeper levels of linguistic and discursive evaluation. The power of expression demonstrated processes of disruption and resolution; the way narratives had been constructed, rehearsed and utilised over a long period to evaluate and resolve crisis. Constructing the story around her husband's decision to have a vasectomy allowed Alex to find resolution. The psychological aspects of language – references to them as a couple in plural for example – revealed the unity that had been regained and process of resolution.

Conversely, similar construction and repetition of narrative by Marie demonstrated unresolved consistent negative emotions. Discursive tactics further indicated the intensity of emotional response, lack of resolution and escalation to a need for revenge. Analytic insight into the descriptive content and the use of language highlight the on-going process of emplotment and social context of narrative construction.
2.6 Discussion

Emotional responses were evident in terms of past, present and future context. Considering cognitive and affective (behavioural) aspects of emotional responses indicated semantic or latent aspects and active or passive emotions respectively. Processes of resolution and disruption were found to influence emotions and these were subject to fluctuation in type and intensity. Integration with context and person, for example in terms of indications of either emotional expression or retention, were important facets of the emotional responses. The concept of isolation was evident in terms of being isolated with or through emotions and also by others or through self-imposed means. Expressions of such complex interactions and processes were evident throughout the narratives, not limited to one-off aspects associated with particular responses but as a potentially fluctuating backdrop.

Published literature provides a strong body of evidence for comorbid depression and anxiety, and broad references to negative emotions, including fear, threat, guilt, sadness, disgust, grief and rage (for example, Bury, 1982; Finlay, 2003; Sa, 2007). Antorak (1995) proposed that such responses represented acute shock associated with diagnosis; Sharpe and Curran (2006) indicated that future-oriented fear could result from concealing symptoms to delay adjustment; and Kalb (2007) also identified grief, anger, anxiety and guilt as temporary responses to relapse.

Concepts of future-oriented fear and resentment at eroded rights evident in the narrative of participants concurred with the general findings in the literature. Recent research proposed a more specific interpretation of emotional responses to MS related to specific health anxieties (Dennison, 2009; Kehler & Hajistavropoulos, 2009) and this seemed to further define certain findings in the present narrative study. Participants' narratives around future-oriented fear resonated with this more specific focus and they also contributed insight into the different manifestations of threat. Two examples of being able to hide early invisible symptoms could be explained by initial threat that translated into fear of future disability as suggested by Sharpe and Curran (2006); however, the concealment continued for eight years in one case (from the participant’s parents) and for the entire career of the second participant. The first could be interpreted as a response to a debilitating relapse that left the participant with catastrophic and unrealistic fear of incapacity but this was
not a temporary phase as indicated by Kalb (2007) and the participant had previously responded emotionally to poster images of people with MS in wheelchairs.

Dennison et al. (2010) found that wheelchair fear in response to diagnosis linked to participants’ avoidance of support groups due to the stigma of disability and protection against association with this unwanted identity. This offered an appropriate understanding of the second participant’s response in terms of threat to her identity as a career woman.

2.6.1 Identity process theory
Models of identity as a complex process for defining and protecting the self (as discussed in section 1.6.1) may explain these fear responses to the threat of disability. Breakwell’s (1986) consideration of intra-psychic (cognitive and emotional) responses within her theory could explain maladaptive responses as a strategy for deflecting threat, with interpersonal and intergroup strategies influencing active rejection of the idea of belonging to MS groups.

Considering why the wheelchair image is so fear-inducing may explain responses. For example, it may relate to some attribution (rather than perception) of dehumanisation of the person to a state of helplessness and dependency. The stigmatisation as discussed above. It is possible that perceptions or interpretations of deformity are repulsive, not beautiful or less than perfect as suggested by one participant’s narrative. In this case, it is possible that the fundamental fear of physical loss is derived not only from an image through a social lens of group stigma, but also resulting from lack of information on the reality, or meaning of, wheelchair use among people with MS. This links to the potential importance of beliefs about MS to responses.

2.6.2 Models of coping and emotional processes
Literature research found that MS does not easily map on to any one theory of chronic illness due to the uncertainty and individuality of the condition. Similarly, the complex and fluctuating approaches to coping and their potential relationship with emotional responses revealed in the narrative analysis of participants' accounts in study one could not be explained by any one model. For example, theories of adaptation and coping, such as Leventhal’s Self-regulatory Model (1980) and Taylor's (1983) proposed process of cognitive adaptation through meaning, mastery and enhancing life by adopting illusions of control, do not accommodate the
fluctuating, uncertain and multi-symptomatic characteristics of MS. It is also possible that adoption of coping strategies according to factors such as illness perceptions is hindered due to uncertain perceptions of MS.

2.6.3 Emotions in newly proposed models of adaptation to MS

As discussed in section 1.10.1, recently proposed working models for adaptation to MS in particular, and chronic illness in general, include emotional responses as central (Dennison et al., 2009; Moss-Morris, 2013). Moss-Morris considers that adverse emotions are not necessarily damaging unless they become persistent. The majority view of early responses to diagnosis with chronic illness is that they represent a temporary stage in adaptation, resembling a grieving process for loss of health. Alternatively, they may relate to the crisis of diagnosis. However, indications from narratives in the present study suggest that early responses may have long-term effect. Focussing on the central role of emotions in the proposed working models (Dennison et al., 2009; Moss-Morris, 2013) such that they represent influential processes rather than temporary aspects may provide a means of understanding responses.

Emotional isolation (being isolated with emotions) was a pivotal concept that was not discussed in published literature. The important facet of this isolation was that it was independent of social contact. In other words, it did not arise from lack of social support, which has been shown as important for coping in other research (Dennison et al., 2009). Emotional isolation was revealed as either a conscious choice or an unintentional aspect of response and potentially subconscious. Being isolated with negative emotions also represented a dynamic and interactive aspect that could influence or moderate emotional responses. Isolation with future-oriented fear, in particular, was represented as potentially damaging and pervasive. Furthermore, this in-depth analysis revealed emotional processes of disruption or resolution that were not explored in any depth in literature on emotional response to MS. The concept of emotions as dynamic, interacting and persistent aligned with Wundt’s (1907) definition of an emotion resulting from a combination of interconnecting processes that could produce arousal at the time of the experience and thereafter. This was demonstrated particularly around future-oriented fear and resentment.
Links between emotional context and expression, thoughts and behaviour are summarised in Figure 8, which represents the emotional person as someone who may share their emotions on not. Emotional isolation could either create, or result from, a context within which the person dealt with feelings. This involved multiple influences or interactions. Throughout the narratives, responses to past, relatively current or future-focused emotions that had been dealt with could be re-awakened or disrupted. This fluctuation contributed to thoughts, conscious or not, behaviour in terms of active or passive responses and to external links with others. Emotional isolation was directly associated with the context in which the emotional person dealt with responses. Whether the emotional person elected to express or retain responses related to thinking and behaviour, both of which related to isolation.
Figure 8: Emotional responses to MS
Responses involve complex interacting influences with the person and emotional context.
2.7 Reflective account: Researcher position

Disclosing my position is important for transparency into influences on researcher-participant relations and the interpretative framework (Lincoln, 2010). I am a mature student, career-oriented, independent, married with strong views on shared responsibilities. I consider myself to be broad minded. I am aware of being talkative with characteristic openness, and conscientiously minimize this to a professional stance within interview situations. I have personal experience (ten years ago; she returned to family abroad five years ago) of a friend's diagnosis with Parkinson's Disease.

2.7.1 Research-interviewer-analyst perspectives

For the in-depth interview to be a viable forum for participant disclosure, exploration and consideration of personal experiences, the research interviewer has to establish a rapport with the participant. It could be argued that skills employed in the counselling interview, a therapeutic tool used by trained counselling psychologists, are valuable for data acquisition in in-depth interviewing in qualitative research (Coyle, 1998). Paraphrasing, summarising and reflecting back to the participant enable the researcher to confirm their understanding of what is said while facilitating “... conveying of the counselling attributes of empathy, genuineness and unconditional positive regard within the research interviews” (Coyle, 1998, p61).

I prepared for interviews by familiarising myself with aspects of MS, particularly physical disability. I visited the MS therapy centre to meet members and understand how I would react to physical disability. This was vital for me to feel at ease in interviews and understand assistance protocols. I learnt to respect participants' ownership of their physicality and not interfere by being over helpful.

I was aware of social positions and when my outlook was likely to influence my response I withdrew. There were two notable cases. The first was descriptions of relying on attractiveness to manipulate people/situations. The second was strong anti-Christian views from a participant with whom I had (unspoken) empathy for being stigmatised as Jewish. This participant described intimidating colleagues. In such situations, my withdrawal made me less empathetic and bland, thus reducing rapport and disclosure.
The first stages of data analysis in these cases was challenging. I had to listen repeatedly to reposition myself and avoid being unintentionally judgemental or shocked. Aware that I was irritated, I would question participants’ interpretations. Therefore, consciously noting my dissention was important for establishing my position in the process. Repeatedly listened to recordings, I was satisfied that I had not disclosed my views to participants; I had made ‘empathetic noises’, encouraged disclosure by summarising and reflecting my understanding. In turn, they had confirmed interpretations and in many instances expanded on them.

Following Gee’s linguistic analysis, I became aware that one participant was working incredibly hard to create a convincing narrative. Based on the linguistic characteristics, my interpretation was that she was aware that her interpretation was questionable: she perceived the use of a walking stick to inhibit her physical, female, attractiveness and this, in her interpretation, was why she was rejected. The more I engaged with the data, the more aware I became of my changing position. While I was not challenging her, I was not empathising readily. My facial expressions were probably bland and I remembered sitting back slightly, reducing the empathetic body language. The participant seemed ambiguous and aware of the potential weakness of her argument and interpretation.

2.7.2 Perspective on narrative selection

Extracting relevant narrative data heightened my awareness of my involvement as researcher, thus contextualising decisions is important to eliminate the following.

i) Researcher-participant interaction

Primarily through his wife, I had known one participant over a decade earlier. It was considered appropriate for him to contribute on the basis that his interview would be conducted last and that, in the event of embarrassment or any other overt influence from previous social contact, the interview could be terminated amicably by either of us at any stage. In the event, the interview proceeded appropriately without any conscious discomfort to either party.

However, I realised when transcribing and reviewing data that I held back when he contextualised his divorce in relation to MS. Whereas (as in other interviews) I would normally have reflected his responses to encourage disclosure, I blanked his proffered opportunities and moved on to another
topic area. Although the interview provided extensive rich data on other experiences, in this pivotal emotional area the social researcher-participant connection inhibited development of an open narrative.

ii) What constitutes expression of narrative?
Transcribing and reviewing data from one young participant highlighted her physiological difficulties speaking. I was neither aware of the problem beforehand nor prepared for this. As the interview progressed and I grew accustomed to the participant, I realised that speaking involved more physical effort than usual. While semantic verbal content was unimpaired, the tone, pace and flow were severely affected. Periods of loud, forced speech were sometimes physiologically induced rather than emotional. Similarly, quietness and minimal comments related to physical tiredness. Had I been aware of the problem in advance, I could have suggested a series of short interviews. The narrative disruption was evident as the recording was reviewed and the extent to which, in places, I had to finish, confirm or qualify (with reflective feedback) broken or unfinished sentences became clear. The data here were set aside because the narrative was disrupted by the collection method.

2.7.3 Support group influence: Consideration of sample bias
Participants were recruited from a support group. Therefore these narrative accounts represent the experiences and interpretations of people who have engaged with and considered their diagnosis and who have support. The heterogenous nature of the sample represents demographic and condition characteristics that are relevant to MS; however, the limitation of recruitment from a therapy group is that people who have not engaged with support are excluded. On the one hand, the sample could be considered to be in a better psychological position in terms of dealing with the chronic condition and data may under represent as well as over represent problematic issues. However, the opposite interpretation could be applied. The same critique could be considered of any self-selection sampling method or consent to involvement in research, particularly using qualitative methods.

2.7.4 Non-verbal narrative
Articulation is not the sole means of acquiring narrative data. Non-verbal narrative data collection includes blogs, emails, letters or diaries. The participant in question
said that she was an amateur singer: singing, composing, playing or selecting musical representations could have provided alternative forms of narrative expression. Visual arts, either one dimensional or in a sculptural form, describe narrative. Pluralistic methods of data collection offer opportunity for complementing verbal semantics with deeper interpretation that may be withheld in articulation, through reluctance, restrictions or inability.

2.8 Chapter Conclusion and Contribution to Understanding Adjustment to MS

This qualitative study found fear and emotional isolation or expression to be universal in complex responses to MS, particularly relating to uncertainty and lack of illness prognosis associated with diagnosis. While the extent of responses varied, such aspects could delay or disrupt engagement with the chronic condition and hinder coping. These findings suggest that the nature and extent of early fears, coping methods and longer-term outcomes should be subject to quantitative research to determine which aspects can be generalised.

The literature review revealed broad references to negative emotional responses but not detailed focus on anxieties and fears; therefore, in the light of findings from this study, further scrutiny of published research in this area is deemed prudent. A systematic review into negative emotional responses, particularly fear, should be undertaken for in-depth assessment of the current research status and to determine whether the findings of this study concord with, or can be qualified by, published work.

Are there other indications to support further study of these findings or, alternatively, are there suggestions (for example from secondary findings) in published research signposting alternative directions of enquiry?
Chapter 3

Systematic Review

Anxiety-related Responses and Adjustment to Multiple Sclerosis: A Systematic Review

3.1 Chapter Overview

Literature reviewed in chapter one provided evidence for poor psychological wellbeing in relation to MS, particularly anxiety and depression generally regarded as comorbid. Findings from a narrative study of experiences and responses in chapter two offered additional insight into negative emotional responses, particularly related to patient perspectives of uncertainty and fear. It seemed possible that complex emotional processes and extreme responses could persist to hinder adjustment.

The above magnified the concept of anxiety represented in the body of published literature and challenged some aspects of current models of adjustment. In order to determine whether there was any support for these findings, a systematic review was considered necessary for evaluating quantitative evidence more specifically relating to anxiety and more widely among periphery research as well as within main publications on psychological responses to MS.

This chapter presents an introduction to the background (section 3.2) followed by aims and objectives (section 3.3). Section 3.4 outlines the method. Findings and discussion are presented in sections 3.5 and 3.6, with limitations and conclusions discussed in sections 3.7 and 3.8.
3.2 Introduction

A narrative analysis of participants' accounts of experiences and responses to being diagnosed with MS (study one) identified four themes relating to past, present and future-oriented emotions that fluctuated in type and intensity. These were emotional isolation, future-oriented fear and resentment. Data suggested that complex emotional processes involved ongoing, and changing, resolution or disruption of interacting responses. Responses at diagnosis could seemingly trigger or influence long-term interactions that may negatively affect wellbeing. Findings potentially challenge accepted models of adaptation. There were no clear indications of possible explanations within the primary body of literature reviewed in chapter one. It was necessary to evaluate evidence around emotional responses further to assess the usefulness of perspectives in study one as either insightful or purely circumstantial.

Preparatory literature research indicated that MS is characterized by uncertainty and heterogeneity in terms of disease classification, symptoms and prognosis. As discussed in sections 1.5.1 and 1.5.2, although there is a large amount of evidence linking depression and MS, and broad general references to emotional responses, such as fear, anger and frustration, information on acute negative emotional responses is more limited. Further checking the research status of this area to decide whether conducting a systematic review was appropriate (or, indeed, whether the lack of published explanation was due to shortfall in preceding general literature research) indicated that studies on emotional responses are often based on broad design criteria, frequently with psychological responses as a secondary measure to physical outcomes. Published systematic reviews investigated aspects of psychological associations with adjustment, interventions and rehabilitation, but no reviews focused specifically on emotional responses.

3.3 Aims and Objectives

This review aims to investigate existing quantitative research into negative emotional responses to multiple sclerosis to assess evidence available on emotional responses and how, if at all, they may influence long-term adjustment. The findings will inform the approach to a quantitative study of emotional responses and transition.
Given the heterogeneity in research design in this field, the approach outlined by Khan et al. (2003) to structuring a research question was adopted. The following *a priori* structured research question was developed and framed to focus on exposure, population and outcome for the initial search: Are negative emotional responses to diagnosis with multiple sclerosis linked to later adjustment?

The exposure focus is diagnosis and/or emotional response, the population refers to those diagnosed with MS and the outcome is adjustment patterns/later adjustment. Initial search terms were devised to address these criteria and test the level of response. In order to reduce and tighten the search results, the research question had to be revised and more closely focused. The distinction between depression and other negative emotions was distinguished by limiting inclusion to work that included specific emotions as outcome measures, primarily anxiety, fear, distress, worry and sorrow. The aims of the review were tightened to focus more precisely and the three research questions were developed.

i) What is known about anxiety type responses (including fear, distress and worry) to MS?

ii) Are there indications of links between anxiety responses and adjustment?

ii) What theoretical explanations, if any, are highlighted in existing literature?

### 3.4 Method

#### 3.4.1 Search methods and inclusion criteria

Electronic database searches were carried out on the Cochrane Library; Medline; psychINFO; PsycARTICLES; PubMed; Web of Science; CINAHL; EBSCO; ProQuest: ASSIA, BNI, PILOTS; and ProQuest: medical and health. An initial set of five combinations of key words was used to test responses. These were revised and extended, with additional terms and different combinations, to provide a set of twenty key-word combinations.

**Initial exploratory set of key terms**

1. 'diagnosis', 'multiple sclerosis', 'emotional response', 'adjustment'
2. 'emotional affect', 'multiple sclerosis', 'emotional responses', 'neurological conditions'
Search terms: key word combinations

1. 'diagnosis', 'multiple sclerosis', 'emotional response', 'adjustment'
2. 'emotional affect', 'multiple sclerosis'
3. 'emotional responses', 'neurological conditions'
4. 'multiple sclerosis', 'anxiety', 'emotions'
5. 'multiple sclerosis', 'mood'
6. 'multiple sclerosis', 'depression'
7. 'multiple sclerosis', 'fear'
8. 'multiple sclerosis', 'emotion'
9. 'multiple sclerosis', 'denial'
10. 'multiple sclerosis', 'avoidance coping'
11. 'multiple sclerosis', 'avoidance coping', 'fear'
12. 'multiple sclerosis', 'adjust', 'emotion'
13. 'multiple sclerosis', 'future fear'
14. 'multiple sclerosis', 'self identity', 'emotion'
15. 'multiple sclerosis', 'uncertainty'
16. 'multiple sclerosis', 'stress'
17. 'multiple sclerosis', 'catastrophizing'
18. 'multiple sclerosis', 'optimism'
19. 'multiple sclerosis', 'negative affect'
20. 'multiple sclerosis', 'distress'

Key criteria for, and results of, preliminary searches (using initial exploratory terms) were recorded in an Excel file and this method was retained for all searches, with EndNote employed for reference management. Citation reports and associated publication reports were searched for missed references.

Results included empirical quantitative research papers and were limited to adult participation (over 18 years old), publication in peer-reviewed journals and in English. Exclusion by non-relevant criteria included, for example, animal studies, and biological research (drug trials). Systematic reviews, literature reviews and grey literature, such as conference papers, seminar and meeting reports, dissertations,
non-academic references and book reviews were excluded. Completion of this first stage of searching produced 25,581 results.

The process of reducing results began by limiting inclusion to publication post-1990, eliminating duplicates and checking for papers that had not been filtered successfully by electronic search criteria. Further refinement to papers with a primary focus on psychological factors reduced the results to 1,213. Reviewing abstracts indicated how criteria should be tightened to address the research question, for example with key focus on terms associated with 'health distress'. Applying this method over a further ten stages of refining reduced results to 867. By checking for general inclusion criteria, then focusing on search words such as 'fear', 'future', 'anxiety', 'worry', 'sorrow', 'chronic worry' and 'chronic sorrow', the results were reduced first to 102 and then to a list of 98 relevant papers. The abstracts were read and full text checked, as necessary, to exclude duplicate or off-topic papers, reducing results to 54. An additional 23 papers hand searched from reference lists and/or citations were reviewed. Final checks and discussion of inclusion criteria produced 57 results.

3.4.2 Quality assessment

Quality assessment focuses on internal validity, whether the research accurately addresses/measures the concepts indicated in the aims/hypothesis, external validity, in terms of generalisability, and statistical analysis (Verghagen, 1998).

In reviewing research with heterogenous approaches, applying a standard rating scale was not practical as direct numerical comparisons could not be made. Aspects were evaluated in terms of standard criteria as far as possible, for example fundamental points included the use of recognised outcome measures (or suitable formulation and testing of new measures) and appropriate application and interpretation of inferential statistics. For transparency and credibility in subjective assessments, each paper was assessed across six aspects covering key areas as appropriate to the particular paper. Aspects were rated on the overall clarity of appropriate information and graded at three levels.

i) Good level of clarity (G)

ii) Moderately clear but with some minor ambiguity (M)

iii) Poor clarity (P)
A poor clarity rating for key methodological or data processing aspects meant the paper should be excluded unless there was good explanation/reason for retaining the work. In addition to rating key aspects, where necessary, notes provided information on criteria for exclusion, or inclusion in spite of ambiguity or lack of clarity. Quality assessment ratings are tabulated in Appendix II. The rating table was referred to for evaluating aspects of individual papers when synthesising their influence, interpretation and contribution to the review findings. The following key aspects were appraised based on examples of points to consider as appropriate to each paper.

i) **Aims**: research question, hypothesis  
   - Appropriate and measurable concepts

ii) **Design**: appropriate design for research objective  
   - Design criteria / bias  
   - Outcome concepts  
   - Variables / confounding  
   - Valid measures  
   - Control or comparison groups

iii) **Sample, participants**: recruitment and description  
   - Inclusion/exclusion criteria  
   - Population, grouping  
   - Sample size  
   - Participant information: demographic/socio-demographic  
   - Condition information  
   - Ethical considerations

iv) **Procedure**: implementation  
   - Bias  
   - Data collection methods  
   - Follow-through consideration  
   - Response rate and attrition

v) **Data processing**: results, dissemination and evaluation  
   - Appropriate/informative descriptive statistics  
   - Appropriate inferential statistics and suitable interpretation  
   - Replicable evaluation
vi) Conclusion and discussion

Logical conclusions
Theoretical considerations and discussion
Appropriate evaluation of relevant limitations
Relevant implications and future focus

Following detailed evaluation, 26 papers were excluded, with key reasons for exclusion noted in the table. Exclusion was not necessarily indicative of extensive inferior rating; in the majority of cases, excluded papers were considered to provide useful background information but they were not suitably tightly focused on, or sufficiently detailed in addressing, the research aims of this review in terms of anxiety related responses. Research studies and/or findings from 31 papers were considered to be relevant to the aims and research questions of this review. Details of these papers are summarised in Table 4.

3.4.3 Data synthesis
When the topic for a systematic review has not been widely explored through standard approaches, and papers cannot be limited to research based on a particular method, with directly comparable measures and statistical analyses, the findings cannot be subject to meta-analysis. Instead, findings have to be described, grouped and compared in words, a method known as narrative synthesis. This method is used for collating and synthesising data from a systematic evaluation of heterogenous studies (Popay et al., 2006) by using an organised approach that respects the research aims and questions of the review as, for example, in the case of inclusion criteria.

This review seeks to collate findings from diverse studies. Searching revealed that data on anxiety responses to MS was often acquired as a secondary factor and not as a primary focus of research. There was no extensive body of homogenous research from which data on anxiety responses could be drawn and directly compared. Therefore the focus was on iterative dissemination, or construction of a story, of what the data indicate about existing knowledge of anxiety type responses to MS. Information on links with adjustment were evaluated and indicators of theoretical explanations included.
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<tr>
<td>14 da Silva (2011)</td>
<td>CS</td>
<td>Portugal</td>
<td>18-80</td>
<td>Men</td>
<td>325</td>
<td>HADS, MSSS, EDSS, MReg, LReg, MANOVA</td>
<td></td>
<td>Anx. and dep. significantly higher than for healthy controls. Age, MS duration, age at onset, EDSS and MSSS positively associated with dep. Low education in MS related to increased anx. and dep.</td>
</tr>
<tr>
<td>15 Dahl (2009)</td>
<td>CS</td>
<td>Sweden</td>
<td>18-80</td>
<td>Men</td>
<td>172</td>
<td>HADS, EDSS, KFSS, Chi-square, LReg</td>
<td></td>
<td>Anx. and dep. higher in MS participants than control and not correlated to duration or disability.</td>
</tr>
<tr>
<td>20 Fruehwald (2001)</td>
<td>CS</td>
<td>USA</td>
<td>18-80</td>
<td>Men</td>
<td>60</td>
<td>MSSS, EDSS, ZARS, ZESS, ZDRS, QoL index</td>
<td></td>
<td>Dep. and anx. correlated negatively to QoL. Duration not correlated with emotional state, dep., anx. or QoL.</td>
</tr>
<tr>
<td>21 Gay (2010)</td>
<td>CS</td>
<td>USA</td>
<td>18-80</td>
<td>Men</td>
<td>115</td>
<td>EDSS, ZDRS, STAI, SEI, TAS, CHIP, SSQ-8</td>
<td>P Corr, SEM</td>
<td>Functional status, trait anx., alexithymia and satisfaction with social support are predictors of dep. Trait anx. (predominantly) and function independently and simultaneously lead to dep.</td>
</tr>
<tr>
<td>22 Giordano (2011)</td>
<td>L</td>
<td>USA</td>
<td>18-80</td>
<td>Men</td>
<td>120</td>
<td>HADS</td>
<td>Multivariate linear mixed model</td>
<td></td>
</tr>
<tr>
<td>23 Goretti (2009)</td>
<td>CS</td>
<td>Italy</td>
<td>18-80</td>
<td>Men</td>
<td>104</td>
<td>BDI, STAI-Y, MSGoL</td>
<td>Sp Corr</td>
<td>Avoidance strategies adopted more frequently than problem-task-focus. Positive strategies positively influenced mental health and QoL.</td>
</tr>
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G6, M4, P1

G5, M1

G6, M1

G5, M1

G6, M1

G6, M1

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G6, M1
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<th>Study</th>
<th>Design</th>
<th>Sample Size</th>
<th>Duration</th>
<th>Sample Characteristics</th>
<th>Tools Used</th>
<th>Statistical Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janssens (2003)</td>
<td>P</td>
<td>37.5</td>
<td>7.8 moths</td>
<td>78 partners</td>
<td>IES SF-36, HADS</td>
<td>ANOVA, t-test</td>
<td>Dep. negatively impacted on QoL and anx. on mental domains.</td>
</tr>
<tr>
<td>Jopson (2003)</td>
<td>CS</td>
<td>50.6</td>
<td>11.5</td>
<td>78.8%</td>
<td>AI, IPQ-R, HADS, SIP</td>
<td>MReg</td>
<td>Illness representations: identity/lack of coherence associated with anx.; severity of consequences related to dep.</td>
</tr>
<tr>
<td>Lester (2007)</td>
<td>CS</td>
<td>82</td>
<td>7</td>
<td>51%</td>
<td>EDSS, HADS, MSIS, SEMCO, INR, MSNSQ</td>
<td>MReg</td>
<td>Dep. related to physical severity, self representations, cognitive impairment and perceived illness management. Anx. not related to perceived illness management. Anx. and dep. separate aspects.</td>
</tr>
<tr>
<td>McCabe (2005)</td>
<td>L</td>
<td>243 (m), 44.86 (f)</td>
<td>45.27</td>
<td>184 WOCQ, POMS-SF, WHOI-100</td>
<td>MANOVA, Reg</td>
<td></td>
<td>Exacerbation increases anx. but dep. and self-esteem were not increased. Increased anx. and confusion from exacerbation persist for 18 months. Non-exacerbation group associated with lower problem-focused coping and higher detachment. No association between coping strategies, mood and self esteem after initial post-exacerbation levels at 6 months, suggesting responses stabilize and persist over 18 months.</td>
</tr>
<tr>
<td>Study</td>
<td>Type</td>
<td>Measure</td>
<td>Method</td>
<td>Note</td>
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<tr>
<td>39 Neter</td>
<td>CS</td>
<td>101 41.21 7.16 - - - - - -</td>
<td>EDSS, IIIRS,</td>
<td>Engagement with goals related to mental</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(2009)</td>
<td></td>
<td></td>
<td>HADS, PIL,</td>
<td>wellbeing in terms of dep. but not anx.,</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>IPQ, MReg</td>
<td>illness intrusiveness and purpose in life.</td>
<td></td>
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<tr>
<td>41 Pakenham</td>
<td>L</td>
<td>402 47.77 9.77 73% 27% chronic progressive</td>
<td>M PAI-cog,</td>
<td>High disengagement and low re-engagement</td>
<td></td>
<td></td>
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<tr>
<td>(2006)</td>
<td></td>
<td></td>
<td>SCL-90, BABS,</td>
<td>related to dep. and low disengagement and</td>
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<td></td>
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<td>SWLS, CMSS</td>
<td>re-engagement related to least dep. Disease</td>
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<td></td>
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<td></td>
<td>Corr, ANOVA,</td>
<td>severity not related to psychological</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>MReg</td>
<td>outcomes.</td>
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<tr>
<td>45 Poder</td>
<td>CS</td>
<td>245 45.1 14.4 172 57 16 - -</td>
<td>EDSS, HRQoL/HUI,</td>
<td>Health control, emotional release and</td>
<td></td>
<td></td>
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<tr>
<td>(2009)</td>
<td></td>
<td></td>
<td>SPIN, HADS,</td>
<td>physical assistance related to positive</td>
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<td></td>
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<td>SPMS, CAGE</td>
<td>outcomes. Avoidance predicted distress and</td>
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<td></td>
<td></td>
<td></td>
<td>Chi-squ, t-test,</td>
<td>was related to dep. and anx. Acceptance</td>
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<td></td>
<td></td>
<td></td>
<td>Mann-Whit, Sp</td>
<td>related to positive outcomes and distress.</td>
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<td></td>
<td></td>
<td></td>
<td>Corr</td>
<td>Avoidance weakly assoc with anx. Higher</td>
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<td></td>
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<tr>
<td>48 Smith</td>
<td>CS</td>
<td>88   46 12 - - - -</td>
<td>HADS, BDI, BI,</td>
<td>Social anx. in just over 30% and comorbidity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2000)</td>
<td></td>
<td></td>
<td>RS</td>
<td>with general anx. and dep. No association</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td>Odds ratio, Sp</td>
<td>with disease severity – may indicated</td>
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<td></td>
<td></td>
<td></td>
<td>corr</td>
<td>influence of anticipated symptoms/uncertainty. Lower MS stability among Ps with soc. anx.</td>
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<tr>
<td>49 Solarii</td>
<td>P</td>
<td>205 46.9 16.7 - - - -</td>
<td>MSQoL-54, CMDI,</td>
<td>Dep. (17% case, 34% borderline from HADS; 39%</td>
<td></td>
<td></td>
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<tr>
<td>(2005)</td>
<td></td>
<td></td>
<td>SF-36, Chi Squ,</td>
<td>case, 47% borderline from BDI) associated with higher perceived disability than GP assessed disability. Anx. at case level in 34%; including borderline anx. increased this to 41%. Dep. associated with anx. in two-thirds of dep. (based on BDI)</td>
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<td></td>
<td>ANOVA, K Wall,</td>
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<td></td>
<td>Wilcoxon, Sp Corr</td>
<td></td>
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<tr>
<td>51 Szelasi</td>
<td>CS</td>
<td>147 36.1 8.4 88 21 5 - -</td>
<td>SF-36, EDSS,</td>
<td>Disability, fatigue and dep. related to</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(2011)</td>
<td></td>
<td></td>
<td>HADS, FSS</td>
<td>physical health status. Anx. dep. and disease</td>
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<td></td>
<td></td>
<td></td>
<td>Reg</td>
<td>course related to perceived mental health</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>status. Dep. and anx. undetected and undertreated.</td>
<td></td>
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</tr>
<tr>
<td>52 Uğuz</td>
<td>CS</td>
<td>74   34.57 5.47 74: 42 in exacerbation; 32 in remission</td>
<td>SDI-1, EDSS, t-test, chi- squ, LReg</td>
<td>Mood and anx. disorders in 40.5% and 45.9% Ps compared to 7.9-20.8% and 10.4-28.8% in general population. Dep. most common</td>
<td></td>
<td></td>
<td></td>
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<td>(2008)</td>
<td></td>
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</table>
psychiatric disorder in MS. Limited data on prevalence of anx. disorders available among MS patients. Dep., panic disorder, OCD and any mood and anx. disorder associated with exacerbation. Exacerbation phase and disability level predicted dep. exacerbation and shorter disease duration predicted anx.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N</th>
<th>Gender</th>
<th>Age</th>
<th>Duration</th>
<th>Primary Measure</th>
<th>Other Measures</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Pfennings (1998)</td>
<td>CS</td>
<td>70</td>
<td>M</td>
<td>48.4</td>
<td>17.7</td>
<td>-</td>
<td>47</td>
<td>30</td>
</tr>
<tr>
<td>Zorzon (2001)</td>
<td>CS</td>
<td>95</td>
<td>M</td>
<td>39.5</td>
<td>9.8</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dennison (2010)</td>
<td>CS</td>
<td>94</td>
<td>M</td>
<td>41.7</td>
<td>3.8</td>
<td>73</td>
<td>9</td>
<td>12</td>
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</table>

**NOTE** Anx. = anxiety; dep. = depression. See Appendix II for abbreviations.
3.5 Findings

Sample size was modest and, apart from one study with access to a medical database for 8,983 participants, the mean number of participants among the remaining 30 studies was 138.4 (range 20 to 402). Of 31 studies, 23 were cross-sectional in design and there were four each of longitudinal and prospective design. Among the cross-sectional studies, one sampled participants with average illness duration in months of 17 (males) and 16.2 (females); two did not provide duration information and among the remaining 20, the mean MS duration since diagnosis was 9.6 years (range 7 to 18.9 years). Acquiring consistent diagnosis definitions is difficult due to the nature of MS, individual interpretation and understanding, and the international context of studies, which can contribute to the use of different terminology and diagnosis criteria. This could explain why eight studies did not provide summary information on type, stage or phase of MS. Fluctuating and/or progressive disease characteristics mean that applying overall or average terms for longitudinal and prospective studies is not practical; similarly, illness duration is defined within studies.

Control groups were used in six studies and comparisons with database-sourced general population statistics were applied in two other studies. Lack of control groups was not necessarily indicative of poor quality research as studies were not experimental (or quasi-experimental) in design and potential confounding variables were identified, measured and subject to statistical analyses in some papers. In other papers, while comparison with general populations provided some benchmark against which to consider findings, its comparative usefulness was limited, for example due to relative sample size and lack of definition of aspects such as cultural or social factors. Measurement and analytic tools were evaluated for all studies and Appendix II provides table summarising the studies and quality assessment in terms of total number of good, medium or poor clarity ratings across all six criteria.

The overall impression is that, while the studies provide useful information and credible indicators, they do not represent a strong body of comparable work providing specific evidence on anxiety and adjustment that could be broadly generalised to MS patients. However, there were strong indicators of relevance of anxiety and depression, how psychological comorbidities between these could relate to MS and their potential origins. The findings are disseminated under five themes as defined overleaf.
Depression and anxiety among MS patients was found to be higher than among healthy controls and, generally, there was comorbidity of depression and anxiety (Anhogue et al., 2011 [3]; Beiske et al., 2008 [5]; McCartney Chalk, 2007 [13]; da Silva et al., 2011 [14]; Dahl et al., 2009 [15]). Pakenham (2006) [41] and Giordano et al. (2011) [22] found anxiety and depression to be highly significantly correlated; however, marked differences for the two according to diagnostic period were evident in the Giordano et al. study. Clinically isolated syndrome (CIS) refers to the phase after the first neurological demyelination event but preceding confirmation of MS diagnosis. In a comparison of patients with CIS and MS, Anhogue et al. (2011) [3] found that depression and anxiety scores in the CSI group were not significantly different from scores for healthy controls.

While Marrie et al. (2009) [37] found mental comorbidity in 48% of MS patients, with 46% depression and 16.5% anxiety regardless of disease factors, Beiske et al. (2008) [5] found depression to be twice as frequent and anxiety to be three times as frequent among MS patients compared to controls. Gay et al. (2010) [21] found higher percentages of anxiety than depression, particularly at more severe levels and for trait anxiety scores: 36.4% participants demonstrated state anxiety, of which 20.4% were at moderate, 10.6% high and 5.4% at very high levels; trait anxiety was higher at 43.8%, with 28.6% at moderate, 13.4% high and 7.1% at very high levels. These compared to depression at 25.9%, with 20.5% at moderate and 5.4% at severe levels. Other papers also indicated greater anxiety than depression (Anhogue et al., 2011 [3]; Brakjovic et al., 2009 [9]; da Silva et al., 2011 [14]; Dahl et al., 2009 [15]; Giordano et al., 2011 [22]; Janssens et al., 2003 [26]; Uguz et al., 2008 [52]; Vleugels et al., 1998 [53]). Poder et al. (2009) found 30% of MS patients demonstrated clinically significant social anxiety symptoms that were correlated
with general anxiety and depression. According to Brakjovic et al. (2009) [9] there was no isolated depression without anxiety.

Among demographic variables, indications of gender differences were inconsistent, with higher anxiety and/or depression reported among female participants in some studies (McCartney Chalk, 2007 [13]; da Silva et al., 2011 [14]; Giordano et al., 2011 [22]; Janssens et al., 2006 [27]) but not in others (Beiske et al., 2008 [5]; Benito-Leon, Morales & Rivera-Navarro, 2002 [6]; d'Alisa et al., 2006 [16]; Gay et al., 2010 [21]; Jopson & Moss-Morris, 2003 [30]; Lester, Stepleman & Hughes, 2007 [35]; McCabe, 2005 [38]; Uguz et al., 2008 [52]). Education negatively correlated with anxiety and depression, with low education significantly associated with more anxiety and depression (da Silva et al., 2011 [14]). Based on previous research indicating higher levels of neuroticism and personality influencing coping strategies among MS patients, and with little existing research into personality temperament and MS, Goretti et al. (2009) [23] investigated the influence of depression, fatigue and anxiety alongside personality. Depression and anxiety correlated with neuroticism traits. MS patients scored higher on psychoticism-socialization, associated with indifference, antisocial behaviour and aggressiveness; however, by contrast, they also scored high on lie sub-scales (which measured socially desirable factors).

3.5.2 Disability, disease progression and duration

While there is long-established evidence for psychological comorbidities with MS, the reasons are unclear and findings on relationships between condition status and psychological factors are inconsistent. Anhoque et al. (2011) [3] suggested that anxiety and depression related to MS severity, with no significant difference between anxiety in CIS and controls but increased anxiety in MS participants and positive correlations between depression, anxiety and disability.

There was evidence for increased negative emotions among recently diagnosed patients and their partners (Janssens et al., 2003 [26]). The increase in depression among partners was not as high as among patients but there were similar increases in levels of anxiety, suggesting anxiety was subject to psychological not physiological processes. In patients, higher anxiety and depression were associated with higher physical disability; in particular, higher intrusion and avoidance were associated with increased physical disability. In partners, anxiety, depression and quality of life were not related to patients' physical disability. Results indicated lower quality of life at
8 months after diagnosis for MS patients compared to controls and, although levels were related to higher disability, reduced quality of life was also evident even when scores indicated low or no disability. Further evidence of different causes of depression and anxiety was presented in an investigation of the relationship between the involvement of brain areas and depression and anxiety by Zorzon et al. (2001) [56]. Comparing MS patients with others diagnosed with alternative chronic illnesses and with healthy controls, Zorzon et al. found similarity of frequency of depression and anxiety between illness conditions that differed from healthy controls, suggesting psychological responses. However, MRI evidence of brain abnormalities relating to depression but not to anxiety indicated that organic brain damage could contribute to depression while anxiety could be a reaction to psychological factors.

While some studies indicated that increased depression and/or anxiety were associated with disability and disease progression factors (Gay et al., 2010 [21]; Benito-Leon, Morales & Rivera-Navarro, 2002 [6]; da Silva et al., 2011 [14]), levels of depression and anxiety did not consistently concord, with indications that psychological outcomes were not necessarily associated with physical effects. Lester, Stepleman and Hughes (2007) [35] proposed that depression and anxiety were related to physical severity and self-reported cognitive impairment but, while depression was also related to perceived illness management variables, anxiety was not. Therefore anxiety and depression could occur through different processes. Furthermore, self-reported perceived illness status may reflect individual interpretation rather than clinical levels of physical illness status, suggesting that depression could contribute to perceived reduced physical functionality rather than arise from it.

There was some evidence for anxiety and mental health being unrelated to disability (McCartney Chalk, 2007 [13]; Giordano et al., 2011 [22]). Giordano et al. (2011) [22] indicated that, whereas depression occurred later in the disease, anxiety could be related to early distress and difficulty in adjusting to a chronic disorder; however, this was related to coping strategies rather than disease subtypes. A study by d'Alisa et al. (2006) [16] found that neither physical nor mental scores related to MS subtypes, gender or marital status. Research highlighted differing associations and interactions between physical symptoms and depression and/or anxiety, including fatigue and pain, younger age and lower disability (Beiske et al., 2008 [5]; Dahl et al., 2009 [15]; Fruehwald et al., 2001 [20]).
Benito-Leon, Morales and Rivera-Navarro (2002) [6] indicated that reduced quality of life and decreased cognitive functioning were associated with MS severity, progression and duration. Higher depression, anxiety and disability correlated with lower quality of life. Fruehwald et al. (2001) [20] also found depression and anxiety to be highly correlated with self-assessed quality of life, in which depression and anxiety were strong predictors of quality of life. The role of mood in determining quality of life regardless of disease severity was emphasised by d'Alisa et al. (2006) [16], with depression predictive of lower quality of life on physical dimensions in patients who demonstrated less severe disability levels. Lower mental outcome scores for quality of life related to higher anxious and depressive scores.

3.5.3 Psychological factors as predictors
In a longitudinal study of patients and partners, Janssens et al. (2006) [27] found that, among patients, levels of anxiety, depression, intrusion and avoidance at baseline all related to levels at 24-month follow up; however, in partners, levels of depression were not as high at 24 months. Anxiety following diagnosis remained unchanged even though disease-related distress decreased over 2 years and levels of anxiety at diagnosis predicted later anxiety at a 2-year follow up. Giordano et al. (2011) [22] also found anxiety at baseline to be associated with – and predictive of – later depression.

Studying the influence of anxiety in a trial of psychotherapies for depression, Burns et al. (2010) [11] found that although comorbid anxiety and depression did not adversely influence improvement during the actual treatment programme, mixed findings were reported at follow-up stages. Breaking anxiety factors down into distress and fear revealed long-term influences, with distress disorders at baseline associated with higher anxiety during and after treatment. Baseline fear disorders were related to later depression. Gay et al. (2010) [21] found that depression was provoked by trait anxiety more than by functional status and social support. In a proposed model (see Figure 9) explaining 57% of the variance in depression, trait anxiety contributed to feeling low satisfaction with social support and it reinforced or interacted with alexithymia.
Figure 1. The causal path model. The values on the arrow represent the standardized path coefficients.

Figure 9: Gay et al. (2010) [21] model of variance, indicating strength of relationship between state anxiety and depression

Researching mood and self esteem following an exacerbation, McCabe (2005) [38] found that anxiety and confusion increased (and remained higher for 18 months) but depression and self esteem did not change, suggesting that established differences remained the same. Coping variables did not predict mood: only levels of relevant mood variables at time 1 predicted follow-up levels at time 2.

3.5.4 Adjustment and coping
As a pilot indicator, a small-scale study suggested that depression correlated with emotion coping; uncertainty about the future correlated with fatalistic coping; and depression correlated negatively with optimistic coping Buelow (1991) [10]. Brakjovic et al. (2009) [9] explored the relationship between coping strategies and anxiety and depression among delegates at a symposium of MS patients. Humour,
and positive reinterpretation and growth negatively correlated with depression. Denial, avoidance and behavioural disengagement correlated with increased anxiety while humour negatively correlated with anxiety. In a short-term prospective study, Pakenham (2006) [41] found that appraised stress in terms of illness events correlated to higher distress (anxiety and depression), which correlated with lower life satisfaction, avoidance, anxiety and depression. The unique coping predictor of distress was avoidance, with a small but significant correlation with anxiety. Acceptance was correlated to positive outcomes and negatively related to distress. Similarly, McCartney Chalk (2007) [13] found high anxiety related to low problem-solving coping. Problem solving and acceptance were associated with positive adjustment and less reliance on harm/threat appraisals. Giordano et al. (2011) [22] found evidence for depression as a consequence of decreased active coping.

3.5.5 Distress and uncertainty: Fear, threat and intrusion

Buelow's (1991) [10] pilot work into stressors and coping methods indicated both physical and psychosocial difficulties as sources of increased stress, including fatigue and uncertainty about the future. In a cross-sectional study of 168 MS patients, Jopson and Moss-Morris (2003) [30] indicated that illness representations were important contributors to adjustment. Lack of illness coherence and understanding of MS related to anxiety. Increased illness identity, in terms of broad attribution of possible symptoms to the condition, related to increased anxiety and worsening of the condition in terms of fatigue levels. Perceptions of inaccurate illness prognosis and outcome also influenced adjustment, with the potential for serious consequences related to depression.

Janssens et al. (2004) [28] studied understandings of MS prognosis among 101 participants compared with measures of distress in terms of avoidance and intrusion. Higher perceived lifetime risk (10 years) related to higher distress in terms of intrusion. Higher perceived short-term risk (2 years) was significantly related to anxiety, depression and distress. Investigating factors contributing to anxiety and depression among 82 patients, Lester, Stepleman and Hughes (2007) [35] found perceived cognitive impairment related to anxiety and depression; however, perceived impairment was higher than actual (measured) impairment. While depression was also related to perceived ability to manage MS, self efficacy was not but intrusiveness was, and anxiety was not related to illness management.
In a longitudinal study of 102 patients, Burns et al. (2010) [11] explored the impact of anxiety on the effectiveness of psychological intervention for depression. During treatment, patients with raised anxiety improved to the same extent as those without. However, by separating out distress and fear factors, distress disorders were related to increased anxiety during and following intervention. Patients with baseline comorbid fear demonstrated more depression at follow up while those who had not demonstrated fear continued to improve in terms of depression.

3.6 Discussion

This systematic review was undertaken when preliminary literature researches for background on associations between MS and emotional responses revealed large volumes of brief but non-specific information. The aim was to establish the status of published research into emotional responses to MS. Unmanageable volumes of results from exploratory searches indicated that the term 'emotional responses' was too broad and the aims were then more closely defined in terms of three research questions. What is known about anxiety type responses (including fear, distress and worry) to MS; are there indications of links between anxiety responses and adjustment; and what theoretical explanations, if any, are highlighted in existing literature? Again, first searches exposed a large volume of information on negative emotional responses, primarily depression and secondly, to a far lesser extent, anxiety. With results of over 25,000 and no immediately clear criteria among the papers for division according to type of research, the review progressed by systematically evaluating the different factors and aspects in research approaches to psychological aspects of MS. Taking an overview of the prolific work on depression revealed the complexity of the condition as comorbid to MS, no only from its definition, assessment and measurement, consequences and implications, but more importantly the multiplicity of factors contributing to its aetiology.

Continuously referring back to the aims of the review also focused attention on emotions: emotional responses and how an 'emotion' is defined. Depression presented as a potential consequence of emotional responses. While most papers bolted depression and anxiety together, there were separate indicators of anxiety involving distinct emotions. This effectively channelled the search, providing criteria for honing down the results. As comorbid psychological responses, depression and
anxiety were frequently measured using complementary tools, analysed and discussed as a unit. However, reviewing abstracts and further spot checking occasional papers suggested that depression and anxiety were not inextricably linked but that they could potentially be subject to etiological and prognostic differences. Throughout the papers, the need for further research into psychological comorbidity of depression and anxiety was highlighted, with particular emphasis on the lack of research into anxiety, and both factors cited as under researched, under diagnosed and under treated.

3.6.1 Aetiology of psychological comorbidities

In spite of frequently (initially) approaching psychological responses as a single unit, papers demonstrated that comorbidity of depression and anxiety was not necessarily based on aetiological similarity. Depression was likely to result from multiple factors, both physiological and psychological. MRI scans indicated that depression could relate to cerebral lesions and regional atrophy, including frontal lobe damage. Although there were no associations between MRI evidence of damage and anxiety, the lack of specific MRI research on this topic was noted. Depression could also be associated with drug treatment (and a majority of research that was excluded from the review studied drug trials) and fatigue. Comparative measures of MS patients and carers also suggested that while depression in patients and not carers could relate to physiological factors, anxiety was found in both carers and patients. Overall the data provided good indicators that depression and anxiety were different aspects that should be subjected to separated research. An important point for future consideration was evidence of anxiety as a predictor of depression.

The potential for anxiety as reactance was suggested by associations with diagnosis and experience of exacerbation, and related to uncertainty and the unpredictability of symptoms. Socioeconomic and education status were associated with anxiety and depression, with lower education levels linked to higher anxiety and depression. Alexithymia, a term for disrupted emotional processing, is associated with MS but in borderline cases an alternate explanation to neural damage could be the known link between alexithymia and somatic disorders, particularly depression. This creates a focus on external thinking that could relate to failure to use appropriate coping, with over reliance on emotion-focused coping.
3.6.2 MS factors, phase and duration
Authors highlighted the need for prospective or longitudinal studies to map disease course, coping and contributory factors. There are few epidemiological studies specifically related to MS but some evidence that education and socio-economic factors influence psychological responses; however, whether these are MS specific is questionable. Common symptoms, such as fatigue and pain, were related to psychological responses. There were indications that baseline fear related to increased stress, that anxiety following diagnosis could endure to become chronic. Increased stress was potentially linked with poor illness prognosis and less remittance. (Among excluded papers, searches indicated research into the influence of everyday stress on physiological prognosis, such as work and financial problems, social and marital factors, rather than illness-related stress and psychological implications.) The concept of chronic uncertainty was proposed and there was evidence that lack of illness coherence related to anxiety, while illness perceptions and identity linked with depression.

Much-needed research into specific phases is clearly hindered by diagnosis involving a long 'process', unpredictability of relapse and symptom patterns, and the practicalities of recruiting and retaining participants for lengthy studies. The research is also complicated by the fact that people with MS are not necessarily 'ill' and that, as demonstrated from findings among papers reviewed, lack of clear illness boundaries means that individual illness perceptions and identity are potentially influential in psychological responses.

3.6.3 Implications for adjustment
Psychological adjustment relates to appropriate coping, broadly categorised as emotion-focused or problem-focused coping. MS is complex and individual, therefore coping should not be simplified to suggest that specific approaches are more successful than others. Both emotion- and problem-focused approaches were presented as relevant, for example, an emotion focus can protect against failure of problem-focused attempts in the face of symptom fluctuation and uncertainty. Although benefit finding was indicated, resilience was not, yet this could also be important, especially in relation to evidence that disease duration was not associated with psychological problems. Opinion on the relationship between disability and depression was divided, with conflicting evidence; however, duration and the certain deterioration associated with primary progressive MS was potentially less
psychologically disruptive than secondary progressive, which followed on from relapsing remitting MS. The suggestion was that becoming accustomed to the condition promoted coping and this concurs to some extent with the concept of acceptance. Conversely, there was no doubt that avoidance and denial were maladaptive, not dealing with stress was problematic and, ultimately, an inability to find some resolution to poor psychological responses could be related to suicide levels among MS patients.

Illness beliefs and behaviours correlated with adjustment, with unhelpful beliefs and behaviours related to distress. Reinforcing the notion of coping explained by more than a single model of response, behaviour and outcome, the idea that a generic illness identity influenced adaptation was suggested through several indicators. Possibly constructed before physical symptoms have real impact (and relating to perceptions of symptoms, control and management), these beliefs and identity could predict impact. Dysfunctional assumptions and negative emotions could evolve, with maladaptive adjustment in terms of avoidance and over reacting and physically submitting or fighting without regard for balance.

3.6.4 Limitations of reviewed research

Methodological limitations were evident in that the majority of studies were cross sectional, making it difficult to map disease progression and contributing factors, particularly in the context of MS having an individual prognosis. Sample sizes were small and therefore most were correlation studies; some did include regression analysis and modelling analysis; however, the results were mainly associative and there was a lack of causative evidence.

There were suggestions that measures used were not sufficiently specific for MS or that they over or under estimated results. HADS was considered suitable for MS as it did not include somatic criteria, but was therefore criticised as under evaluative, while BDI included somatic aspects, such as tiredness (which is common in MS), and therefore over estimated results. Some studies included clinical measures but the majority were self report and some researchers highlighted the difficulty of achieving accurate estimation, particularly of cognitive ability where participants were found to underestimate their ability compared to clinical tests. This could relate to backward comparisons of 'how things used to be'.

Data collection included on line and paper methods but the context varied, making comparisons across studies difficult. Some participants were recruited during
in-patient stays in hospitals or clinics, others when attending out-patient clinics because of current needs for medical attention, and others were recruited through support associations. Those not engaging with organisations were generally not represented. Thus, the circumstances varied widely in terms of general 'condition well being' at the time of response. Those in a post-exacerbation hospital phase may have felt less stressed and more secure or, conversely, participants visiting a clinic because of current MS-related problems may have presented a stressful phase.

Although key terms exist for types of MS, definitions and criteria vary and the studies were international. Cultural differences also influence the availability of services and support and responses to conditions such as MS.

The research was not designed to study and measure emotional responses. Investigations of psychological implications were based on broad aims and, in many studies, psychological factors were contributory rather than cited among primary research aims.

3.7 Limitations of This Review

The topic breadth and lack of quantitative studies specifically investigating psychological affect meant that refining the research was a lengthy and complex task. A pre-review stage could have sought opinions of MS experts on how current MS research could be categorised to assess the contribution of psychological factors. Practicalities and purpose made this an unrealistic option, so detailed search records and criteria for refining and directing the review were discussed at each stage.

The heterogeneity of papers meant that quality assessment and data dissemination could not be categorical and rated objectively. Criteria for assessing papers were produced in detailed form, piloted against a sample of papers, discussed and revised to provide suitable guidelines.

Research reviewed is from published sources, which excludes 'grey' data and unpublished or on-going work that may contribute. The review could be extended to research the status of on-going work in the field and seek further opinions from authors of the included papers.
3.8 Conclusion and Contribution to Understanding Adjustment to MS

This systematic review suggests that emotional responses are potentially important in adjustment following diagnosis with MS. The review highlights the dearth of robust quantitative studies focussed on emotions and general agreement on the need for further research into psychological responses. The vital contribution is to reveal early indications that anxiety and depression may be aetiologically unrelated.

This supports the current research focus into anxiety responses. Insights into patient-centred perspectives on anxieties and future-oriented fear in study one are seemingly worth further study and could usefully be subject to general measurement. Study two will quantitatively evaluate negative emotional responses, including general and specific aspects of anxiety.
Chapter 4

Study Two

Anxiety Responses to Multiple Sclerosis:
Potential predictors of poor adjustment and coping

4.1 Chapter Overview

The first qualitative study indicated future-oriented fear following diagnosis and emotional isolation were potentially influential for long-term coping. Findings from study two, a systematic review of quantitative research into emotional responses, highlighted anxiety as an under-investigated response. This chapter presents a quantitative study of emotional responses to diagnosis, current coping strategies and current general psychological wellbeing. The introduction (section 4.2) discusses relevant background; section 4.3 outlines aims and objectives; and section 4.4 presents the study method. Sections 4.5 and 4.6 present results (descriptive and regression statistics respectively), followed by a chapter discussion in section 4.7 and conclusion in section 4.8.
4.2 Introduction

Study one defined four themes relating to past, present and future-oriented emotions indicated that they fluctuated in type and intensity. Complex emotional processes involved ongoing (and changing) resolution or disruption of interacting responses. Furthermore, responses at diagnosis seemingly influenced long-term interactions that, in turn, negatively impacted on long-term wellbeing.

4.2.1 Theoretical background

Qualitative findings concurred with long-established theories on avoidance and denial that are consistently relevant to MS. Shontz (1975) proposed stages of shock; despair and helplessness; retreat and denial; with retreat and denial being temporary, and avoidance-coping phases leading to reorientation and acceptance. Leventhal's (1980) cognitive self-regulatory model proposed a three-stage dynamic of interpretation leading to coping in terms of avoidance and/or approach coping, followed by appraisal. Roth and Cohen (1986) summarised a dynamic and simultaneous process of approach or avoidance coping, with one or the other selected to primacy according to different threat. Taylor (1983) suggested that cognitive adaptation involved finding meaning, mastery and restored esteem. Sharpe and Curran (2006) highlighted adjusting as necessary for coping, finding meaning and quality of life, and proposed an integrated model of adjustment and re-assessment of identity as long-term, not limited to diagnosis. Importantly, concealing early symptoms to delay adjustment could create future-oriented fear.

Emotional responses included fear, guilt, sadness, disgust and regret (Bury, 1982). According to Moos and Shaefer (1984), unexpected illness, particularly the uncertainty of MS, created disruption, fear and crisis. Universally expressed fear dichotomized into present (short term actual threat) and future (potential or anticipated threat) as outlined by Sharpe and Curran (2006). Future-oriented fear could hinder coping, and being unable to engage effectively with an individual condition created isolation and vulnerability. Data indicated a coping framework could be constructed within the limitations of MS. Piecemeal engagement and emotional responses could result in understanding, acceptance and management. Identifying controllable or uncontrollable aspects supported problem-focused or emotion-focused strategies (Lazarus & Folkman, 1984).
4.2.2 Existing research

Due to relapsing-remitting being the most common diagnosis, with minimal symptom presentation sometimes occurring for a long period following diagnosis, existing research overlooks the potential for problems in early stages following diagnosis. The focus on first relapse means an important opportunity for promoting early engagement with MS is missed. Findings from the qualitative study suggested that early avoidance and/or unrealistic engagement could set an unsuitable pattern for the future.

In a key systematic review considering psychological adjustment (Dennison, Moss-Morris, & Chalder, 2009), evidence of relationships among multiple psychological factors was assimilated and perceived stress, uncertainty and emotion-focused coping were related to poor adjustment. Dennison et al. drew on Beck's cognitive model of emotional disorders (Beck, 1976, as cited in Dennison, Moss-Morris, & Chalder, 2009, p. 151) to propose a tentative model of adjustment (see Figure 10). Strongly evidenced concepts included associations between positive reappraisal, problem-focused coping and high perceived social support and positive adjustment. High perceived stress, uncertainty and avoidance coping related to adjustment difficulties.

A systematic review of published papers indicated a gap in the research: the majority of research focussed on the pathology of MS, particularly neurological studies and drug-treatment trials, with psychological responses frequently sought as secondary responses to broad psychological constructs. Funnelling review findings to distinguish between depression and other negative emotions identified 1) depression as broadly defined and 2) correlating psychological factors grouped for simplified dissemination of overall constructs. There was strong evidence for comorbidity of anxiety and depression with MS, levels of anxiety sometimes exceeded those of depression and depression did not occur in isolation. Although existing research explored anxiety and depression as joint factors, findings suggested they are subject to separate processes. Anxiety was under researched compared to depression, with a need for separate studies exploring processes and responses at
Figure 10: A working model of adjustment to MS (Dennison et al., 2009)

different disease stages. Therefore the current study evaluates associations between anxiety at diagnosis and adjustment in terms of coping as proposed in Figure 11. Anxiety at diagnosis can create future-oriented fears and isolation with anxiety leads to avoidance coping. Anxiety may be resolved through emotional integration (and expression) to allow engagement and problem-focused coping. Renewed anxiety can disrupt emotions to provoke further avoidance. However, avoidance can be resolved through emotional integration.
4.3 Aims and objectives

This study aims to evaluate anxiety responses to diagnosis and the long-term implications for psychological wellbeing. Based on literature reviewed and findings from study one, anxiety is potentially associated with poor long-term adjustment, especially in the context of being emotionally isolated with future-oriented fears. Avoidance coping is associated with poor adjustment while problem-focused coping relates to positive adjustment.

It is proposed that anxiety is associated with maladaptive coping strategies, such as long-term avoidance, and that low levels of emotional support are associated with adverse coping. In other words, emotional integration, or seeking emotional support with future-oriented anxieties, will reduce unhelpful coping. Key objectives of this study can be summarised as follows.

1 To evaluate the influence of anxiety (fears and concerns) and the potential contribution of emotional support, which is identified separately from social support.

2 To evaluate anxiety responses to MS from diagnosis through to relapse; for example in the first weeks and months after diagnosis, 12 to 18 months later and in relation to relapsing or remitting phases.
To evaluate evidence in support of intervention to promote emotional expression, sharing and integration, thus avoiding isolation with negative emotions.

Three specific hypotheses are defined to focus on associations influenced by anxiety.

i) **Hypothesis 1**: Current maladaptive coping and low levels of emotional support predict poor psychological wellbeing.

ii) **Hypothesis 2**: Recalled anxiety and fear at diagnosis are associated with maladaptive coping, recalled and current.

iii) **Hypothesis 3**: Isolation with unresolved anxiety is associated with avoidance, recalled and current.

### 4.4 Method

#### 4.4.1 Design

A cross-sectional study was designed around a structured self-report questionnaire available online and through hard-copy distribution. A copy of the questionnaire is included in Appendix III. Responses to questions focused on diagnosis also involved retrospective measures. Recall time depended on individual participants' status in terms of time since diagnosis.

#### 4.4.2 Measures: Current and recalled responses

Social and illness demographics were measured in study-specific questions, including information on diagnosis, duration, progression, physical and cognitive status. The questionnaire assessed participants' responses to MS and its influence, firstly in current context and then in terms of recalled responses at retrospective stages following diagnosis. The measures were clearly dividing into the following sections in the questionnaire.

1. **Current responses**
2. **Recalled responses to diagnosis at 1 to 2 weeks and 2 to 3 months**
3. **Recalled responses 12 to 18 months after diagnosis**
4. **Recalled responses to the first significant relapse (where applicable)**
4.4.2.1 Measures of current psychological wellbeing

In two measures of current psychological wellbeing, participants were asked to respond according to how they usually feel, 'now'. Acute condition variability and individual symptom presentation was acknowledged by asking participants to respond in terms of how they usually feel. The shorter, twelve-item version of the General Health Questionnaire (GHQ-12; Goldberg 1992, as cited in Johnston, Wright, & Weinman, 1995) was used to measure the extent of psychological responses to MS. The Work and Social Adjustment Scale (WASAS; Mundt, Marks, Shear, & Griest, 2002) was used to assess the influence of MS in terms of everyday function and mental wellbeing.

4.4.2.2 Measures of current coping and support

The Brief IPQ (see section 1.7.4) is used to evaluate participants' current understanding of their condition. Selected scales from the coping orientation for problem experiences (COPE) multidimensional coping inventory (Carver, Scheimer, & Weintraub, 1989, as cited in Johnston, Wright, & Weinman, 1995) were used to assess coping responses to MS, specifically, active coping, planning, seeking instrumental social support, seeking emotional support, denial, mental disengagement, venting emotions and behavioural disengagement. Additionally, distancing and escape-avoidance scales were included from the Ways of Coping questionnaire (WoC; Folkman, et al., 1986).

The Significant Others Scale (SOS; Power, Champion, & Aris, 1988, as cited in Johnston, Wright, & Weinman, 1995) evaluated the level of emotional and social support available to participants from up to seven important people they could elect to include. In the context of MS care, this allowed for professional sources of support (MS nurse, doctor, physiotherapist and so on) to be included as well as family or friends. The aim was to assess the level of emotional sharing that participants access.

4.4.2.3 Measures of current disability

A final study-specific set of questions (based on findings from previous research) assessed current mobility and disability.

4.4.2.4 Retrospective measures of recalled responses

Participants were asked to think back to diagnosis and defined periods of time after they were confirmed as having MS. Anxiety and depression at diagnosis were
measured using the Hospital Anxiety and Depression Scale (HADS-AD, Zigmond, & Snaith, 1983, as cited in Johnston, Wright, & Weinman, 1995), a fourteen-item self-report measure of frequency of anxiety and depression symptoms in those diagnosed with a medical illness. This is frequently used in assessing responses to MS as it provides robust, recognised and well-validated measures.

Existing measures of fear used to assess fear avoidance in chronic conditions (such as cancer or diabetes) do not address the type of future-oriented fear that was reported in the preceding qualitative studies or the areas of fear related to MS, such as potential disability and extreme uncertainty. Therefore a study specific measure based on a ten-point Likert scale assessed participants' MS-related fears during the first three months after diagnosis. Relevant items were found in The Bypass Grafting Fear Scale (BGFS; Koivula, et al., 2002), which was developed to assess fears relating to coronary artery bypass grafting surgery. A pilot study into posttraumatic stress disorder following MS diagnosis (Chalfont, Bryant, & Fulcher, 2004) also indicated relevant aspects of future fear.

Appropriate items from the Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979, as cited in Turner & Lee, 1998) test psychological stress reactions to major life events in terms of intrusion and avoidance. This scale was used to measure distress in terms of intensity of thoughts and feelings related to MS 12 to 18 months following diagnosis.

The penultimate set of questions investigated first significant relapse. Based on responses from the qualitative research, participants were asked to rate a series of statements on response to relapse. The aim was to explore the influence of first relapse, the extent to which it came as a shock or was expected and whether it was a source of future concern. Participants could also contribute open-ended comments about relapse. This section will indicate the potential and direction for future measures of responses to relapse.

4.4.3 Data preparation and analysis
4.4.3.1 Scoring and sub-scale computing
Standard scoring methods that were provided with measures were used. Items were reverse coded appropriately so that scoring consistently represented the same outcome direction. Subscales and total scores were computed for multiple-item measures. Missing values were coded and defined as 'not applicable' or 'no response',

147
as appropriate. A copy of the questionnaire is included in Appendix III and the following is a summary of scoring methods for measures.

1 **General Health Questionnaire GHQ-12:** The Likert scoring method 0-3 was used, as recommended for evaluating the degree of non-psychotic disorder and mental health. Higher scores indicate poorer mental health or greater disorder.

2 **Brief Illness Perceptions Questionnaire:** Eight items were individually scored on a scale of 0-10, with higher scores indicating higher levels on individual items.

3 **Work and Social Adjustment Scale:** The five items were scored on a scale of 0-8 and total score across all items calculated. Higher scores indicate greater impairment, with scores of 10 or less related to sub-clinical levels, scores of 10-20 indicating significant functional impairment, and scores of 20 or more related to moderately severe impairment.

4 **Coping Orientation for Problem Experiences (COPE):** Responses were recorded in terms of frequency of using the approach as 'not at all', 'a little', 'medium amount', and 'a lot'. These were scored as 1-4 respectively. Following standard guidelines for using the inventory, total scores were calculated for items in each sub-scale and totals for relevant sub-scales were computed in measures of active and maladaptive coping.

5 **Ways of Coping (WoC):** Scales for distancing and escape-avoidance were calculated for six and eight items in each case (following to guidelines provided for the measures). The items were scored on the same scale as that used for COPE.

6 **Significant Others Scale (SOS):** The scale includes two items each for measuring emotional and social support provided by each individual elected by the participants. Participants can include up to seven individuals who provide support. A scale of 1-7 measured support levels, with 1-2 indicating never, 3-5 sometimes, and 6-7 always. Maximum score per person elected is 14 each for emotional and practical support. The possible total score is 196 for seven people (98 maximum score each for emotional and social support). For purposes of comparison, mean total, emotional and practical support were calculated by dividing the total score by the number of people elected.

7 **Hospital Anxiety and Depression Scale (HADS-AD):** Individual items were scored on a 4-point scale (0-3) according to statements of applicability and total scores for anxiety and depression sub-scales were calculated. Higher scores indicate
increasing levels of anxiety, with 0-7 indicating a normal range, 8-10 relating to mild levels, 11-14 to moderate levels and 15-21 to severe anxiety or depression.

8 Impact of Events Scale (IES): Items were scored on a four-point scale of 'not at all', 'rarely', 'sometimes' and 'often' according to statements measuring intrusion (7 items) and avoidance (8 items). Total scores were calculated for sub-scales.

9 Fear Scale: Items were scored on a ten-point Likert scale and the total score was calculated. Higher scores related to higher fear, with a score of 19-76 indicated no or low fear, 77-133 medium fear and 134-190 related to high levels of fear.

10 Responding to Relapse: Items were scored on a four-point scale (1-4) of 'not at all', 'a little', 'medium amount' and 'a lot' according to responses to individual statements. Total scores were calculated for separate sub-scales of relapse impact (7 items) and future concern arising from relapse (4 items).

4.4.3.2 Distribution
Skewness and kurtosis were checked; however, the sample of over 200 meant relatively low standard errors could inflate the statistics, therefore visual assessment of histograms was relevant. Z-score distributions and percentages of outliers were analysed using Field's suggested SPSS syntax (Field, 2005) as a basis for identifying percentages of outliers with Z scores exceeding ± 3.29. Extreme outliers were filtered by item or scale where necessary and the maximum number of cases excluded on any one item was four. With the exception of some items in the Illness Perception Questionnaire, data were normally distributed.

4.4.3.3 Factor analysis
Matrices for factor analyses are included in Appendix III. Study-specific measures of fear and responses to relapse were subject to factor analysis, using principal axis factoring and oblique rotation by Direct Oblimin. This rotation method was selected as it tolerates some correlation among factors and it would be unrealistic to expect uniqueness among items exploring MS influences.

Considering both pattern and structure matrices for the nineteen-item fear scale, fifteen items loaded independently on factor I. An item on marriage loaded modestly on to factor I but not independently (it also loaded on to factor III). Two items relating to disability loaded on factor I but not independently as they also loaded negatively on factor II. An item exploring parenthood fears (thus with limited relevance to some participants) loaded independently on factor III. Reliability
analysis for the 19-item scale was high at $\alpha = .93$ and since the inclusion of the last
item was unlikely to inflate scores all 19 items were included in the total score.

From factor and reliability analysis of the relapse scale, nine items were
redefined as a seven-item measure of overall impact and further into a four-item
measure of future concern arising from relapse. Calculating Cronbach's alpha for
reliability analysis returned an $\alpha = .73$ for the overall impact scale and $\alpha = .86$ for the
future concern scale. One of the original nine items that did not load highly on any
factor was identified as poorly worded in the questionnaire and was excluded. The
other item asked about coping levels before relapse and, as such, was set apart as a
single item.

Measures selected from coping orientation for problem experiences (COPE) had
been defined as grouping into either adaptive or maladaptive in circumstances
benefitting from active coping. Factor analysis of current data confirmed that COPE
1, 2 and 3 loaded independently onto a single factor defined as active coping. COPE
10, 11 and 13 loaded on to a measure of maladaptive coping. Cope 4 (seeking
emotional support) was retained as a separate (four-item) measure. Internal
reliability was acceptable in all cases (see Table 6). The COPE 12 measure of mental
disengagement did not load on to either maladaptive or active coping and internal
reliability for this data was low ($\alpha = .5$).

4.4.3.4 Inferential analysis: Multiple and hierarchical regression
Initially, standard multiple regression was used to analyse the predictive value of all
variables to establish which reached individual statistical significance in terms of
influence on current wellbeing. The two measures of current wellbeing as an
outcome were general health questionnaire (GHQ) and work and social adjustment
scale (WASAS).

Hierarchical regression was applied to separate predictor variables in models
chronologically related to diagnosis as summarised by:

1. time since diagnosis; time since any updated diagnosis; age
2. retrospective predictor variables around diagnosis (1 to 2 weeks;
   2 to 3 months) and 12 to 18 months after diagnosis
3. current predictor variables (coping and support).
4.4.4 Procedure
Participants were recruited through MS Therapy Groups, at centres and on-line (following appropriate review of the study credentials). The MS Society also reviewed relevant research credentials and promoted the study on their website. The study was also promoted through a poster, which was distributed to all MS Therapy Groups across the UK. See Appendix III for recruitment and consent paperwork.

Information sheets and consent forms were provided to participants before they filled in questionnaires; these preceded the questionnaire on-line and paper copies were distributed around centres. The questionnaire was available via an online link or as paper copies through centres (these could also be posted out on request by email or telephone). Participants were made aware of their right to withdraw or discontinue at any time. Participants could elect someone to assist them complete the questionnaire: guidance and consent to confidentiality was provided for those assisting participants with completion.

The questionnaire was followed by debriefing information. Personal information was isolated from all other data to ensure anonymity. Questionnaires were coded in order that participants could be traced by the researcher should there be any necessity for tracking data, for example if a participant elected to retrospectively withdraw or if there were any other ethical considerations that should be addressed. Anonymous coding also allowed non-verbal contributions to be linked with case numbers for disseminating data from the final open-ended section.

4.4.5 Participants and sample size
4.4.5.1 Ethical considerations The study received a favourable ethical opinion from the University of Surrey Ethics Committee (Appendix III). Recruiting through MS organisations ensured that participants were actively in contact with a support network. The MS Society assessed the protocol before agreeing to promote the study. Trustees and/or clinical leads at MS therapy centres and other groups also assessed the study before allowing recruitment. Adult participants were recruited from MS support groups and associations.

4.4.5.2 Inclusion criteria The heterogenous and idiosyncratic nature of the condition allowed for the following broad inclusion criteria.

i) Confirmed diagnosis with multiple sclerosis

ii) Over 18 years old
4.4.5.3 Exclusion criteria

i) Cognitive impairment likely to impair capacity to consent and/or complete questionnaire

ii) Evidence of neurological emotional impairment or condition (such as alexithymia)

Of 317 total responses, 229 people viewed the on-line version of the study and 88 completed paper questionnaires. Disqualifications included 50 on-line respondents who did not proceed to consent, 14 who consented but did not proceed, 13 who did not progress beyond demographics or current influences of MS, one participant diagnosed with alexithymia and one duplicate response. Data from the resulting 238 responses were analysed using SPSS.

4.5 Results: Demographics and descriptive statistics

4.5.1 Demographics

Table 5 provides demographic information and details of MS status. Over half the participants (148, 62.2%) had not relapsed within the last 12 months and 24 (10.1%) were currently relapsing.

<table>
<thead>
<tr>
<th>N=238</th>
<th>female 169 (71%)</th>
<th>male 69 (29%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>50.72</td>
<td>153.83</td>
</tr>
<tr>
<td>SD</td>
<td>11.88</td>
<td>124.88</td>
</tr>
<tr>
<td>Min.</td>
<td>33</td>
<td>3</td>
</tr>
<tr>
<td>Max.</td>
<td>74</td>
<td>804</td>
</tr>
<tr>
<td>Range</td>
<td>41</td>
<td>801</td>
</tr>
<tr>
<td>Diagnosis type</td>
<td>RR (41%)</td>
<td>PP (28.2%)</td>
</tr>
</tbody>
</table>

4.5.2 Descriptive statistics

The questionnaire first explored perceptions of current influences of MS before asking participants to think back to when they were diagnosed, and then to when they first experienced a significant relapse (where relevant). Summary descriptive and reliability statistics for measures used in all sections of the questionnaire are provided in Tables 6 and 7.
Table 6: Perceptions of current influence of MS on everyday life: Descriptive statistics and reliability (Cronbach's alpha score)

<table>
<thead>
<tr>
<th>General Health Questionnaire (GHQ)</th>
<th>Total Scores</th>
<th>Higher Score = Worse mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHQ</td>
<td>234</td>
<td>4</td>
</tr>
<tr>
<td>Brief Illness Perceptions Questionnaire (IPQ)</td>
<td>Individual Item</td>
<td>Total Scores</td>
</tr>
<tr>
<td>Consequences</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Time line</td>
<td>236</td>
<td>2</td>
</tr>
<tr>
<td>Personal control</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Treatment control</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Identity</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Concern</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Comprehensibility</td>
<td>236</td>
<td>2</td>
</tr>
<tr>
<td>Emotions</td>
<td>237</td>
<td>1</td>
</tr>
<tr>
<td>Work and Social Adjustment Scale (WASAS)</td>
<td>Total Score</td>
<td>Higher Score = Higher negative impact</td>
</tr>
<tr>
<td>WASAS</td>
<td>235</td>
<td>3</td>
</tr>
<tr>
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Table 7: Recalled phases of diagnosis and relapse information: Descriptive statistics and reliability (Cronbach's alpha score)

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Table 8: Current influence of MS: current coping approaches and current support

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<td>77 (32.5)</td>
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4.5.2.1 Current perceptions

Response levels on current influences were as follows: GHQ 234 (98.3%); IPQ 236-237 (99%); WASAS 235-237 (99%); COPE 233-236 (98-99%); WOC 235-236 (99%); SOS-B 237 (99.6%). Responses to the Illness Perceptions Questionnaire indicated high levels of cognitive and emotional engagement. Participants considered MS to be concerning and emotionally upsetting. Understanding of the condition was perceived as medium to high, with impact considered to be high and control to be poor. Over 70% of participants indicated moderately severe impairment and 39% reported higher impairment, while current wellbeing was either the same or less than usual, with a fifth perceiving their wellbeing as much less well than usual. These responses and others relating to approaches to coping and social support are summarised in Table 8.

Table 9: Recalled post-diagnosis anxiety and depression, and impact at 12 to 18 months

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<th>Scale</th>
<th>Frequency (%)</th>
<th>Scale</th>
<th>Frequency (%)</th>
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<td>IES total 12 to 18 months after diagnosis</td>
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<td>rarely</td>
<td>73 (32.1)</td>
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<td>severe</td>
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<td>often</td>
<td>42 (18.5)</td>
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<td>HADSd 1-2 weeks after diagnosis</td>
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<td>moderate</td>
<td>9 (4.7)</td>
<td>sometimes</td>
<td>76 (33.1)</td>
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<td>severe</td>
<td>11 (4.7)</td>
<td>often</td>
<td>41 (17.8)</td>
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<td>rarely</td>
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<td>sometimes</td>
<td>100 (43.9)</td>
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<tr>
<td>severe</td>
<td></td>
<td>often</td>
<td>47 (20.6)</td>
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Note: Response levels
Of total 238 participants, descriptives per scale are based on following response:
HADSa 232 (97.5%) HADSd 234 (98.3%)
IES total 227 (95.4%) IES – intrusion 230 (96.6%) IES – avoidance 228 (95.8%)

4.5.2.2 Recalled responses to diagnosis and relapse

Recalled responses to diagnosis are summarised in Table 9. These indicate anxiety and depression in the first two weeks after diagnosis and the impact of being diagnosed 12 to 18 months later. Table 10 summarises early concerns and fears during the first three months after diagnosis. Total scores for recalled MS-related fears during the first 1-3 months after diagnosis indicated that over 70% of participants experienced medium to high fear.
Response to questions on relapse was 66% (Table 11), reflecting the fact that this section was not relevant to all participants. While 29% had always expected a relapse and 31% immediately recognised the relapse onset, 26% did not realise they were relapsing. Participants indicated that impact of relapse was medium or high and relapse was associated with medium or high concern for the future.

Table 10: Recalled fears and concerns 1-3 months following diagnosis

<table>
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<th>item</th>
<th>frequency(%)</th>
<th>item</th>
<th>frequency(%)</th>
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<td>low</td>
<td>41 (13.8)</td>
</tr>
<tr>
<td>medium</td>
<td>49 (21.1)</td>
<td>medium</td>
<td>44 (18.0)</td>
</tr>
<tr>
<td>high</td>
<td>62 (26.7)</td>
<td>high</td>
<td>93 (40.3)</td>
</tr>
<tr>
<td>images of disability</td>
<td></td>
<td>disabled people</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>53 (22.8)</td>
<td>no</td>
<td>46 (19.9)</td>
</tr>
<tr>
<td>low</td>
<td>33 (14.3)</td>
<td>low</td>
<td>36 (15.6)</td>
</tr>
<tr>
<td>medium</td>
<td>64 (27.6)</td>
<td>medium</td>
<td>56 (24.2)</td>
</tr>
<tr>
<td>high</td>
<td>82 (35.3)</td>
<td>high</td>
<td>93 (40.3)</td>
</tr>
<tr>
<td>not knowing affect on me</td>
<td></td>
<td>losing memory</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>20 (8.6)</td>
<td>no</td>
<td>46 (19.9)</td>
</tr>
<tr>
<td>low</td>
<td>41 (17.6)</td>
<td>low</td>
<td>33 (14.3)</td>
</tr>
<tr>
<td>medium</td>
<td>55 (23.6)</td>
<td>medium</td>
<td>55 (23.8)</td>
</tr>
<tr>
<td>high</td>
<td>117 (50.2)</td>
<td>high</td>
<td>97 (42.0)</td>
</tr>
<tr>
<td>being dependent</td>
<td></td>
<td>coping with everyday life</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>31 (13.4)</td>
<td>no</td>
<td>45 (19.4)</td>
</tr>
<tr>
<td>low</td>
<td>31 (13.3)</td>
<td>low</td>
<td>43 (18.5)</td>
</tr>
<tr>
<td>medium</td>
<td>38 (16.4)</td>
<td>medium</td>
<td>54 (23.3)</td>
</tr>
<tr>
<td>high</td>
<td>132 (56.9)</td>
<td>high</td>
<td>90 (38.8)</td>
</tr>
<tr>
<td>having partner</td>
<td></td>
<td>thinking about being disabled</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>109 (47.0)</td>
<td>no</td>
<td>28 (12.1)</td>
</tr>
<tr>
<td>low</td>
<td>40 (17.2)</td>
<td>low</td>
<td>44 (16.9)</td>
</tr>
<tr>
<td>medium</td>
<td>36 (15.1)</td>
<td>medium</td>
<td>50 (21.6)</td>
</tr>
<tr>
<td>high</td>
<td>48 (20.7)</td>
<td>high</td>
<td>110 (47.4)</td>
</tr>
<tr>
<td>being in pain</td>
<td></td>
<td>nightmares about future</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>60 (26.0)</td>
<td>no</td>
<td>111 (43.7)</td>
</tr>
<tr>
<td>low</td>
<td>59 (25.5)</td>
<td>low</td>
<td>47 (20.4)</td>
</tr>
<tr>
<td>medium</td>
<td>55 (23.8)</td>
<td>medium</td>
<td>38 (16.4)</td>
</tr>
<tr>
<td>high</td>
<td>57 (24.7)</td>
<td>high</td>
<td>45 (19.5)</td>
</tr>
<tr>
<td>financial independence</td>
<td></td>
<td>being able to get out</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>54 (23.4)</td>
<td>no</td>
<td>39 (16.8)</td>
</tr>
<tr>
<td>low</td>
<td>38 (16.4)</td>
<td>low</td>
<td>39 (16.8)</td>
</tr>
<tr>
<td>medium</td>
<td>39 (16.9)</td>
<td>medium</td>
<td>51 (22.0)</td>
</tr>
<tr>
<td>high</td>
<td>100 (43.3)</td>
<td>high</td>
<td>103 (44.4)</td>
</tr>
<tr>
<td>normal sex life</td>
<td></td>
<td>uncertainty</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>53 (22.8)</td>
<td>no</td>
<td>26 (11.2)</td>
</tr>
<tr>
<td>low</td>
<td>62 (26.8)</td>
<td>low</td>
<td>33 (14.2)</td>
</tr>
<tr>
<td>medium</td>
<td>61 (26.3)</td>
<td>medium</td>
<td>43 (18.6)</td>
</tr>
<tr>
<td>high</td>
<td>96 (21.4)</td>
<td>high</td>
<td>130 (55.5)</td>
</tr>
<tr>
<td>being in a wheelchair</td>
<td></td>
<td>losing eyesight</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>34 (14.7)</td>
<td>no</td>
<td>44 (19.0)</td>
</tr>
<tr>
<td>low</td>
<td>25 (10.7)</td>
<td>low</td>
<td>34 (14.8)</td>
</tr>
<tr>
<td>medium</td>
<td>47 (30.3)</td>
<td>medium</td>
<td>35 (15.1)</td>
</tr>
<tr>
<td>high</td>
<td>126 (54.3)</td>
<td>high</td>
<td>118 (51.1)</td>
</tr>
<tr>
<td>having a baby/parenthood</td>
<td></td>
<td>BGFS total</td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>151 (85.1)</td>
<td>no</td>
<td>5 (2.2)</td>
</tr>
<tr>
<td>low</td>
<td>28 (12.1)</td>
<td>low</td>
<td>63 (27.4)</td>
</tr>
<tr>
<td>medium</td>
<td>18 (7.7)</td>
<td>medium</td>
<td>87 (37.8)</td>
</tr>
<tr>
<td>high</td>
<td>35 (15.1)</td>
<td>high</td>
<td>75 (32.6)</td>
</tr>
</tbody>
</table>

Note: Response levels
Descriptive statistics are based on a response of 230 (96.6%)
Table 11: Recalled responses to relapse

<table>
<thead>
<tr>
<th>item</th>
<th>frequency (%)</th>
<th>item</th>
<th>frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>did not recognise relapse</td>
<td></td>
<td>created concern re.</td>
<td></td>
</tr>
<tr>
<td>low</td>
<td>58 (36.7)</td>
<td>future physical disability</td>
<td></td>
</tr>
<tr>
<td>medium</td>
<td>35 (22.2)</td>
<td>no</td>
<td>17 (10.7)</td>
</tr>
<tr>
<td>high</td>
<td>23 (14.6)</td>
<td>low</td>
<td>30 (18.9)</td>
</tr>
<tr>
<td></td>
<td>42 (26.6)</td>
<td>medium</td>
<td>34 (21.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>high</td>
<td>78 (49.1)</td>
</tr>
<tr>
<td>relapse related future</td>
<td></td>
<td>created uncertainty</td>
<td></td>
</tr>
<tr>
<td>concern</td>
<td></td>
<td>about future</td>
<td></td>
</tr>
<tr>
<td>low</td>
<td>19 (11.9)</td>
<td>no</td>
<td>19 (12)</td>
</tr>
<tr>
<td>medium</td>
<td>30 (18.9)</td>
<td>low</td>
<td>35 (22.2)</td>
</tr>
<tr>
<td>high</td>
<td>34 (21.4)</td>
<td>medium</td>
<td>34 (21.5)</td>
</tr>
<tr>
<td></td>
<td>76 (47.8)</td>
<td>high</td>
<td>70 (44.3)</td>
</tr>
<tr>
<td>post relapse, got back to</td>
<td></td>
<td>always</td>
<td></td>
</tr>
<tr>
<td>normal</td>
<td></td>
<td>expected relapse</td>
<td></td>
</tr>
<tr>
<td>low</td>
<td>15 (9.4)</td>
<td>no</td>
<td>45 (28.3)</td>
</tr>
<tr>
<td>medium</td>
<td>45 (28.3)</td>
<td>low</td>
<td>43 (27)</td>
</tr>
<tr>
<td>high</td>
<td>64 (40.3)</td>
<td>medium</td>
<td>24 (15.1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>high</td>
<td>47 (29.6)</td>
</tr>
<tr>
<td>immediately recognised</td>
<td></td>
<td>overall</td>
<td></td>
</tr>
<tr>
<td>relapse</td>
<td></td>
<td>relapse</td>
<td></td>
</tr>
<tr>
<td>low</td>
<td>53 (33.5)</td>
<td>none</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>medium</td>
<td>29 (18.4)</td>
<td>low</td>
<td>32 (20.4)</td>
</tr>
<tr>
<td>high</td>
<td>64 (40.3)</td>
<td>medium</td>
<td>63 (40.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>high</td>
<td>60 (38.5)</td>
</tr>
<tr>
<td>coped with everyday</td>
<td></td>
<td>future concern resulting</td>
<td></td>
</tr>
<tr>
<td>practicalities</td>
<td></td>
<td>from relapse</td>
<td></td>
</tr>
<tr>
<td>beforehand</td>
<td></td>
<td>none</td>
<td>6 (3.8)</td>
</tr>
<tr>
<td>low</td>
<td>30 (18.9)</td>
<td>low</td>
<td>17 (10.8)</td>
</tr>
<tr>
<td>medium</td>
<td>43 (27.0)</td>
<td>medium</td>
<td>68 (43.4)</td>
</tr>
<tr>
<td>high</td>
<td>36 (22.6)</td>
<td>high</td>
<td>66 (42.0)</td>
</tr>
<tr>
<td></td>
<td>50 (31.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>forgetting and getting back</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to normal time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>low</td>
<td>29 (18.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>medium</td>
<td>45 (28.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>high</td>
<td>46 (29.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>38 (24.1)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.6 Results: Regression Analyses

The preceding qualitative study suggested that anxiety and emotional social support affected approaches to coping and subsequent outcomes for psychological wellbeing. Based on this, three hypotheses were proposed.

i) **Hypothesis 1**: Current maladaptive coping and low levels of emotional support predict poor long-term psychological wellbeing.

ii) **Hypothesis 2**: Recalled anxiety and fear at diagnosis are associated with long-term maladaptive coping, recalled and current.

iii) **Hypothesis 3**: Isolation with unresolved anxiety is associated with long-term avoidance, recalled and current.

Since the hypotheses were derived from a number of different influences, initial analysis tested the predictive power of all variables on general health questionnaire scores (GHQ) and work and social adjustment scale scores (WASAS). Standard
multiple regression was used to establish which predictors reached significance in their own right when regressed on to GHQ and WASAS total scores.

The following predictor variables were entered: active coping (activecope), maladaptive coping (malcope), distancing (WOC2), escape-avoidance (WOC6), mean emotional support (SOSmeanemot), mean practical support (SOSmeanprac), mean total support (SOSmeantotsup), anxiety (HADSa), depression (HADSd), fear (BGFSStot), impact of events intrusion (IESint), impact of events avoidance (IESavoid), future concern arising from relapse (relfutconcern), relapse impact (relimpact) and seeking emotional support (COPE 4).

The contributions of all predictors in all models and corresponding correlation tables are provided in Appendix III. The following sections include summary tables of models and significant predictors.

4.6.1 Regressing on GHQ

Preliminary analysis indicated that collinearity parameters were exceeded by mean total support (SPSS automatically excluded this variable), future concern arising from relapse and relapse impact. Therefore standard regression was run without these predictors and results are summarised in Table 12.

Table 12: Model summary and significant predictors in standard regression of anxiety, fear, impact and coping on GHQ

<table>
<thead>
<tr>
<th>Standard regression on outcome variable: GHQ total score</th>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>.340</td>
<td>4.50</td>
<td>.379**</td>
<td></td>
</tr>
</tbody>
</table>

a) predictors: malcope, SOSmeanprac, HADSd, activecope, WOC2, BGFSStot, COPE4, IESavoid, SOSmeanemot, WOC6, HADSa, IESint.

<table>
<thead>
<tr>
<th>Significant predictors of GHQ in above model</th>
<th>Unstandardised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
<td>B</td>
</tr>
<tr>
<td>COPE4</td>
<td>-.451</td>
</tr>
<tr>
<td>WOC2</td>
<td>-.323</td>
</tr>
<tr>
<td>malcope</td>
<td>.359</td>
</tr>
</tbody>
</table>

Note: **\( p < .001 \); *\( p < .05 \)

See Appendix III for full predictor summary.

The statistically significant model explained 34% of the variance in general health outcome. Of the significant predictor variables, maladaptive coping was numerically accounted for most change, followed by similar levels of change in GHQ predicted
by not seeking emotional support (COPE 4) and not distancing (WOC2). Active coping was the least important of the significant predictors (in terms of predicting levels of change). It is interesting that distancing negatively influenced wellbeing.

4.6.1.2 Introducing demographic predictors

Hierarchical regression was run to separate predictors chronologically in relation to diagnosis and to introduce demographic predictors. Variables were regressed in the following models: 1) time since diagnosis, time since any updated diagnosis and age; 2) predictors at diagnosis and 12 to 18 months after diagnosis; 3) current coping and support predictors. Results are summarised in Table 13.

Neither demographic nor diagnosis and early stage models 1 and 2 reached statistical significance until current coping was introduced. Although age (negatively related to wellbeing) and avoidance during the first 12 to 18 months after diagnosis were significant in model 1, they were not important in model 3, which reached overall significance. Model 3 explained 29.3% of the variance, with maladaptive coping as the only significant predictor.

Table 13: Model summary and significant predictors in hierarchical regression of demographics, diagnosis variables, early impact, and coping on GHQ

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>Change Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>.036</td>
<td>6.96</td>
<td></td>
</tr>
<tr>
<td>2b</td>
<td>.107</td>
<td>6.70</td>
<td></td>
</tr>
<tr>
<td>3c</td>
<td>.293</td>
<td>5.96</td>
<td></td>
</tr>
</tbody>
</table>

- **a** predictors: time since updated diagnosis, age in years, time (months) since diagnosed.
- **b** predictors: time since updated diagnosis, age in years, time (months) since diagnosed, malcope, HADSd, IESavoid, BGFStot, HADSa, IESint.
- **c** predictors: time since updated diagnosis, age in years, time (months) since diagnosed, malcope, HADSd, IESavoid, BGFStot, HADSa, IESint, COPE4, WOC2, SOSmeanprac, malcope, activecope, SOSmeantot, WOC6.

A further standard multiple regression analysis for diagnosis and early impact predictors, current coping and age on wellbeing (with time since first and updated diagnoses excluded) predicted 34.8% of the variance in the overall model. Results are summarised in Table 14.
Table 14: Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on GHQ

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.348</td>
<td>4.98</td>
<td>.391**</td>
</tr>
</tbody>
</table>

a) predictors: malcope, SOSmeantot, HADSd, age in years, WOC2, activecope, IESavoid, SOSmeanprac, BGFStot, COPE4, WOC6, HADSa, IESint.

Significant predictors of GHQ in above model

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPE 4</td>
<td>-.452</td>
<td>.165</td>
<td>-.226*</td>
</tr>
<tr>
<td>WOC 2</td>
<td>-.356</td>
<td>.098</td>
<td>-.234**</td>
</tr>
<tr>
<td>activecope</td>
<td>.133</td>
<td>.061</td>
<td>.163*</td>
</tr>
<tr>
<td>malcope</td>
<td>.353</td>
<td>.092</td>
<td>.321**</td>
</tr>
</tbody>
</table>

Note: **p = < .001; *p = < .05
See Appendix III for full predictor summary.

Maladaptive coping was the highest of the significant predictors. Not distancing and not seeking emotional support were followed by a small but unexpected association between active coping and poor wellbeing.

4.6.2 Regressing on WASAS

Standard multiple regression was used to enter all predictor variables on to work and social adaptation as a second outcome measure. Results are summarised in Table 15.

Table 15: Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on WASAS

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.244</td>
<td>8.64</td>
<td>.244**</td>
</tr>
</tbody>
</table>

a) predictors: SOSeantotsup, WOC2, HADSa, age in years, activecope, malcope, IESavoid, HADSd, COPE4, BGFStot, WOC6, IESint, SOSeanemot.

Significant predictors of WASAS total score

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>age in years</td>
<td>.155</td>
<td>.056</td>
<td>.177*</td>
</tr>
<tr>
<td>WOC 2</td>
<td>-.608</td>
<td>.170</td>
<td>-.246**</td>
</tr>
<tr>
<td>WOC6</td>
<td>.652</td>
<td>.189</td>
<td>.316*</td>
</tr>
<tr>
<td>meanemot</td>
<td>-.247</td>
<td>.580</td>
<td>-.314*</td>
</tr>
<tr>
<td>malcope</td>
<td>.327</td>
<td>.160</td>
<td>.185*</td>
</tr>
</tbody>
</table>

Note: **p = < .001; *p = < .05
See Appendix III for full predictor summary.
As before (regressing on GHQ), all predictor variables were evaluated and relapse variables excluded. Mean practical support did not comply with collinearity tolerance and this variable was excluded by SPSS.

The overall model explained 24.4% of the variance in outcome. Unlike regression on general health outcome, age made a small but significant contribution to the variance in work and social adjustment. Escape-avoidance (WOC6) and SOS measure of emotional support (correlating negatively) were important independent predictors. Distancing (WOC2) again correlated negatively and maladaptive coping also made a small significant contribution.

4.6.3 Regressing on current coping

Unhelpful current coping, measured by maladaptive coping (malcope), was a consistent predictor of poor wellbeing. Escape-avoidance (WOC 6) was also a significant predictor of poor outcome for work and social adjustment. Distancing (WOC2) correlated negatively as a predictor of poor current wellbeing and therefore was not used as a dependent variable for unhelpful coping.

Standard multiple regression was used to test: 1) the influence of diagnosis anxiety/fear and impact at 12 to 18 months regressed on to maladaptive coping; 2) the influence of diagnosis anxiety/fear and intrusion at 12 to 18 months regressed on to escape-avoidance; and 3) fear and anxiety at diagnosis; concerns arising from relapse; and seeking emotional support regressed on to maladaptive coping. All models were significant, as summarised in Table 16, along with significant predictors in each model.

Model 1  Avoidance at 12 to 18 months was an important (the only significant) predictor for maladaptive coping. While intrusion was not significant as an independent predictor, it was correlated with avoidance ($r = .7, p = < .001$). Similarly, anxiety (HADSa) and fear correlated significantly with intrusion ($r = .61, p = < .001$ and $r = .58, p = < .001$ respectively) even though they did not reach significance as predictors in the overall model. It was also noted that depression (HADSD) at diagnosis did not significantly correlate with maladaptive coping.
Table 16: Model summaries and significant predictors in regression of early impact and emotional support on to maladaptive coping (malcope) and escape-avoidance (WOC6)

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.209</td>
<td>5.05</td>
<td>.227**</td>
</tr>
<tr>
<td>2a</td>
<td>.180</td>
<td>4.36</td>
<td>.191**</td>
</tr>
<tr>
<td>3</td>
<td>.092</td>
<td>5.40</td>
<td>.109**</td>
</tr>
</tbody>
</table>

a) predictors: IESavoid, HADSd, BGFSint, HADSc, IESint.
b) predictors: IESint, BGFSint, HADSc.
c) predictors: HADSc, COPE4, reflutoconcern, BGFSint.

Significant predictors in above models 1, 2 and 3

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>.206</td>
<td>.044</td>
<td>.384**</td>
</tr>
<tr>
<td>2a</td>
<td>.142</td>
<td>.038</td>
<td>.298**</td>
</tr>
<tr>
<td>3a</td>
<td>.189</td>
<td>.088</td>
<td>.176*</td>
</tr>
</tbody>
</table>

Note: **p < .001; *p < .05
See Appendix III for full predictor summary.

Model 2 In terms of escape-avoidance, intrusion 12 to 18 months post diagnosis was the only significant predictor. Fear did not reach significance (p = .075) as a predictor but it correlated significantly (p = < .001) with anxiety and intrusion (r = .63 and r = .58 respectively). Anxiety, also non-significant as a model predictor, correlated significantly with intrusion (r = .61, p = < .001).

Model 3 A revised regression on to maladaptive coping was run to evaluate anxiety and fear at diagnosis when later intrusion was excluded. Although the model was significant, it explained just 9.2% of outcome (low compared to other regressions). Anxiety was a significant predictor (p = .034). Fear correlated significantly with maladaptive coping at a similar level to anxiety (r = .28 for fear; r = .29 for anxiety) but was only marginally significant as a model predictor (p = .047). Neither post-relapse concerns nor seeking emotional support significantly influenced the overall model outcome.

4.6.4 Regressing on early stage impact
Impact of events measures of avoidance and intrusion (at 12 to 18 months) were significant predictors of current coping. Therefore diagnosis-stage variables, age and time since diagnosis were evaluated as predictors of avoidance and intrusion.
Table 17: Model summaries and significant predictors of IES avoidance

Standard regression on outcome variable: IESavoid

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>.188</td>
<td>9.50</td>
<td>.195**</td>
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<tr>
<td>2b</td>
<td>.185</td>
<td>9.52</td>
<td>.196**</td>
</tr>
<tr>
<td>3c</td>
<td>.451</td>
<td>7.81</td>
<td>.461**</td>
</tr>
<tr>
<td>4d</td>
<td>.186</td>
<td>9.48</td>
<td>.201**</td>
</tr>
</tbody>
</table>

a) predictors: BGFSstot, HADSa   b) predictors: HADSd, BGFSstot, HADSa.

c) predictors: IESint, HADSd, BGFSstot, HADSa.  d) predictors: age in years, HADSd, BGFSstot, HADSa.

Significant predictors in above models 1, 2, 3 and 4

<table>
<thead>
<tr>
<th>Models and variables</th>
<th>Unstandardised</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADSa</td>
<td>.553</td>
<td>.155</td>
</tr>
<tr>
<td>BGFSstot</td>
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<td>.018</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
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<td>HADSa</td>
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<td>.019</td>
</tr>
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<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADSd</td>
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</tr>
<tr>
<td>IESint</td>
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<td>.071</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADSa</td>
<td>.606</td>
<td>.174</td>
</tr>
<tr>
<td>BGFSstot</td>
<td>.045</td>
<td>.019</td>
</tr>
</tbody>
</table>

Note: **p = <.001; *p = <.05
See Appendix III for full predictor summary.

Standard multiple regression was used to regress the following predictors on to IES avoidance: 1) anxiety and fear; 2) anxiety, fear and depression; 3) anxiety, fear, depression and intrusion; and 4) anxiety, depression, fear and age in years. All models were significant and Table 17 summarises results, including significant predictor variables for each model.

Models 1, 2 and 4 All three models accounted for a similar level of variance (19-20%) in avoidance at 12 to 18 months, with anxiety and fear explaining similar levels of model variance. Neither depression nor age reached significance as predictors.

Model 3 The influence of intrusion as a predictor greatly increased the explained variance in the model to 45%, with intrusion contributing prominently. Anxiety was no longer a significant predictor and depression negatively correlated to account for a numerically small explanation of variance.
Further standard multiple regression was used to evaluate predictors of intrusion: 1) fear, anxiety and depression; and 2) fear, anxiety, depression, time since diagnosis and age. Table 18 summarises results and predictor models.

Table 18: Model summaries and significant predictors of IES intrusión

<table>
<thead>
<tr>
<th>Model</th>
<th>Adjusted R²</th>
<th>Std. Error of the Estimate</th>
<th>R² Change</th>
</tr>
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</tr>
<tr>
<td>2</td>
<td>.595</td>
<td>6.98</td>
<td>.625**</td>
</tr>
</tbody>
</table>

a) predictors: BGFStot, HADSd, HADSa. b) predictors: time since updated diagnosis, HADSd, BGFStot, age in years, HADSa, time since diagnosis.

Significant predictors in models 1 and 2

<table>
<thead>
<tr>
<th>Unstandardised</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
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<tbody>
<tr>
<td>1 HADSa</td>
<td>.576</td>
<td>.134</td>
<td>.301**</td>
</tr>
<tr>
<td>HADSd</td>
<td>.510</td>
<td>.148</td>
<td>.210**</td>
</tr>
<tr>
<td>BGFStot</td>
<td>.067</td>
<td>.014</td>
<td>.297**</td>
</tr>
<tr>
<td>2 HADSd</td>
<td>.901</td>
<td>.240</td>
<td>.314**</td>
</tr>
<tr>
<td>BGFStot</td>
<td>.109</td>
<td>.021</td>
<td>.468**</td>
</tr>
</tbody>
</table>

Note: **p = <.001; *p = <.05
See Appendix III for full predictor summary.

Model 1 This explained 45.5% of variance in intrusion at 12 to 18 months. All three predictors reached significance, with anxiety and fear making similar contributions to explaining model variance. Depression made a significant but lower contribution as a predictor of overall model variance.

Model 2 Introducing time since diagnosis, updated diagnosis and age altered the result such that fear and depression were the only significant predictors. Anxiety correlated significantly with intrusion (r = .61, p = < .000) and there was a very small but significant negative association between time since updated diagnosis and intrusion (r = -.22, p = .024). Age and time since diagnosis did not correlate significantly with intrusion, anxiety or depression. There were small but significant negative correlations between fear and age, time since diagnosis and time since updated diagnosis (r = -.293, p = .004; r = -.330, p = .004; and r = -.206, p = .032 respectively). This would suggest that perceptions of recalled fear were diminished rather than inflated over time.
4.7 Discussion

This cross-sectional study into anxiety responses tested three hypotheses: 1) that maladaptive coping and low levels of emotional support predict poor long-term psychological wellbeing; 2) that anxiety and fear at diagnosis are associated with long-term maladaptive coping; and 3) that isolation with unresolved anxiety is associated with long-term avoidance.

Results provided evidence that maladaptive approaches to coping (including denial, behavioural disengagement and focusing on becoming distressed and venting anger) predicted poor psychological wellbeing, both in terms of general health outcome and work and social adaptation. Emotional support was negatively associated as a predictor of poor outcome, that is seeking emotional support would improve outcome. Distancing (in terms of not letting MS dominate or 'looking for the silver lining') was predictive of improved psychological wellbeing. Length of time since diagnosis did not predict wellbeing and the only influence of age was related to social and work adaptation, which possibly reflected the impact of increasing physical limitations.

4.7.1 Perceptions of MS

As discussed in section 1.7, perceptions and beliefs have been found to influence both the way in which people respond to illness and health outcomes. In the current study, participants considered their comprehension of MS to be good (rated highly by 60% of participants) with 80% expressing medium levels of concern and 70% finding the condition highly emotionally upsetting. Given that current expert opinion positions MS as incurable but treatable and with excellent symptom management (as discussed in section 1.4), responses and beliefs seem pessimistic. For example, while MS was accurately interpreted as a long-term condition (by 90% of participants), treatment control was perceived to be only low to medium by 32% and 41% respectively. It is not unreasonable that participants should consider illness effect to be medium (46%) to high (42%), with correspondingly medium to high impact of symptoms (51% and 36% respectively); however, low to medium perceptions of personal control (45% each) are not aligned to the emphasis MS nurses, centres and support groups place on achieving broad treatment and personal control.
In this context, current wellbeing measured on the general health questionnaire was indicated by 41.9% of participants as the same as usual, 49.1% less well than usual and 9% much less well than usual. However, response to the work and social adjustment measure indicated that over 70% of participants experienced moderately severe impairment and 17% reported higher impairment.

4.7.2 Coping and support
Given that personal control was perceived as low, it is not surprising that potentially maladaptive approaches to coping were common. Over 25% of participants adopted potentially maladaptive approaches a medium to a lot of the time and over 70% used these a little of the time. While high and medium levels of active coping were used by 14% and 55% respondents respectively, 30% of respondents used active coping only a little of the time or not at all. Moderate levels of escape avoidance were reported by 39% of respondents and a further 51% adopted this approach a little. Distancing was less frequent, with 36% using this a little, 49% a small to medium amount and 14% moderately to a lot.

Support was investigated by the extent to which emotional support was sought for coping and by asking participants to rate perceived levels of practical and emotional support available from significant others. Over 30% participants sought no more than low levels of emotional support; 54% sought medium levels of emotional support; and only 11% looked for emotional support to aid current coping. The measure of available support indicated that 55% participants had medium levels of emotional support compared to 70% who had a similar level of practical support. Data indicate that emotional support was not taken or sought as much as it could have been, suggesting opportunity for increasing proactive approach in this area.

4.7.3 Recalled responses to diagnosis
Recalling reactions from the first one to two weeks after diagnosis, most participants remembered raised anxiety and 50% indicated moderate while 13% severe levels. Over 70% of participants experienced medium to high illness-related fears during the first three months after diagnosis and recalled that a year to eighteen months later impact was moderate to high (among 41% and 18% of participants respectively). Moderate intrusion was experienced by 33% and 17% recalled high intrusion.

Given these emotional responses, levels of moderate and high avoidance among over 40% and 20% of participants respectively seems natural. However, inferential
statistics indicate that responses during the first 12 to 18 months following diagnosis were important predictors of current, or long-term, unhelpful approaches to coping. Avoidance was a strong predictor of maladaptive coping, suggesting that relatively early avoidance as a strategy for dealing with the impact of diagnosis was not necessarily a temporary phase. Furthermore, avoidance could relate to a potentially unhelpful long-term pattern of coping. Intrusion 12 to 18 months after diagnosis was particularly important as a predictor of both current coping and avoidance around the same time. Anxiety and fear at diagnosis predicted avoidance and intrusion.

Depression did not make a prominent contribution to results, with recalled responses indicating that levels at diagnosis were low. It has to be acknowledged that this could be a recall effect. The only prediction equations depression contributed to were for avoidance and intrusion. Depression accounted for a small proportion of intrusion but, interestingly, related to avoidance as a negative predictor. This would suggest that depression and anxiety after diagnosis could exacerbate intrusion: by reducing avoidance, depression could be associated with increased intrusion due to rumination or dwelling on MS and associated fears.

4.7.4 Supporting and challenging existing research

The volume of literature on emotional responses was large and generally non-specific, therefore a systematic review was conducted to evaluate types of anxiety responses (fear, distress and worry), links between anxiety and adjustment and possible theoretical explanations. Although depression and anxiety were generally considered to be comorbid (for example, Anhogue et al., 2011; Beiske et al., 2008; McCartney Chalk, 2007; da Silva et al., 2011; Dahl et al., 2009; Pakenham, 2006; and Giordano et al., 2011), Giordano et al. found marked differences between anxiety and depression and diagnostic stage, and there was also evidence that levels of anxiety are higher than depression (for example, Beiske et al., 2008; Gay et al., 2010; Anhogue et al., 2011; Brakjovic et al., 2009; da Silva et al., 2011; Dahl et al., 2009; Giordano et al., 2011; Janssens et al., 2003; Uguz et al., 2008; and Vleugels et al., 1998). Descriptive statistics from the present study (study two) concurred with this body of data, with differing levels of anxiety and depression at diagnosis. While 13% and 50% of participants had severely and moderately raised anxiety levels (respectively), 80% of participants were in the normal range for depression.
The systematic review highlighted the critical fact that anxiety was psychological but depression was likely to result from physiological as well as psychological factors. Giordano et al. (2011) found anxiety also potentially related to early distress and difficulty in adjusting in terms of coping strategies; furthermore, anxiety at baseline was predictive of later depression. Janssens et al. (2006) indicated that anxiety could be persistent, with anxiety and distress (in terms of intrusion and avoidance) at baseline related to levels at 24-month follow up. Anxiety following diagnosis remained unchanged even though disease-related distress decreased over two years and levels of anxiety at diagnosis predicted later anxiety at a two-year follow up.

While there is much evidence linking anxieties and coping, the data are complex, drawing on different constructs and including multiple aspects such that there does not seem to be a coherent, concise or consistent understanding or explanation of these responses. For example, uncertainty about the future has been correlated with fatalistic coping (Buelow, 1991) and more recent research (Brakjovic et al., 2009) proposed that denial, avoidance and behavioural disengagement correlated with anxiety. Pakenham (2006) found that appraised stress in terms of illness events correlated to higher distress (anxiety and depression), which correlated with lower life satisfaction, avoidance, anxiety and depression. The unique coping predictor of distress was avoidance, which demonstrated a small but significant correlation with anxiety. Similarly, McCartney Chalk (2007) found that high anxiety related to low problem-solving coping.

Illness perceptions have consistently contributed to findings. For example negative illness perceptions, especially uncertainty, have been related to poor psychological outcome (Buelow, 1991). Lack of coherence and understanding of MS related to anxiety, while inaccurate perceptions of illness prognosis hindered adjustment (Jopson & Moss-Morris, 2003). Findings from the present study signpost high levels of concern and emotional upset as well as negative illness perceptions and uncertainty. Low levels of problem-focused coping in previous research are also in evidence here, with over 25% of participants in the present study adopting potentially maladaptive approaches a medium to a lot of the time and over 70% using these a little of the time. Meanwhile, high and medium levels of active coping
were used by only 14% and 55% of respondents respectively, and 30% of respondents used active coping only a little or not at all.

While anxiety and depression, general mood and distress were discussed in preceding research, there is a lack of information on MS-specific fears and concerns of the type expressed in narrative in study one in this thesis. Thornton, Tedman, Rigby, Basforth and Young (2006) developed a scale to assess worries among patients with MS, based on rating statements about physical, social, work/daily life, family and mobility, split factorally into mobility/physical vulnerability and social/family/work/daily routine scales. The statements were not tightly worded and open to subtle interpretation, therefore not precise enough to elicit levels of specific concern or fear. Bruce and Arnett (2009) also highlighted the lack of preceding research in this area and proposed that worry and anxiety were related but distinct constructs. Burns et al. (2010) found that breaking anxiety factors down into distress and fear revealed long-term influences, with distress disorders at baseline associated with higher anxiety during and after treatment.

Findings from study two accord with those of previous research, indicating that MS-specific fears were potentially different from general anxiety, with over 70% of participants experiencing medium to high fear in the first three months after diagnosis. Evidence in the present study suggesting that anxiety persists beyond diagnosis and predicts coping 12 to 18 months later contributes to results in previous research. In addition, responses to a concise scale developed to assess MS-specific fears indicated that fears around diagnosis contributed to avoidance at 12 to 18 months. Fear and anxiety were significant separate predictors of avoidance, again suggesting that the two should be differentiated in future research. As proposed by Kehler and Hajistavropoulos (2009) and Dennison (2009), this suggests that health-specific fears, as well as anxiety, may contribute to poor outcome.

4.7.5 Study limitations

The obvious limitations of this study are the cross-sectional design and the retrospective gathering of information around diagnosis and during the following 12 to 18 months. While aspects of anxiety may have been forgotten, there was also the possibility that fears could have been inflated over time; however, negative correlations with age and time since diagnosis suggest this was unlikely. While findings from cross-sectional data can be considered useful for indicating potential
links and aspects for further evaluation, longitudinal research is necessary for collating robust evidence suggestive of causal relationships.

The study was advertised nationally through support groups and associations, including on-line promotion and via managers and organisers at centres, as discussed in section 1.4.3. Therefore all volunteer participants were in touch with some type of support group. Centres have difficulty in engaging those who are newly diagnosed and it is possible that those not associating with support groups may be in the earlier phases of the condition and / or experiencing minimal effects. Although this may bias the data towards participants with a more severe experience of MS, since the majority of respondents completed the on-line questionnaire, this is not necessarily the case. It does, however, mean that all participants were volunteers who were prepared to engage with the diagnosis of MS. Organisers at MS therapy centres comment on the number of newly diagnosed people who seek information but then stay away for a number of years. Group members frequently comment that they would have benefitted (especially physically) by earlier membership. Belonging to an MS therapy group implies engagement with diagnosis and a proactive approach to seeking at least physical, if not social, support.

4.8 Conclusion and Contribution to Understanding Adjustment to MS

Results demonstrate links between high anxiety and fear at diagnosis; high impact and unhelpful avoidance at 12 to 18 months; and unhelpful approaches to coping for long-term psychological wellbeing. Participants in this study have high levels of support available to them, therefore the effects of maladaptive coping and need for emotional support demonstrated by the results may be understated. Those without access to emotional support and whose approach is less problem focused are not necessarily represented in the current sample.

The implications for practice are that addressing early anxieties and fears could reduce intrusion and promote engagement with the less-catastrophic aspects of long-term diagnosis rather than avoidance as a consequence of unrealistic fear of severe disability. Encouraging people to seek emotional support could improve wellbeing.
Chapter 5

Study Three

A feasibility study of using visual methods for expressing and amending responses to MS

5.1 Chapter Overview

Study two provided evidence of links between anxiety and fear at diagnosis and long-term wellbeing. This study explores the participant perspective on using visual methods for expressing responses to MS and assesses the potential for interpreting and rescripting images. The purpose is to find out whether participants engage with visual techniques and whether those who do respond differ from those who do not. The type of data provided and participants' responses to the process are evaluated.

The introduction (5.2) provides brief background on the context of visual methods for this research. Study aims and objectives are covered in section 5.3 and the method is outlined in section 5.4. Findings are presented in section 5.5. Chapter discussion and conclusions are summarised in sections 5.6 and 5.7.
5.2 Introduction

Study 1, a qualitative study into emotional responses to being diagnosed with MS, indicated that future-oriented fear following diagnosis and emotional isolation with negative responses were potentially influential in long-term outlook and coping. Narratives also indicated that, while some participants conscientiously avoided sharing their concerns, others could be unaware that they were either isolating themselves with underlying anxieties or becoming isolated when no-one readily listened to their concerns. From evidence of the long-term negative influence of such factors on wellbeing in study two it seemed that an intervention to promote expression and evaluation of anxieties could help introduce a balanced perspective to promote adaptive coping. Such an intervention may access subconscious fears as well as concerns that participants readily acknowledge.

5.2.1 Visual versus verbal

Visual methods have been used for understanding patient experiences of both physical and psychological disorders. For example, physiological-based drawings of illnesses have been shown to provide insight into patients' perceptions of heart attack and these have been linked with recovery (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). Drawings with non-physical focus have provided rich insight into holistic experiences of headache (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009). Philips (2011) found that people could be unaware of avoiding existing mental images that had powerful influence on emotions, cognitions and behaviour in relation to pain. Intrusive or involuntary images are also associated with post traumatic stress and anxiety disorders (Brewin, Gregory, Lipton, & Burgess, 2010).

While art therapy may be used for psychotherapy, it is not a method for diagnosing mental state and interpretation is not an objective exercise but subject to the relationships between the person, image and therapist (Shaverien, 1992). Shaverien outlined the basis of trust and confidentiality necessary for successful engagement in art therapy and an understanding that artistic ability is not required. In fact, someone experienced in visual expression may have a developed ability to think through and control the expressive process rather than spontaneously represent unconscious responses (Shaverien, 1992).
The current study considers the opportunity to access the full depth and breadth of responses, including those subconscious interpretations and impressions of which the participants may be unaware. Revealing retained, unspoken, adverse responses to being diagnosed with MS could provide a first step to evaluating their relevance and providing a means of adopting a different perspective. Rescripting or amending adverse images to introduce positive aspects has been successfully tested as a treatment for depression (Brewin et al., 2009). With MS, rescripting could relate to early fears around severe disability.

Feedback from those diagnosed with MS suggests that some non-verbal method of expression would be helpful due to physical restrictions of the condition. For example, symptoms include speech difficulties and fatigue, and the latter applies to processing ideas into coherent written form even when using a computer can overcome deterioration in physical dexterity. Drawing pictures or diagrams also provides a relatively quick way of capturing substantial amounts of information.

5.3 Aims and Objectives

This study sets out to assess the feasibility of using an art-based intervention for amending unrealistic or potentially unhelpful responses in the early stages following diagnosis. To be useful for an intervention, the method should facilitate access to in-depth responses to MS, both conscious (but possibly not readily expressed) and subconscious. Therefore one of the aims of this study is to evaluate the level of information in images participants provide to express their responses. If images demonstrate rich data content, then the study also aims to explore the ways in which they could (or should) be interpreted.

A key objective of this study is also to consider the type of interpretative structure that can be used as a basis for analysing images in descriptive terms. The aim is to develop a coherent and analytic approach to interpreting expressions of responses to, and understanding of, MS. The pragmatic approach has to enable the researcher to nurture a dyadic process of reflection with the participant in an intervention situation; thus, the criteria have to be relatively simple for providing a quick initial overview. Criteria should provide direction for engaging participants in reflection and validation of their meaning making, and for introducing rescripting.
Finally, the study asks whether visual methods are acceptable in principle, how they could be carried out and what effect they may have. These objectives can be summarised in five key research aims.

1. Would participants elect to use non-verbal methods and would volunteers who used visual techniques differ from participants who did not (non-respondents)?
2. Would participants find visual methods different from verbal / written responses?
3. Would images provide detailed responses?
4. Define an analysis framework for potential application in an intervention context.
5. Explore the possibilities for rescripting.

5.4 Method

5.4.1 Design
A qualitative method was used in a cross-sectional questionnaire study of responses to MS expressed through visual methods. Participants were invited to use any media they wished and told they could annotate images or give them a title. Broad, minimum-guidance notes were provided. Two closed questions and an open-ended question invited explanations.

The questionnaire was distributed as an optional section following the quantitative survey in study two and this was available online or in paper form. Participants were asked to provide an identity code on images and responses to preserve anonymity while also allowing images to be linked to data on the main survey. Participants were asked to post responses to the researcher by traditional mail. They were told that images could not be returned and therefore asked not to send precious original work.

5.4.2 Materials
The relevant section of the questionnaire is reproduced in Figure 12 (details of creating a code using initials, year of diagnosis and time since diagnosed was provided on the reverse). Participants used their own media or materials. A study summary and identification form for the researchers who assessed the images is shown in Figure 13.
Figure 12: Qualitative questionnaire used for pilot study

Figure 13: Summary of aims, researcher identification and coding form
5.4.3 Participants
Table 19 summarises demographic information. From the total of 238 complete responses to the questionnaire survey, forty one participants (17.23%; 34 female, 5 male and 2 anonymous) sent images. Two emailed electronic files, twenty five sent them by traditional mail and the remainder included their images on the questionnaires. Two images were anonymous. The mean age of participants was 55.44 years and mean time since diagnosis was 13.09 years.

Table 19: Demographic information

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</table>

Diagnosis type

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<td>16</td>
<td>11</td>
<td>3</td>
<td>9</td>
</tr>
</tbody>
</table>

(41%) (28.2%) (7.7%) (23.1%)

Note: Authors of images 18 and 34 were anonymous

One person said they had posted a drawing but it never arrived and another person said they would be posting a drawing, but that was not received. Accompanying information ranged from categorical responses to questions to insightful comments and essays on multiple aspects of diagnosis, condition and personal implications.

Among all 238 respondents, 14 indicated that they could not draw, either because images did not come readily to mind, they did not feel sufficiently skilled or they were not physically able to hold a pencil. Three people wrote angry comments on the questionnaires in response to the concept of drawing: "CRAP"; "Is this a joke?"; and "silly".

5.4.4 Analytic approach to visual data
Due to optional participation and the relatively unstructured framework for visual responses, the analytic approach could not be clearly defined in advance. Therefore, to inform the approach to analysis, the study objectives and the data were reviewed by independent academics who proposed the following five guidelines.

i) The epistemological position for interpreting data should be clarified.

ii) Fundamental concepts expressed in images should be defined to provide a framework for analysis.
iii) Focusing on intervention context was vital and the agreed analysis framework should function as a practical intervention tool within the structuring process.

iv) The analysis framework should be suitable for interpretation relevant to participants and intervention practice. The concepts should be easily explained to participants, understood by them and acceptable (and relevant) to their ownership of rescripting.

v) The analysis framework should reflect academic approaches used in visual research methods.

Academics suggested that the images should be evaluated by a panel of researchers who were not associated with the project but familiar with qualitative methods and/or health psychology.

**Researcher panel: Approach to preliminary interpretation**

The objective in evaluating visual data was to acquire a broad perspective from a number of PhD researchers associated with visual, creative or qualitative methods and/or health psychology, and who were not involved with the MS research. Six researchers were informed of the study aims and questions provided to the participants. They were briefed following the guidelines proposed by the academics and provided with copies of all images.

Researchers worked individually and were asked to consider the images as for the preliminary stages of thematic analysis. The focus was idiographic, with possible constructs, codes or themes noted separately for items of visual data. Researchers were requested not to attempt to define commonalities.

Each researcher provided brief written notes on their preliminary interpretations. The researchers were asked to express interpretations in academic terms rather than trying to make them 'user friendly' for participants in an intervention context. They were also encouraged to comment on any aspects they considered relevant to further developing or refining an analysis framework.

Researchers' notes were reviewed individually before an overview of commonalities was compiled to form the analysis framework. All visual data items were evaluated using the analysis framework to assess its applicability as a practical tool for interpreting images and guiding rescription.
The study aimed to assess participant readiness to engage with visual methods and to compare those who volunteered with those who did not for any potential group differences. Qualitative feedback on the experience of providing visual representations of responses was also reviewed for participants' opinions on the difference between using visual methods and verbal (written or spoken) responses. Two further aims focussed on interpreting and using visual data in an intervention-practice context with a view to defining a strategy for interpreting images and identifying possibilities for, and practicalities of, rescripting. Findings are considered in relation to participants' impressions of providing visual data; the nature and interpretation of the data; and application of suitable framework for analysis.

5.5.1 Participant readiness to engage with visual methods

Drawings were provided by forty one survey respondents (17.23%) of whom twenty five (10.92% of all respondents) sent images separately from the questionnaire, with twenty three using traditional mail (the remainder were drawn on the questionnaires or sent as email attachments). Six of the forty participants did not answer the corresponding questions on whether drawing made them think or focus differently and on whether it was useful. Twenty (48.8%) said they found drawing made them think or focus differently from answering questions, fifteen found no difference (36.6%) and six did not respond (14.6%).

5.5.2 Using visual methods: Comparison of volunteers and non-respondents

The study aimed to assess whether participants who volunteered to use visual methods were different from those who did not. A demographic comparison of participants who sent images and those who did not complete this optional part of the questionnaire is provided in Table 20. The percentage of female respondents was slightly higher than male (87.2 compared to 67.3) and they were slightly older at 55.89 compared to 49.71 years but time since diagnosis was similar and percentage who had not experienced relapse was similar. Respondents had slightly higher levels of primary progressive MS and 'other' types and none of the respondents had secondary progressive MS; however, there were no strongly defining characteristics that would suggest the this method may be acceptable to a particular cohort. The pattern of relapses was slightly different for the two groups and among those who
sent an image, the percentage who had not experienced relapse was higher than for those who did not send and image. Although percentages experiencing one, three, and three or more relapses in the last year were higher for those who did not send images, there was a higher percentage of people experiencing one relapse in the group who sent an image (see Table 20).

Table 20: Comparison of demographic mean values for volunteers (v) and non-respondents (n/r) to optional visual response section of questionnaire

<table>
<thead>
<tr>
<th>female %</th>
<th>male %</th>
<th>age months since diagnosis</th>
<th>MS type %</th>
<th>Relapses in last year %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>RR</td>
<td>PP</td>
</tr>
<tr>
<td>v</td>
<td>87.2</td>
<td>12.8</td>
<td>55.89</td>
<td>157.05</td>
</tr>
<tr>
<td>n/r</td>
<td>67.3</td>
<td>32.2</td>
<td>49.71</td>
<td>153.21</td>
</tr>
</tbody>
</table>

5.5.2.1 Influences of MS on volunteers compared to non-respondents

In terms of everyday influence of MS, those who provided visual images responded similarly to those who did not. Table 21 compares current influences and illness perceptions. Table 22 compares recalled phases of diagnosis and illness responses.

Table 21: Comparison of descriptive statistics for mean rating values of current influence of MS on everyday life for volunteers (v) and non-respondents (n/r)

<table>
<thead>
<tr>
<th>GHQtot</th>
<th>Wanas</th>
<th>Coping</th>
<th>SOS mean support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>active</td>
<td>malcope</td>
</tr>
<tr>
<td>v</td>
<td>15.56</td>
<td>25.08</td>
<td>29.92</td>
</tr>
</tbody>
</table>

Scores indicating levels of current responses were similar for those who opted to use visual images and those who did not. Those who provided images showed slightly lower support and an independent t-test found the difference for mean emotional and mean total support to be marginally significant, with \( t = .967 \) (df, 222); \( p = .045 \) for levels of emotional support and \( t = 1.673 \) (df, 222), \( p = .052 \) for mean total support. Although descriptive statistics suggested slightly higher active coping responses among the group who provided images, this was not significant. Illness perceptions were similar for both groups.
Table 22: Comparison of descriptive statistics for mean rating values for recalled influences during phases of diagnosis and relapse for volunteers (v) and non-respondents (n/r)

<table>
<thead>
<tr>
<th></th>
<th>Diagnosis 12-18 months post diagnosis</th>
<th>Relapse responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diagnosis</td>
<td>Impact</td>
</tr>
<tr>
<td>HADSa</td>
<td>BFGStot</td>
<td>IESint</td>
</tr>
<tr>
<td>v</td>
<td>9.89</td>
<td>9.72</td>
</tr>
<tr>
<td>n/r</td>
<td>10.24</td>
<td>105.62</td>
</tr>
</tbody>
</table>

In terms of recalled responses to diagnosis and relapse phases, those who responded with visual images showed slightly lower anxiety and fear at diagnosis but neither score reached statistical significance. Slightly lower responses to both impact and future concern related to relapses (Table 22) and an independent t-test for the difference in impact was significant: \( t = 2.266 \) \((df, 154), p = .038\).

5.5.3 Differences between visual and verbal: Participants' qualitative feedback

The study sought opinions of participants on whether using visual methods was different from filling in a questionnaire or responding verbally in an interview. Comments indicated that drawing invoked emotional responses related to memories. For example, one person wrote 'I hated the neurologist' and another noted that drawing brought back memories of receiving diagnosis:

'It conjured up my feelings of fear and uncertainty very clearly. I was back in the room with the cold uncaring consultant neurologist.'

It seemed possible that drawing could prompt disclosure of aspects that would not be discussed. For example one participant wrote about sexual dysfunction as, '... the most worrying and yet secret symptom at the moment ...'. Another person found drawing different from writing and useful but it was difficult to describe accurately why this was the case. However, this reflection resulted in a description of being isolated with emotions in the early stages after diagnosis:

'I didn't always understand that I wasn't able to do things, so I carried on, trying to keep everything as normal as possible, when it just wasn't. I kept my sopping [sobbing] to the car and when I was away from everyone.'

Drawing seemed to provide a way of thinking holistically and objectively. While one person 'realised how tired in both body and mind I feel' another commented that drawing:

'Made me think of how I look at my attitude to life overall with MS a forced member of it. Made me look from "outside" me as objectively as I can "at" me.'
Drawing also allowed consideration of a collective perspective on problems in terms of, 'potential problems we all face and what we can use to fight the common enemy'.

5.5.4 Overview of visual data: Did images provide detailed responses?
The data demonstrated participants' readiness to participate at different levels. This could relate to the individual, uncertain and complex nature of MS symptoms. Complex and competent responses suggested that an artistically orientated cohort was selected for the study; however, this was not the case and the opportunity to participate was advertised nationally through support groups in the quantitative questionnaires. It was also noted that the range of drawings included simple as well as sophisticated images.

The data included drawings that could be rescripted easily and there were also images showing balanced aspects of responses to MS. This indicated the potential for visual methods as a means of expressing in-depth responses to MS and ethical considerations of using visual methods should focus on implications for participants. This was relevant to images revealing subconscious responses and a coherent strategy for interpretation of images during delivery of intervention sessions was necessary to manage engagement.

The researcher role and influence in intervention context was also important. Some of the images submitted included potentially disturbing and personal responses that participants may produce in a form of 'private' engagement that would not necessarily have been revealed in conversation. The researcher should be occupied while participants were drawing to minimise researcher influence but available for interaction if necessary.

5.5.5 Summary of methods used for creating an image
Figure 15 (see end of section 5.5.8) provides a numbered guide to all images submitted, including those drawn on questionnaires. Spontaneous expressions were expected but there were also formulated and artistic images. Even simple images provide insight into perspectives and reactions that would possibly not be readily described. For example, a dense scribble (28) seemed symbolic of complexity and negativity combined with control in terms of the limited size and shape.

Temporal expressions
Images 20, 34, 33 and 11 indicated how numerical diagrams, such as graphs, were used to express temporal understanding of a range of aspects. The same evaluation of
condition over time was expressed in simple images (31) or complex representations of journeys (24, 9). There were in-depth images based on linguistic interpretation, particularly 15 and 29.

Familiar diagrams or language

The diversity and idiographic nature of the data set were striking. The above examples demonstrate how some participants called upon familiar, diagrammatic representations or language, while others combined familiar sorting procedures (graphs, words) with symbolism.

Drawing, art and annotation

The broad range of expression involved traditional descriptive approaches to drawing and art (13,17, 6, 7, 8, 9, 14, 24, 26) and complex abstract images (4, 19, 18). Participants readily annotated or explained the images and some wrote extensively; however, this was not always the case and, for example, image 18 was uncoded and unexplained.

5.5.6 Research panel findings: Potential approach to framework for analysis

The diversity of responses highlighted the need for constructing a contextual framework that could be applied to a broad range of individual images in order to define the author's meaning making of MS or the aspects of it represented in the image. It was important to understand whether an image was intended to demonstrate reality in a descriptive sense; relate a metaphorical narrative of some situation; or provide a symbolic representation of an aspect. To facilitate intervention delivery, the researcher had to be prepared to deal quickly with different types of approaches. Responding to participants' drawn responses could involve encouraging them to explain or expand on indirect references. The development or amending of ideas could form part of rescripting. Working in the same 'visual language' as individual participants would be important for engaging them in amending an outlook and taking ownership of the extended or revised approach. In order to facilitate a dyadic reflection, the researcher needed a simple analytic framework tool for finding and sharing the visual language.

Figure 14 summarises themes and constructs that were evident in the visual data. Personal images (physical and emotional) of threat, anger, loss, darkness and victimisation were external and internal. Nature as something normal but not controllable was present, particularly in the context of weather metaphors, including
darkness, bright spells, storms, clouds and rain. As a changing feature of nature, weather represented balance of positive and negative spells. However, sunshine as a metaphor for hope could also relate to physiological significance as potentially protective against MS, which is associated with climate and lack of sunlight.

![Diagram showing various elements related to MS and visual data interpretations.]

Figure 14: Summary of research panel interpretations of visual data

Journeys were common, with hazards, trials, hills and diversions, representing either temporal aspects or problems encountered in terms of everyday endurance. Progression was potentially hindered, restricted or blocked. Blocking could be problematic, threatening and limiting in some images, even to the extent of imprisonment. Being trapped or prevented from carrying on with everyday aspects of life was threatening and traumatic. Sadness, fear and threat were often evident.

While some images represented straightforward perspectives or distinct opinions, others indicated the confusion associated with MS. Instead of coherent images of good, bad or an interaction between these, in some cases the different aspects were not clearly linked. Responses could be represented by randomly drawn items. Therefore coherence and unity in some compositions contrasted with uncertainty,
disruption and fragmentation in others. Some images balanced positive and negative responses, opportunity for considering support and introducing positive aspects were clear in others.

5.5.7 Research panel findings: Defining visual language analysis framework

Identifying different approaches in terms of a visual language provides a simple overall framework within which to understand, interpret and engage with participants' images. Categories of descriptive content, symbolism, syntax and holistic representation summarise the type of content, cohesion and flow. The following provide a basis for discussing and rescripting.

i) **Descriptive content** Aspects of direct reference included in images, such as drawings of objects or representations of actual situations. Descriptive content could be represented symbolically, for example by using a journey metaphor. Annotation or comments could provide descriptive content.

ii) **Symbolism** Metaphors and iconic items could be used to represent specific points or reactions. Alternatively, they convey a complex series of responses. A relatively limited figurative form could demonstrate an overall outlook or enduring experience.

iii) **Syntax** This focuses on composition – the coherence, links and flow of content. Whereas some images could tell a comprehensive story about one or more aspects, others could present a series of unrelated responses to different experiences. Structure could indicate understanding or confusion. The composition could demonstrate a well-rehearsed understanding or meaning. Conversely there could be ongoing confusion of multiple ideas or a collection of images created on impulse.

iv) **Holistic representations** This related to the extent and balance of content, either in terms of overall life with MS or in response to a particular aspect.
5.5.8 Overview of rescripting potential

Many images included clear opportunity and direction for rescripting (see Figure 15). For example, image 3 represented a before-and-after annotated response to MS that was catastrophic. The imbalance could be addressed by exploring the potential reality of the shark and helium-balloon images. Considering the multiple sources of help available, both physically and psychologically, as well as the relationship between MS and death, could lead to opportunities for amending the image. Introducing new, less-threatening symbolism could create a better-balanced outlook.

Similar examples of negative images include 10, 12, 13, 14, 20, 25, 30, 31, 32, 36, 37 and 40. Images 1, 2, 4 and 23 could provide an opportunity for solution-seeking and then rescripting, offering a way forward. Some work featured positives as well as negatives and these demonstrated approaches that could be used in rescripting.

MS as a block was common and image 26 symbolised ways around the block; however, concepts of happiness and fulfilment are not static and these change according to different ultimate aims that can be just as rewarding. Therefore it would be possible to rescript the drawing to include revised objectives.

Note: Image 5 has been adjusted to preserve anonymity. The face has been obscured and a grid overlay applied to the image.
Figure 15: Testing analysis framework for preliminary coding of visual data as a basis for rescripting consideration and/or analysis

- Descriptive content
- Symbolism
- Syntax
- Holistic aspects
This feasibility study aimed to find out whether participants in a questionnaire survey of living with MS would additionally elect to draw their responses to the condition. Would volunteers who provided images be representative of participants or would they demonstrate different characteristics? How useful would drawings be as a data source in terms of complexity and richness? The objective was to assess the potential for using visual methods as a basis for an intervention focussed on amending unhelpful perceptions and promoting a balanced outlook for coping.

In spite of the effort to create and mail items, twenty five people submitted images separately from the questionnaire, with two sent electronically. The number and type of impulsive responses on questionnaires also indicated readiness to respond with a drawing and the usefulness of visual methods for expressing responses that may not be verbally processed. Artistic skill was not necessary and the usefulness of data did not necessarily correspond to complexity and artistic effort. Even tiny images conveyed emotional responses and perceptions of MS.

Those participants who responded were demographically similar to those who did not. A small but statistically significant difference indicated lower mean emotional support for those who sent an image and slightly less relapse impact. The two results provide contradictory indications in terms of emotional burden but it is possible that drawing provided an outlet for those who did not share emotions.

All images could be used as a basis for an intervention. While some demonstrated dysfunctional negative perceptions that could be amended, others suggested topics for evaluation, either to promote balanced outlook or understand the basis for emotional responses. These images indicate useful understanding of coping processes, physiological symptoms and meaning making around everyday experiences of chronic illness.

Testing the proposed framework for analysis on the images suggested that it would provide a useful basis for opening dyadic reflection. The concept of a visual language of interpretation to be used as a basis for exploring and amending images in an intervention delivery seems practical. As well as using descriptive approaches to open discussion, syntax or holistic interpretation to explore the narrative in the
image, deconstruction of symbolism could offer a useful basis for reconstruction of a new symbolic image for future reference.

The negative responses to the invitation to provide a drawing signalled potential barriers to using the method and highlight the need for sensitivity. Participants perceived lack of skill or physical disability as barriers, that would need to be clarified or overcome in planning an intervention. The three angry responses also indicated that a minority of participants interpreted the request as trivialising their situation. This highlights of the need for sensitivity and respect, with appropriate explanation and presentation of visual methods as valued and valuable.

5.7 Conclusion and Contribution to Understanding Adjustment to MS

Participants' responses suggested that using visual images for expressing responses to MS would be acceptable. Images may provide broad insight into emotional responses, experiences and approaches to coping. Negative and positive responses to different aspects or holistic experiences could be evaluated and amended. From preliminary consideration, a fundamental approach to analysis was proposed for evaluating the language of imagery. The basic framework suggested provided a mental schematic approach – a way of thinking – to facilitate interpretation and empathetic interaction with participants' data. Using visual methods for expressing and amending perceptions of MS is deemed to be practical and useful.

This feasibility study indicates that visual methods may be acceptable and practical both for researching adjustment to MS and as a potential intervention. Visual methods may enable people with MS to express complex and detailed emotional responses and experiences more easily than by using verbal approaches. The data suggested that rescripting may be a viable method for amending or updating responses or perceptions.
Chapter 6

Study Four

Images of Multiple Sclerosis: Uncovering the Unsaid

6.1 Chapter Overview

Study two provided evidence of links between anxiety and fear at diagnosis and long-term wellbeing. Study three demonstrated three positive aspects of the patient perspective on drawing responses to MS: firstly, a readiness to participate; secondly, images containing rich data; and, thirdly, clear potential for rescripting.

This chapter presents a pre-/post-study to evaluate an intervention using visual methods for representing and rescripting responses to MS. The purpose of the intervention is to promote a balanced perspective in place of unrealistic fears. The introduction (section 6.2) discusses relevant background; section 6.3 outlines aims and objectives; and section 6.4 presents the study method. Section 6.5 presents data preparation. Sections 6.6 and 6.7 provide results and case-wise interpretations considering qualitative findings. Section 7.0 presents a summary, brief discussion and conclusion.
6.2 Introduction

Literature research indicated that potential problems following diagnosis were overlooked; an important opportunity for promoting early engagement with MS was possibly missed, allowing avoidance and/or unrealistic engagement to set an unsuitable pattern for the future. Among five systematic reviews, one key work evidenced poor adjustment resulting from relationships among multiple psychological factors, including perceived stress, uncertainty and emotion-focussed coping (Dennison, Moss-Morris, & Chalder, 2009). High perceived stress, uncertainty and avoidance coping related to adjustment difficulties.

6.2.1 Influence of emotional responses: Present research evidence

The first qualitative study indicated future-oriented fear following diagnosis and emotional isolation were potentially influential in long-term coping. Findings from study two, a systematic review of quantitative research into emotional responses, highlighted anxiety as an under-investigated aspect of response. Quantitative evidence from study three provided predictive links between negative responses to diagnosis and early maladaptive coping; persistent intrusion and maladaptive coping; and continued maladaptive coping with lack of emotional support and poor long-term wellbeing.

A cross-sectional questionnaire study of 238 participants (study three) investigated anxiety responses. Data analysis provided a series of significant regression models indicating that maladaptive approaches to coping and lack of emotional support predicted poor psychological wellbeing; maladaptive coping was predicted by earlier avoidance, intrusion (intrusive thoughts) and anxiety; avoidance was predicted by anxiety and fear at diagnosis stage; and intrusion was predicted by anxiety and fear. Seeking emotional support related to improved outcome. Anxiety and fear around the first few weeks and months of diagnosis predicted avoidance and intrusion 12 to 18 months thereafter, which in turn predicted current maladaptive coping that influenced general health and work and social adjustment.

In a pilot study (study four) into the feasibility of using visual methods, participants from the cross-sectional study were invited to draw their responses to MS. The aim was to investigate whether any participants would elect to use non-verbal expressions of MS; whether drawings would provide additional insight into
responses; and whether visual data indicated the potential for an art-therapy intervention to improve psychological outcome. Forty-one participants submitted expressions of complex responses to MS with representations of journeys, hazards and diversions. Threat, anger, loss and darkness were important concepts. The opportunity for rescripting included introducing supportive concepts or, in some cases, creating a more realistic, less-catastrophic, image for putting MS threat into perspective.

6.2.2 Important influence of images
Knowledge (information) and emotions influence response to risks, such as threat resulting from diagnosis. Perceptions of likelihood of contracting an illness are increased with knowledge about the illness and, conversely, decreased with ignorance (Sherman, Cialdini, Shwartzmann, & Reynolds, 1985), suggesting that heuristics are more influential than rational evaluation. Decisions on how to respond to future threat are influenced by emotional responses, which are subject to the vividness and extent of exposure to the potential outcome (Loewenstein, Hsee, Weber, & Welch, 2001). Results of rational evaluation of the threat – weighing up the chances of risk coming to fruition – based on realistic probability are different from those based on an emotional response, and, when faced with making decisions based on risk, emotions influence cognitions (Loewenstein et al.). Thus, vivid images of disability associated with MS are likely to elicit a powerful emotional response to diagnosis and its uncertain consequences. In a study of imagery related to pain, Philips (2011) noted that people were often unaware of the mental images that demonstrated powerful influence on their emotions, cognitions and behaviour: negative emotions and cognitive interpretations of threat were accompanied by distraction tactics to avoid the images.

6.2.3 Identifying and rescripting images
Research suggests that adults' drawings of their illnesses can provide insight into their perceptions of conditions and, in the case of heart attack, relate to recovery (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). The physical size of drawing related to illness anxiety level as well as rate of recovery following heart attack: the bigger the drawing the greater the concern and slower recovery (Broadbent, Ellis, Gamble, & Petri, 2006). Moving away from physiological definitions on a body outline or representations of familiar heart shapes, free-form drawings of headache
have provided rich insight into holistic experiences of illness (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009). Participants' perceptions were evident in terms of severity, control and time; and the relationship with, along with reactions to, pain. Preliminary analysis of visual data provided by MS participants in the feasibility study (study three) indicated that the content of images reflects that found by Broadbent et al. (2009) in demonstrating rich and holistic insight into individual experiences.

Intrusive or involuntary images are associated with adult psychological disorders, including post-traumatic stress and anxiety disorders (Brewin, Gregory, Lipton, & Burgess, 2010). Rescripting as cognitive therapy to redefine adverse images and introduce more positive aspects has also been successfully tested as a treatment for depression (Brewin et al., 2009) and this method has been as effective as image exposure in treating phobias and intrusive memories in depression (Hagenaars & Arntz, 2012). Hagenaars and Arntz summarised image restructuring as a way of introducing alternative responses and outcomes by proposing an amended image. The meaning of the source stress may be reinterpreted and additional concepts may be introduced, such as support, power and mastery over an underlying stressor. Suggested changes work at a sensory, emotional level rather than at a verbal, cognitive and rational level, thus providing amended heuristic references.

Metaphorical images can be used to help evoke, manipulate and transform negative aspects that are difficult to access verbally (Hackmann, Bennett-Levy, & Holmes, 2011). Drawing can symbolise problems and reflecting on what is drawn can provide step-by-step stages of re-thinking barriers and considering support or strategies for coping with them (Johles, 2005, as cited in Hackmann, Bennett-Levy, & Holmes, 2011, p. 163). Restructuring, or transforming, metaphorical images may involve several stages of drawing and building emotional bridges to the past, which could be useful for overcoming subconscious associated fears about the future that promote avoidance.

6.2.4 Summary

During lengthy pre-diagnosis assessment, patients may encounter images of severe disability related to MS. While these are powerful fundraising tools, they reflect a rare outcome and such images may interact with uncertain prognosis to exacerbate future-oriented fear and promote avoidance. Conversely, engagement and adaptation
are important for long-term wellbeing. Recognising, evaluating and restructuring images associated with MS could promote illness perceptions that include aspects of control and support, which in turn diminish threat and provide less-catastrophic heuristic reference.

6.3 Aims and Objectives

This study aims to evaluate the short-term efficacy of image restructuring as a method of cognitive training. Could visual methods provide a means of encouraging participants to engage with being diagnosed with MS? Are visual methods useful for expressing personal responses and providing a way of amending inaccurate interpretations or dealing with stressful concepts? Three key objectives can be summarised as follows

1 To promote informed evaluation of diagnosis with MS in terms of a balanced perception of long-term outlook. That is, considering the uncertainty and likely prognosis with reference to treatment and other options.

2 Where necessary, to encourage expression of, and address, anxieties, fears and unfounded or unrealistic illness perceptions.

3 To introduce concepts of support, symptom management, neutral or positive future-oriented perspectives and potential personal control as appropriate.

These objectives is addressed by two key research questions.

i) Does engaging participants in an intervention activity using visual methods offer the opportunity to influence a) general mood; b) illness perceptions; c) condition-specific fears about the future; and d) anxiety and depression?

ii) When asked to comment on visual methods, do participants experience any difference in using visual methods instead of verbal or written responses; if so, do they find visual methods beneficial in any way?
6.4 Method

6.4.1 Design
This study is a randomised pre-/post-assessment of an intervention using visual expression methods (a drawing or art activity), with rescripting as an intervention and both within- and between-groups comparisons of responses to a self-report questionnaire. Two one-to-one sessions with each participant were facilitated by the researcher, with the intervention and control conditions embedded in the art activity. Measures of illness perceptions, anxiety, depression, illness-specific fears and mood were taken immediately before the first session and immediately after the second (and final) session. The questionnaire administered at the end of the study included an additional final open-ended question asking for any comments on the sessions. Qualitative data from the final question and participants' drawn images complemented the quantitative data providing a mixed-method design.

6.4.2 Experimental and control conditions
Detailed standard instructions and guideline for delivering both intervention and control conditions are provided in Appendix IV. Intervention and control conditions followed the same format and consisted of two, one-to-one sessions with each participant. The sessions were conducted by the researcher. The same stages were used for both conditions.

Session 1 In the intervention condition participants were asked to represent any response they wished to MS. Participants in the control condition were asked to draw any subject they wished without reference to MS. For participants in the control condition the sessions represented a relaxing pastime or resembled occupational therapy.

Session 2 Participants in the intervention condition engaged in restructuring their images produced in session one. Participants in the control condition produced another general drawing of their choice or experimented with different media.

6.4.3 Measures
Information was collated on condition, diagnosis, duration and cognitive status. The following widely used measures of psychological responses and illness perceptions are established reliable indicators in MS studies. With the exception of the positive and negative affect schedule, these were used in the preceding quantitative study.
i) The brief Illness Perceptions Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006) assessed cognitive and emotional representations of illness. ii) The brief Positive and Negative Affect Schedule (PANAS, Watson, Clark, & Tellegen, 1988) assessed mood state in terms of feelings and emotions. The succinct items are appropriate indicators of responses to health conditions and are easy to administer and complete. iii) A specific measure based on a 10-point Likert scale was used to assess participants' MS-related fears as in the preceding study (in which a reliability test returned a Cronbach's alpha of .93). This scale was adapted from a coronary artery bypass measure, The Bypass Grafting Fear Scale (Koivula et al., 2002). A pilot study into post-traumatic stress disorder following MS diagnosis (Chalfont, Bryant & Fulcher, 2004) also indicated relevant aspects of future fear. iv) Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS-AD, Zigmond & Snaith, 1983, as cited in Johnston, Wright & Weinman, 1995), a 14-item self-report measure of frequency of anxiety and depression symptoms in those diagnosed with a medical illness. This is frequently used in assessing responses to MS as it provides robust, recognised and well-validated measures.

Open-ended questions explored in-depth responses to the sessions. Participants were asked whether, and how, they found sessions enjoyable or beneficial and whether drawing responses to MS was different from answering questions. They were also asked whether they thought it would be useful to draw responses to MS in a small group class situation as well as in one-to-one sessions. All relevant comments made by participants were noted by the researcher. Interactions and prompts by the researcher were noted and retained. The researcher made case notes during sessions and completed them post-session. The researcher wrote a reflexive log after sessions.

6.4.4 Materials
Examples of recruitment stationery, information sheets, consent forms, questionnaire and debriefing information are included in Appendix IV. A standard set of materials and equipment included soft and hard pencils, large carpenter's pencils, charcoal, coloured ordinary and watercolour pencils, felt-tip and marker pens, wax crayons.
(large and small), pastels, chalk (large and small) and an inexpensive palette of watercolour paint. Rubber eraser, large and small brushes, a small sponge and fixative were provided. A few simple general images demonstrating these media were prepared for reference. Paper of different size, type and colour was available. Rolls of wallpaper lining paper were available and these could be stuck on the wall for wheelchair access and to assist participants with limited dexterity, if necessary. Tracing paper was used as an overlay for visual rescripting. The kit was arranged in a small suitcase such that it could be wheeled to participants' homes, if necessary, and opened to display materials. A selection of items and tear sheet images were provided as subjects for participants in the control group to draw.

6.4.5 Participants

The heterogenous and idiosyncratic nature of MS allowed for broad inclusion criteria. Receptionists and centre staff advertised the study and encouraged members to take the information sheets that were provided. They emphasised the fact that 'artistic ability' was not necessary. Volunteers provided contact details on sign-up sheets and the researcher contacted them individually. Preliminary discussions with participants was important to explain inclusion and exclusion criteria. Art experience did not necessitate exclusion but previously engaging in art therapy was deemed unacceptable as knowledge of the method could influence the way people engaged with the activity.

Inclusion criteria

i) Confirmed diagnosis with multiple sclerosis.

ii) Over 18 years old.

iii) Ability to participate in art sessions.

Exclusion criteria

i) Cognitive impairment likely to impair capacity to consent or concentrate long enough to complete a drawing and questionnaire.

ii) Evidence of neurological emotional impairment or condition (such as alexithymia).

iii) Currently participating in cognitive therapy.

iv) Current or previous participation in art therapy.
Twenty-six volunteers expressed interest in the study and twenty one were recruited, including one additional person to replace a participant who declined to draw responses to MS at the beginning of session 1. Two volunteers were excluded for previous experience of art therapy; three withdrew due to personal circumstances.

6.4.6 Demographics

Tables 23, 24 and 25 summarise participant demographic information and MS status.

**Table 23: Summary of age, education and diagnosis status**

<table>
<thead>
<tr>
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<th>max.</th>
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<td>15</td>
<td>24</td>
<td>9</td>
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<tr>
<td>years since diagnosis</td>
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<td>1.5</td>
<td>40</td>
<td>38.5</td>
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<td>years since updated diagnosis</td>
<td>3.58</td>
<td>5.63</td>
<td>1</td>
<td>15</td>
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</tr>
</tbody>
</table>

**Table 24: Types of diagnoses (by number of participants)**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Original</th>
<th>Current</th>
</tr>
</thead>
<tbody>
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</tr>
<tr>
<td>primary progressive</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>secondary progressive</td>
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<td>6</td>
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<tr>
<td>benign</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>other</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

**Table 25: Employment and marital status (by number of participants)**

<table>
<thead>
<tr>
<th>Employment</th>
<th>Marital status</th>
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</thead>
<tbody>
<tr>
<td>paid full time</td>
<td>single</td>
</tr>
<tr>
<td>paid part time</td>
<td>widowed</td>
</tr>
<tr>
<td>unemployed</td>
<td>married / with partner</td>
</tr>
<tr>
<td>other</td>
<td>9</td>
</tr>
</tbody>
</table>

Of twenty-one participants (all Caucasian), one was Australian, one 'British and Maltese' and all others were either British or English. Five participants lived alone and eleven had children. None were diagnosed with emotional or cognitive impairment and none were currently relapsing; however, three had experienced one or more relapses within the last twelve months. Six participants had received updated diagnoses (for example, from relapsing remitting to secondary progressive) and some had never been given a clear definition.

6.4.7 Ethical considerations

The study received a favourable ethical opinion from the University of Surrey Ethics Committee (Appendix IV). Recruiting volunteers from MS therapy centres ensured participants were actively in contact with a support network. The researcher checked
participants' understanding and expectations in terms of art and potential therapeutic benefits. Questions were encouraged and participants were fully informed of their rights before signing consent forms. The researcher emphasised the fact that participants would not be leaving sessions with finished artwork and that this was an academic study, not an art class. The respectful treatment of work, anonymity, confidentiality and the post-study publication or display of work was clarified.

Previous experience of interviews and data-collection at MS centres prepared the researcher for engaging empathetically with participants. Awareness of potential emotional upheaval and being ready to reduce distress was important. There were no instances when sessions had to be diverted or terminated; however, providing suitable time for participants to respond to any unexpected way in which they engaged with their condition was essential. Using visual responses meant that participants faced aspects they had not previously consciously processed. Some were surprised by what they produced. Therefore the stages of review, wind down and debriefing included reflection and validation that were useful for emotional wellbeing. Beginning the rescripting stage at the end of session was also vital for ensuring that participants gained ownership of a suitably balanced perspective.

6.4.8 Procedure
6.4.8.1 Recruitment and randomisation
The contribution of MS Therapy Centres is summarised in section 1.4.3 and reflection on potential sample bias in recruiting from support groups is included in section 2.7.3. Appendix IV includes copies of promotional and recruitment information. MS centre managers and staff were briefed so that all volunteers received suitable information about the study and were able to contact the researcher with queries. The researcher answered queries and organised bookings. Table 26 summarises the procedure in terms of activity stages of the study, including the phases covered within the two intervention sessions.

When twenty suitable volunteers were recruited they were randomly assigned to the intervention or control activity group by picking papers with group allocation out of an envelope. Allocation was either to expressing responses to MS (MS) or taking part in general art activity (NMS). Two one-to-one sessions were booked at the outset when possible, including a rest break if participants wanted to complete both
sessions on the same day. In many cases participants agreed in principle to a time for the second session but reserved the right to confirm the date after the first session.

Table 26: Procedure summary

<table>
<thead>
<tr>
<th>Study stages</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment stages</td>
<td>Poster awareness, info sheet from centre, provide contact details, discuss with researcher inclusion/exclusion</td>
</tr>
<tr>
<td>Pre-session liaison</td>
<td>Understanding, MS or NMS groups, expectations, book session 1 and book/pencil in session 2</td>
</tr>
<tr>
<td>Sessions: 90-120 mins</td>
<td>Phase 1, Phase 2, Phase 3, Phase 4</td>
</tr>
<tr>
<td>Session 1</td>
<td>Informed consent, Pre-questionnaire, Warm up, Time-one activity, Activity review, Reflection and validation, Rescripting / prep for session 2, Close</td>
</tr>
<tr>
<td>Session 2</td>
<td>Recap, Warm up, Time-two activity, Reflect and validate, Post-questionnaire, Evaluation, Debriefing, Questions</td>
</tr>
</tbody>
</table>

Participants were aware that they may be asked to draw responses to MS, and the researcher checked that this would be acceptable, but they were not informed of the group to which they had been assigned until the first session. The researcher asked participants to try not to think about the sessions in advance. One person stated at the beginning of the first session that drawing MS would not be acceptable and was reassigned to the NMS control group (rather than being turned away). An additional participant was recruited and assigned to the MS group. This resulted in 11 NMS and 10 MS participants.

6.4.8.2 Study environment, set up and approach

The same procedure was used for all participants, in both intervention and control activity conditions (see Appendix IV). The room was arranged in a standard set up. Travel difficulties meant that three sessions were held in participants’ homes but the same materials were available. The researcher pointed out that she would take notes throughout and some participants contributed to these. The researcher opened the activity by describing materials and demonstrating (all such prompts were retained). During sessions, the researcher was encouraging and non-judgemental. Support was provided on request but the researcher avoided directing the content or development of images. Participants took control of their activity and decided when they had finished. They were invited to comment on and discuss the image. If prompting was necessary, participants were asked if any title came to mind.
6.4.5.3 Questionnaire completion

Pre-intervention measures were completed at the beginning of session one, before participants were informed of the subject for their activity (that is, whether they were in the intervention or control activity group, expressing responses to MS or engaging in general art). Post-session measures were taken at the end of session two, before debriefing and thanking the participants.

6.4.5.4 Session 1

For both intervention and control conditions, it was important to creating a trusting, supportive, confidential and non-judgemental environment. Participants were assured that the researcher was neither an art teacher nor a therapist and settled into a relative comfort zone with context and activity. Participants were told that the quality or finished nature of work was not important and reassured that they were not being covertly psychoanalysed.

Participants needed minimal support once they began work and took the lead in deciding when it was nearing completion. The pace varied and some participants produced more than one image. All participants were satisfied that they had reached task saturation in terms of not wanting to continue developing an image or creating further images. Participants were invited to reflect on the image and this developed into a dyadic process, with the researcher prompting or inviting different consideration. When an alternative perspective could be offered, the researcher asked permission to comment and tentatively suggested ideas.

The first session closed with discussion of the image produced and ways in which it could be rescripted, if relevant. A rough visual record of potential restructuring was made, either as notes or on a tracing-paper overlay. The researcher sought participants' validation for all notes and retained all work.

Participants in the control condition ended the session by discussing their work and the ways in which they could develop the subject or method, or whether they wished to attempt something different in the second session.

6.4.8.5 Session 2

The procedure was the same for participants in both intervention and control conditions (see Appendix IV for researcher guidelines). Work from the preceding session, any overlay and preparatory notes from session one were set out and participants confirmed the direction in which they wished to progress. Researcher
guidance and suggestions for reflection were provided either when requested by the participants or with their permission. The second session sometimes involved simultaneous activity, reflection and validation. Participant ownership of the activity and its conclusion were important. The questionnaire was completed and participants were asked for their perspectives. Debriefing ensured participants were comfortable with their perspectives and they were reminded of support and resources available.

6.4.8.6 Summary comparison of activities in intervention and control conditions

**Intervention condition**

1. Produce art based on response to MS
2. Evaluate meaning of image
3. Plan rescription of meaning
4. Revise image based on meaning

**Control condition**

1. Produce art based on any subject
2. Evaluate art technique/method
3. Rescript art approach or topic
4. Revise technique or topic

6.4.8.6 Rescripting procedure for closing session 1

A sheet of tracing paper was prepared for covering the image and the researcher explained to participants that rough sketches or notes would be made in preparation for the second session. While the approach was the same for both intervention and control conditions, obviously the nature of reflection and discussion for participants taking part in the intervention was different from general evaluation of art activity. Participants in the control condition discussed their artistic endeavours, the topic, technique, composition and how they would like to progress.

In the intervention condition, participants were encouraged to discuss the content and meaning of their images. Three approaches were prepared in case participants in needed encouragement to evaluate and discuss their images.

1. Invitation to describe image.
2. Invitation to consider meaning of image.
3. Invitation to give the image a title.

Comments were noted and participants were invited to explain or verify the notes and any interpretation made by the researcher. Participants were invited to consider
the meaning and interpretation of their images, how these could differ and ways in which the image could be altered to demonstrate different meanings or responses. Participants were invited to sketch changes or make notes on the tracing paper overlay. All records about the images made by the researcher were with the permission of participants and validated by them. The rescription process was closed when the participant considered that it was complete, with no further comment or benefit to be gained from discussion.

At the end of the first session, the researcher and participant checked that the image, tracing and notes were appropriate for beginning the second session. The researcher retained the images and booked or confirmed the second session. The researcher closed by summarising the session and rescription, ensured that participants were not distressed and that they knew what to expect next session.

6.5 Data Preparation

Items for the Brief Illness Perceptions Questionnaire were analysed individually; Positive and Negative Affects Schedule items were analysed individually; total positive affects and total negative affects scores were computed; adapted Bypass Grafting Fear Scale was analysed individually and as a total score; Hospital Anxiety and Depression Scale was re-coded so that scoring consistently represented the same outcome direction. Total scores for anxiety and depression were computed.

There were two sets of missing values at time two data collection, one in each condition. One paraplegic participant went on holiday. She had booked the second session for the day before leaving but did not turn up due to packing (she frequently missed appointments at the centre). During the first session (at her home due to transport issues) essential drawing stages for NMS group study participation were completed, but the participant was positive about wanting to participate in another session and therefore the post-intervention questionnaire was not completed. Another participant (in the MS group) could not complete session two due to commitments to an elderly parent who was unexpectedly hospitalised and discharged.

Distribution was checked using skewness and kurtosis, with a Z score value above 2.58 as cut off for this sample size. Data were normally distributed with the exception of treatment control among illness perceptions. Data were checked for
outliers using boxplots; since the data set was small, outlier scores were considered to contribute to the overall story and were retained. A mixed two-way analysis of variance (ANOVA) was used to assess pre-/post-intervention effects within and between the MS and NMS groups.

6.6 Results

The research evaluated the influence of visual methods on quantitative measures of mood, illness perceptions, fear, anxiety and depression. Open-ended questions assessed participants' experiences of participating in the study and feedback on perceptions of benefits or drawbacks.

6.6.1 Summary descriptive statistics

The questionnaire evaluated responses among the MS and NMS groups before and after the activity. A study specific measure evaluated fears. General mood (positive or negative affect), depression and anxiety were measured. Summary group descriptive statistics for all scales are provided in Table 27.

Volunteers were told before booking that participation could involve drawing responses to MS and the researcher requested that they should try not to think about this in advance. Activity group assignment was not confirmed until the start of the session. However, comparing baseline scores, the MS group demonstrated higher adverse responses, suggesting that being assigned to the MS condition had some negative influence. For example, in terms of illness perceptions (IPQ items), concern (MS = 6.1; NMS = 3.91), identity implications (MS = 7.4; NMS = 5.55) and emotional impact (MS = 5.4; NMS = 3.64) were higher. From the measure of positive and negative mood (PANAS), total negative affect mean score was higher for the MS group (MS = 16.6; NMS = 14.27), while total positive affect mean score was lower (MS = 34; NMS = 36.27). MS responses to the majority of items on the fear scale (BGFS) were higher than for NMS and mean total fear, anxiety and depression (HADS-a/-d) were higher for the MS than for the NMS group (MS = 93.4, 5.1 and 6.1 respectively; NMS = 57.9, 3.18 and 4.45). By comparison, perceived understanding of the condition among illness perceptions – potentially beneficial for coping – was higher (MS = 8; NMS = 6.73).
Table 27: Comparative summary group descriptive statistics for MS and NMS groups
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MS mean (M) group scores

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7.1
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7.4
7.56
6.1
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7.22
5.4
5.33

NMS mean (M) group scores
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1.24
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1.51
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3.01
3.62
3.41
3.95
2.94
3.13
2.98
3.2
2.88
2.72
2.4
1.89
2.62
2.16

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3.84
3.23
2.05
2.78
1.61
3.77
3.35
2.95
2.92
2.45
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3.6
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36.27
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Time one and time two results across scales and items fluctuate without coherent patterns of consistent change. Case-wise scores for MS (experimental) and NMS (control) groups are tabulated in Appendix IV, with individual changes of at least two score points highlighted to indicate the lack of consistent improvement or deterioration in individual cases, either by scale or across all items.

6.6.2 Inferential statistics
A mixed two-way analysis of variance (ANOVA) was used to assess pre- / post-intervention effects within and between the MS and NMS groups for illness perceptions, positive and negative mood sub-scales, fear, anxiety and depression.

6.6.2.1 Within-groups Effects The ANOVA did not reach significance for positive affect, negative affect or fear, indicating that there were no main effects represented by pre- / post-intervention scores within groups. There was no significant interaction effect between the MS and NMS groups for difference in pre- / post-intervention scores on these variables. ANOVA results for illness perceptions provided small but statistically significant main and interaction effects for perceived consequences: $F(1,17) = 5.26$ (partial $r^2 = .24$), $p = .035$ in both cases. Perception of consequences was unchanged for the MS group but the consequences were perceived as lower post-intervention for the NMS group, see Figure 16. A paired-samples $t$ test for

![Figure 16: Comparison of pre- (1) post-intervention (2) IPQ consequences scores by MS and NMS group](208)
differences in pre-/post-intervention IPQ consequences scores did not reach significance for the MS condition. The reduction in post-intervention perceptions of consequences for the NMS group was statistically significant: $t(8) = 2.86, p = .021$. Difference in consequences pre-intervention between MS and NMS groups did not reach statistical significance. The difference in post-intervention scores between groups was statistically significant: $t(8) = 2.38, p = .029$.

6.6.2.1 Between-groups Effects ANOVA results for between-groups effects did not reach significance for illness perceptions, mood or fear. While results for anxiety did not reach significance for main effects for within-group pre-/post-intervention scores, there was a small but statistically significant difference between groups $F(1,17) = 4.27$ (partial $\eta^2 = .20$), $p = .054$. The modest interaction effect according to group was also significant $F(1,17) = 7.91$ (partial $\eta^2 = .32$), $p = .012$. Anxiety levels differed for the MS and NMS groups at both pre- and post-intervention assessment; however, while anxiety had reduced at post-intervention stage for the NMS group, it had increased among the MS group (see Figure 17). A paired-samples $t$ test for differences in pre-/post-intervention anxiety scores did not reach significance for the MS group; however, the reduction in post-intervention anxiety scores for the NMS group was statistically significant: $t(8) = 3.04, p = .016$. An independent

![Figure 17: Comparison of pre- (1) post-intervention (2) anxiety scores by MS and NMS group](image)
samples analysis of difference in anxiety pre- / post-intervention between MS and NMS groups did not reach statistical significance.

An overall reduction in depression scores at post-intervention for both groups was statistically significant $F(1,17) = 5.55$ (partial $n^2 = .25$), $p = .031$ but the effect size was small. There was no interaction according to MS or NMS group, as shown in Figure 18. Paired-sample t test of separate pre- / post-intervention scores for MS and NMS groups did not reach significance. Although the data indicated an overall reduction in depression, the effect was not significant for the smaller within-groups sample sizes.

![Figure 18: Comparison of pre- (1) post-intervention (2) depression scores by MS and NMS group](image)

### 6.7 Case-wise Interpretations and Qualitative Data

Differences in results between MS and NMS groups are not characterised by distinct patterns of statistics. Complementary evaluation of case-wise descriptive statistics, particularly in terms of illness perceptions and fears, and participants’ feedback reveals possible explanations for the seemingly random shifts.

Participants were asked for their general impressions of the activity, whether it was useful or beneficial in any way and, if so, how. They were invited to comment freely about the experience, their drawings and whether sessions made them think about MS in a different way. Many participants commented throughout sessions as
well as at the end. To contextualise participants' comments on the experience of taking part in the sessions, they are considered in the context of descriptive statistics.

6.7.1 Comments and feedback from control group: Non-MS images

Feedback from participants in the control group (NMS), who did not draw responses to MS, could be summarised under three key headings of enjoyment, relaxation and escape; ability; and involvement. This focus on general mood reflects greater improvement among individual participants' mood scores for NMS group compared to the MS group (see Appendix IV). By comparison, there were higher mean score changes in responses to illness perceptions (IPQ) and fear (BGFS) among participants in the MS group.

Enjoyment, relaxation and escape

There were several straightforward expressions of enjoyment, such as "What a lovely time I've had" (C4) and "I've enjoyed it" (C3, C9). Enjoyment and relaxation together meant participants defined the experience as "occupying time peacefully" (C5) and "relaxing is positive" (C11). Escaping from MS was "freedom", "total focus on something outside yourself" and "nothing to do with anything else", all of which "lifts you" (C3, referring to mood). One participant summed up the sessions as:

"Good to escape from the reality of MS rather than sitting and doing nothing. Pondering MS. (C9)"

Ability

Practical methods of overcoming lost dexterity seemed to improve mood. One participant (C1) described "realising" that it was possible to take control of materials and equipment, and therefore to enjoy doing art rather than being frustrated by it. Although it was "difficult to put an absolute value on anything" in terms of responding to the questionnaire, "sessions opened up possibilities" and it was as though a "closed book becomes open". He described his paraplegic situation and lack of dexterity in terms of "working with [a] failing instrument" but through sessions he could find "another way to do things" and this provided a "route map for future reference". This common opinion was also summarised by a comment that it was "hard to find things you or anyone can do" and lost ability meant that it was good to "try new things instead of being put off [by those that I] could not do as well" (C6).
Involvement
Referring to isolation, one participant noted that, in spite of MS, art showed she had "still got something to offer" and she could join a group because "if you don't go out and join the world, it forgets you" (C9). The sessions gave another participant the "enthusiasm for doing something" and she would "join a group with others" with MS and physical disability, a group where she "could get around and see what others were doing " (C3).

6.7.2 Comments and feedback from experimental group: MS images
Whereas comments from the NMS group revolved around the general effect of participating in the activity, feedback from those who had expressed responses to MS related to the experience of producing, and considering the content of, the images. While those in the MS group enjoyed the sessions, and scores indicated improvement or increase in scoring for positive change, there were some references to negative implications. For example "Drawing MS was exposing, intense ... [I'm] Not upset but angry at negative [aspects]" (C8). This participant had "had psychotherapy in the past and it was exposive – I bared my soul." Drawing was similar but the experience of the sessions " was positive ". Distress or guilt about unrelated situations surfaced, for example, the recent death of a parent (C17). These aspects could explain poorer scores for MS than NMS group, as representative of temporary deterioration.

Cases 7, 15 and 19 are used to illustrate the process of rescripting. Results for these participants show relatively large changes (see Appendix 6) and their comments are summarised individually. In general the overall experience of participating was summarised under the three headings of finding balance; alternative options; and holistic perspective.

Finding balance
A need for acknowledging balance was exposed during the process of creating an image (C7) or realised, sometimes through an insightful process, when reviewing the result. When one participant "stood back and looked at the drawings" this "brought a balance" (C2). Furthermore, a week after the second session, he found telling his wife about the experience and the images useful for confirming that there was "no point in going back to a dry well" but that he had to "bring in the things that were
possible, not only what was not" for a balanced outlook (C2). This was also described as "this was positive – gave mental balance" (C8).

**Alternative options**

Sessions facilitated insight into a different perspective on some aspects of life, realising that there were alternatives or "other things to turn to" (C2) and opening eyes to "different approaches" (C15).

**Holistic perspective**

The opportunity to consider responses to MS holistically was unexpected for many. This reflexive approach confirmed or amended multiple aspects that were possibly overlooked. One participant summarised this response and its potential benefits in the following way:

"Interesting – putting all thoughts and feelings together. Do not usually do this. Seeing it on paper gathers all together in one place. Not thought of it holistically before ... Good to get an holistic view ... Often think about different aspects but don't often think about it holistically." (C17)

The ability to bring everything together was possible because it did not "need a lot of words... This was also good because could do it with a few words." (C17). The participant knew "friends/people who do struggle and have not come to terms with MS" and made the following comment:

"this would be good for those who struggle with articulating ... Realistic ... good form of expression for coming to terms with MS" (C17).

**6.8 Examples of Rescripting**

Although rescripting involved the researcher in encouraging and prompting participants as they reviewed their images, and many participants closely followed the procedure through from first image and tracing overlay to producing a revised image, all participants took ownership of the process of revision as well as the final image. Appendix IV shows MS group rescripting. Ownership was demonstrated by participants' selective use of prompts or suggestions to develop interpretations. Some participants individualised the process by drawing more than one image, changing media or completing quickly and opting also to draw a non-MS subject. Three cases are selected to show different approaches to rescripting. The pseudonyms Michael (C15), Anne (C19) and Linda (C7) are used.
(i) **Michael** (C15) Aged 61, Michael was diagnosed 19 years ago with relapsing remitting MS. He uses a stick. Married with young grandchildren. Recently made redundant but with good work prospects.

(ii) **Anne** (C19) Aged 40, Anne was diagnosed 4 years ago with relapsing remitting MS. She uses sticks, lives with her partner and works full time.

(iii) **Linda** (C7) Aged 60, Linda was diagnosed 17 years ago. Her diagnosis was not defined by one of the standard terms until her updated diagnosis of secondary progressive 1 year ago. Linda cannot walk far, uses a mobility scooter and sticks in the house. She stopped working in recent years.

### 6.8.1 Michael (C15)

Although Michael was stressed during the early stages, he commented that he found the sessions "very enjoyable", "very useful and interesting". He described the experience as one of "seeing what's going on in my life" and it had "opened [my] eyes to different approaches and how I can change certain things in my life". He realised he could adopt a "more realistic approach".

Michael's fear scores fluctuated and he demonstrated both an increase in negative outlook and improvement. These include illness perceptions of reduced comprehension, personal and treatment control along with increased concern; however, emotional impact was slightly lowered. Fear associated with wheelchairs was reduced: 2 to 1 in terms of images of disability and 8 to 5 for being in a wheelchair (BGFS items 2 and 9). However, particular increases on the fear scale were being able to care for his family (item 11, 3 to 8), carry out everyday household tasks (item 14, 2 to 8) and being able to get out and about alone (item 17, 1 to 9). Sessions provided the opportunity for Michael to express the well-formed negative images he already carried in his head. They related to fears of reduced mobility, reluctance to use a wheelchair and isolation with helplessness.

Michael asked to see his scores and commented that he felt he had been through a lot during the sessions. He was not surprised that some of his fear scores were elevated. He realised he had to take some control. This was important and he kept repeating the fact that sessions had been useful.
Session 1

Image 1: Michael is unsure how to express feeling separated from grandchildren

i) Decreasing mobility: cannot walk far
ii) Missing out on grandchildren growing up
iii) Isolation: left at home
iv) Red football: no reason for red

Figure 19: Session 1, image 1

Rescripting: Note Michael’s discussion of Image 1 and reflect options for change

i) Grandchildren growing away from him: he cannot play with him, so they do not know him
ii) Practical ideas: crafts, cooking, scrapbook
iii) Mechanics of interaction: shared activities

Figure 20: Rescripting notes for image 1

Image 2: Michael takes ownership of idea for shared activities with grandchildren

i) Maps out loose pebbles in one area of the garden
ii) Grandchildren like aliens: he will paint family of aliens on pebbles
iii) Grandchildren keep pebbles in pocket: they like this sort of thing; they will remember him

Figure 21: Rescripting image 1

215
Session 2

**Image 1:** Michael wants to share an existing persistent and powerful mental image

i) Dinghy, lost, helpless, no oars  
ii) Dark green sky and black rough sea  
iii) Oilskins and hat only protection  
iv) Boat filling with water but it will not sink  
v) Bright light in far left corner over the horizon  
vi) Help will come but do not know when or how

Figure 22: Session 2, image 1

**Rescripting:** Discuss alternative interpretations and simultaneously build Image 2

i) Boat in trough between waves  
ii) Green sky and light over crest of the wave  
iii) Will help be visible when sea becomes calm?  
iv) Quay with life belts  
v) MS centre: people throw life belts  
vi) He has to shout; has to take charge of getting help

Figure 23: Session 2, rescripting image 1
6.8.2 Anne (C19)

Anne said it was "good to try something different ... nice to try something you used to enjoy". Having MS meant it was easy to "get bogged down" in reduced options and think in terms of "I can't do this, I can't do this ... This is what it's like". The sessions had been "relaxing, [a] breath of fresh air" and provided Anne with an alternative pastime to try "at home – can doodle – will do something ".

Anne described her panic at being trapped alone in a symbolic black whirlwind that was dragging her down. Restructuring on a tracing paper overlay explored the way Anne escaped and moved towards sunlight. She had methodically found solutions. Image 2 was drawn in the same session. It reflected the process she initiated unaided, in fear and determination, by crawling into her car, driving with failing eyesight to hospital, abandoning the car and feeling her way along the walls in the building.

Anne decided to continue with a non-MS drawing in her second session, when she returned after a break. She became confident and inspired. In post-activity questionnaire responses, Anne's fear of memory loss or confusion, not being able to cope with household tasks or being able to get about alone, and losing eyesight had not changed but all others had reduced dramatically. Her illness perceptions of personal and treatment control had increased (5 to 8, 0 to 8 respectively), while concern and emotional impact had reduced (9 to 5 in each case).

Reflecting on her experience of loss of eyesight and mobility provided a perspective on the way she had sought help alone and dealt with the crisis. This was different from her previous focus on being trapped without help. Her confidence in being able to cope seemed to have increased. There was dramatic change in her drawing: when she outlined her hands, then linked the shapes, she looked confident and delighted. Observing was breathtaking.
Session 1

Image 1: Anne strongly expressed lack of confidence in ability to produce image

i) Trapped in black whirlwind with symptoms
ii) Lost mobility: crawling from house to car
iii) No help from social, familial or NHS sources
iv) Drove to hospital, eyesight failing and distorted
v) Dragged herself out of blackness

Left. Figure 24: Session 1, image 1

Rescripting: Analyse how Anne progressed from bottom left to top right in image 1

i) Never say no: Ann crawled into A+E
ii) Physiotherapist reduced acute spasticity
iii) Pilates/personal trainer re-built mobility
iv) Process: determination and management
v) New home to suit disability
vi) Problem of financial burden

Left. Figure 25: Session 1, overlay on image 1

Image 2: Not confident but likes colour, selects pink and yellow crayons

i) Anne's ability and outlook are central
ii) Defines problems; works out solutions
iii) Spends money on help
iv) Physiotherapist as angel
v) Money problems: cannot give up
vi) Pale image: encouraged to crayon confidently

Left. Figure 26: Session 1, rescriting image 1

Session 2

Image 3: Anne re-stated lack of confidence but wanted 'have a go' at drawing

i) Why not draw buttons?
ii) Sheet of wallpaper
iii) Outlines buttons, cup
iv) Pauses; outlines hands
v) Prompt: link circles?
iv) Energetically continues

Left. Figure 27: Session 2, non-MS
6.8.3 Linda (C7)

In session one Linda described herself symbolically as a flower:

"almost complete with just a couple of broken petals ... this is the positive person. Still bright, colourful and jolly; just slightly damaged."

She had thought about it and this was what she wanted to say. There seemed to be little to rescript. She worked meticulously, absorbed in her drawing. She thought about session two and said she would do a collage.

Linda arrived prepared for the second session. She realised she had been collecting negative images of loss, such as not being able to wear high heels, missing walking hand in hand with her husband and not being able to dance. So she decided she needed to include the positive aspects of her life; for example, her mobility scooter brought her freedom and mobility, her religious faith, her garden with birds, her hobbies, holidays and being able to hold her grandchildren on her lap even if she could not carry them when standing.

Linda commented on taking part, saying, "It was the best thing I've ever done ... it balanced my thinking". She said filling in the questionnaire made her sad. However, the experience of creating the collage was positive because it was difficult to explain MS. Her husband could not deal with her MS and although she tried to tell him how she felt he would not listen. Whenever she tried to tell him, he could not deal with it. "He said he was not listening". She wanted a copy to show him, so that he could see what it was like, then he would understand.

Going over her life with MS was accompanied by deterioration in outlook. Affect and emotional impact were inflated (8 to 9, 3 to 9) as was negative affect (15 to 32) and fear of disability images (4 to 8). Despite these scores, Linda was inspired and relieved by the collage, which was a vehicle for sharing emotions that her husband would not listen to. Linda continued to comment on how positive and beneficial the experience was for days and weeks after the session. It seemed to address the emotional isolation imposed by her husband.
Session 1

**Image 1:** *Linda already has a strong image of herself and MS*

i) She is a flower with damaged petals  
ii) Damage is only a small part of the beautiful flower  
iii) MS is part of her but it does not define her  
iv) She is still a happy, beautiful, smiling person  
v) She would like to do a collage next

*Left. Figure 28: Session 1, image 1*

Session 2 (2 weeks later as Linda was away for a week)

**Image 2:** *Linda researched, evaluated and prepared images to represent MS*

i) Loss  
ii) Positives added: My MS versus Me  
iii) Iconic image: sports car adapted for disabled drivers  
iv) Balanced reality  
v) Fold back car door to see representation of her  
vi) This shows her reality of life she can enjoy  
vii) He will see this: he does not want to talk about MS but he will be able to see the balanced picture in this collage

*Left. Figure 29: Session 2 collage*

*Figure 30: Session 2 collage detail*
6.9 Summary of Findings

The current pre-/post-activity study evaluated an intervention based on visual methods for expressing responses to MS. Would the use of non-verbal means influence illness perceptions, MS-specific fears, mood, anxiety and depression? How would participants describe the experience of drawing responses to MS?

The study demonstrated that participants were willing to take part in one-to-one sessions involving drawing and they were capable of visual expression. Artistic ability was not a prerequisite as diagrams or symbolic shapes worked well. Freedom to engage in an individual way in the sessions and the rescripting process, in particular, was important, especially for participants who had limited mobility or dexterity. Two sessions were adequate opportunity for expressing, evaluating and rescripting responses. Time at the end of sessions for taking ownership and interpretation was important and colour photocopies of the images were sent to all participants at the end of the study. Many participants engaged the researcher in conversation in the days and weeks after they had completed their participation to share their reflections on the sessions and provide feedback. There were clear indications that visual methods modified preceding ideas and installed mental images that were easily remembered. It was interesting to note that some participants remembered how drawings changed from a negative image and the way they had actually drawn the revised picture. The practice of drawing seemed to act as a stamp of ownership. The drawing itself became an unchanging item of reference and participants were surprised at the richness of content.

Results were compared for an experimental condition (MS, drawing responses to their condition) and control condition (NMS, engaged in general art). Whereas descriptive statistics suggested greater improvement post-activity in the MS condition improvement than for the NMS group, inferential analysis did not provide significant results for main effects of pre-/post-intervention scores for mood or fear. The only changes to reach statistical significance were small effects in terms of reduced anxiety and reduced perceptions of consequences for those in the NMS condition rather than the MS condition.

Whereas case-wise descriptive statistics demonstrated broad fluctuation with no consistent patterns of change across illness perceptions, fears and mood, considering
participants' perceptions of the experience alongside their scores indicated strong potential for overall benefit. Implications for outlook, identity and actions can be summarised as inter-dependent and representing a map for coping rather than an instant solution.

i) Sessions demonstrated that by visual methods, participants could express and realise that they were isolated with fears or negative responses they had not verbally expressed or were not fully conscious of.

ii) Rescripting provided opportunity for evaluating concerns or problems, putting them into perspective and, if applicable, indicating potential solutions.

iii) Considering adopting some solutions could mean confronting unwelcome realities, such as acknowledging deterioration in mobility.

iv) The readiness to own alternative perspectives or ways of coping could necessitate taking personal responsibility or control.

v) Confidence was necessary to express responses, engage in a reflexive evaluation and express readiness or ability to deal with the consequences.

6.10 Discussion

This study focussed on the potential for using visual methods as a method for intervention to elicit and amend responses to MS. People may experience intrusive or involuntary images related to psychological disorders, including post-traumatic stress and anxiety disorders (Brewin, Gregory, Lipton, & Burgess, 2010). In researching the experience of illness, drawings of physical images have been shown to provide insight into anxieties and perceptions of illness in the case of heart attack and relate to recovery (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). The physical size of drawings were found to be relevant, with bigger drawings related to greater concern and slower recovery (Broadbent, Ellis, Gamble, & Petri, 2006). Non-physical representations have also been researched and abstract impressions of headache have provided rich insight into holistic experiences (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009), with perceptions evident in terms of severity, control and time; and the relationship with, along with reactions to, headache pain.
Art therapy is generally thought of as an aid to diagnosis in terms of analysing drawings produced by patients. It has also been tested as a therapeutic method to address unhelpful responses, which involves rescripting as cognitive therapy to redefine adverse images and introduce more positive aspects. This has been successfully tested as a treatment for depression (Brewin et al., 2009) and shown to be as effective as image exposure in treating intrusive memories in depression (Hagenaars & Arntz, 2012). Metaphorical images can be used to help evoke, manipulate and transform negative aspects of response that are difficult to access verbally (Hackmann, Bennett-Levy, & Holmes, 2011). Drawing can symbolise problems and reflecting on what is drawn can provide step-by-step stages of re-thinking barriers and considering support or strategies for coping with them (Johles, 2005, as cited in Hackmann, Bennett-Levy, & Holmes, 2011, p. 163).

The characteristics of images produced by the participants in this study (study four) corresponded to those in research cited above. Many illustrated multiple aspects of the physical MS experience, illness perceptions and responses referred to by Broadbent et al. (2004; 2006). In addition, there were indications of approaches to coping and how these changed over time, for example from crouching in a black hole to gradually emerging towards sunlight through downcast to upright stages. Some of these visual images represented condensed, complex equivalents of verbal narrative, demonstrating past, present and future perspectives. The data reflected the findings relating to headache pain (Broadbent et al., 2009) by using abstract images and also including metaphorical indicators of complex and sometimes long-term relationships with MS. An image of a plant gradually withering in places, still living in others and not actually dying demonstrated some complexity proposed by Hackmann, Bennett-Levy, & Holmes (2011) and the participant gradually rescripted it to include multiple images of protection, nurturing and improvement.

Illness anxiety in these images was not evident in large size as found by Broadbent, et al. (2006) but seemingly related to confidence or control. Small, tight drawing reflected aspects of high anxiety or low control. This could reflect the lack of coherence and uncertainty around MS. While some participants created one picture, many drew several small images, in some cases linked to form a coherent narrative or in others left as separate unrelated aspects. Complexity, flow and coherence grew as participants worked, suggesting that the visual task evoked
forgotten aspects or intrusive memories (that were occasionally upsetting) as suggested by Hagenaars and Antz (2012).

All participants took ownership of their images and the rescripting task. There was unanimous surprise at the extent of expression and insight. Some participants worked silently, others commented as they were working or readily offered an explanation when they had finished. Some looked silently at their work when they had finished or at the very end of the task and expressed their different responses, including surprise at the holistic nature or individual aspects of what they had created. There were instances when participants suddenly realised what they had to do (as in the rescripting of the boat-at-sea image and recognising the need to take control) or realised what they had done. One participants’ countenance changed as she realised how she had managed MS problems. She progressed from drawing a pale, timid image to creating a large, energetic and colourful abstract picture, with growing confidence as she completed the task.

The depth of information and coherence that was achieved through making and rescripting images could not have been achieved verbally. Although the task induced sadness in some participants, they all felt the process had been valuable. Some commented on the fact that they felt their responses to the questionnaire at the end of the task were probably negative because completing the task had make them go back over all their responses to MS. Although they felt negative about MS, the images provided a positive perspective and a balanced view of how they could deal with – or had dealt with certain aspects – of the condition.

6.11 Study Limitations

Completing the questionnaire immediately after the sessions seemed to influence the results and at least two participants commented on this, while others seemed to find it stressful. Completing the questionnaire immediately before the study could have been emotionally disruptive, which may have influenced baseline scores. The participants were all members of MS support groups, therefore responses in this study will not necessarily represent those of recently diagnosed patients or persons without support. In such circumstances it may be necessary to provide more than two sessions to elicit rich responses and promote evaluation.
6.12 Conclusion and Contribution to Understanding Adjustment to MS

Participants described the experience of participating in positive and beneficial terms even though they also said that considering and describing MS was stressful. The study contributed to the understanding of adjustment by supporting findings from preceding studies in this research, demonstrating fears and anxieties experienced by those diagnosed with MS and, furthermore, reinforcing their fluctuating nature across all stages of the condition. This study also showed how these fears could be retained, disrupted or resolved.

Visual methods afforded the participants and researcher holistic and detailed insight that could not have been accessed quickly or in a few words. Drawing provided opportunity for reflecting, confirming and validating past responses and experiences in the current context as well as with reference to future possibilities. The storied nature of the visual method corresponded to narration but the unique opportunity for rescripting opened valuable possibilities for therapeutic resolution.

The ways in which participants engaged with, and responded to, the study suggested that this type of intervention would be helpful for those who have long-established identities with MS as well as for the newly diagnosed, particularly for assisting people facing changing illness circumstances.
Chapter 7

Discussion

7.1 Chapter Overview

This chapter reviews the key contribution of each study before considering the collective findings of the research in response to the thesis. The findings are discussed in the context of relevant models of chronic illness and published research, in terms of the support for these results and aspects that do not map on to existing theories. Implications for future research and practice are assessed and the potential contributions of this work are considered with reference to its research limitations.
7.2 Research Overview

This thesis proposed that early maladaptive responses to diagnosis are not necessarily a temporary phase and unresolved adverse reactions may persistently hinder adjustment, coping and long-term wellbeing.

Following background research and literature review, three key studies provided a main framework for the research and these were supported by a systematic review and feasibility study. Firstly, an inductive qualitative study explored narrative expressions of emotional responses to being diagnosed with MS. To establish whether the narratives of anxiety and fear were unusual, a systematic review assessed research into anxiety in particular. Findings from the qualitative research and systematic review informed the protocol and hypotheses for the second quantitative study. The second study evaluated the implications of early anxiety responses for long-term wellbeing, in terms of illness perceptions, anxieties and general mental health outcomes. A participant-centred feasibility study tested the acceptability and value of visual methods for expressing responses to MS. Based on evidence from the second study and findings from piloting visual methods, the final study used a before-and-after approach to evaluate an art intervention for rescripting negative responses to MS. The influence on mood, anxieties and illness perceptions was measured.
7.3 Study-wise Summary of Findings

Figure 31 summarises the literature background, research framework and key findings of the three main studies in this thesis: one, two and four.

7.3.1 Study one

Study one explored emotional responses to MS. Three key concepts were evident in the narratives: emotional isolation; future-oriented fear; and resentment at eroded or violated rights. In particular, emotional isolation (being isolated with emotions) was a pivotal concept revealed in narratives as either a conscious position or an unintentional (and potentially subconscious) aspect of response. The in-depth investigation of idiographic narratives highlighted the importance of emotional processes in response to being diagnosed with MS. These emotional responses were expressed as processes of disruption or resolution. Isolation with future-oriented fear, in particular, was represented as potentially damaging and pervasive.

7.3.2 Study two

A cross-sectional study into anxiety responses tested three hypotheses: 1) that maladaptive coping and low levels of emotional support predict poor long-term psychological wellbeing; 2) that anxiety and fear at diagnosis are associated with long-term maladaptive coping; and 3) that isolation with unresolved anxiety is associated with long-term avoidance.

Results provided evidence that current maladaptive coping and poor emotional support predicted poor current psychological health. Retrospective evaluation of avoidance coping 12 to 18 months after diagnosis predicted long-term maladaptive coping. Retrospective study of recalled levels of anxiety and fear at diagnosis predicted avoidance at 12 to 18 months.

7.3.3 Study four

Study four evaluated the potential for using an art intervention to amend disproportionately negative illness perceptions and introduce a balanced perspective on future fears. Case-wise results suggested that rescripting visual representations of MS could reduce fears and improve perceptions of control. Qualitative data in response to open-ended questions about the experience of participating provided insight into the benefits of considering MS holistically; contextualising the past, present and future with the condition; and understanding the need to take control.
Figure 31: Overview of literature background, research framework and key findings
7.4 Discussion Overview

This thesis proposed that early maladaptive responses to diagnosis are not necessarily a temporary phase and unresolved adverse reactions may persistently hinder adjustment, coping and long-term wellbeing. Findings from the empirical studies support the thesis, primarily and simplistically with behavioural approaches to coping evidenced by statistically predictive relationships between recalled anxiety and fear at diagnosis with retrospective evaluations of avoidance at 12 to 18 months; and avoidance at 12 to 18 months with long-term maladaptive coping.

Evaluating findings across all three studies provides a thread of patient-centred experiences and research evidence that relate and interact to reveal an insightful montage of coping approaches. The condition-context environment of diagnosis; patient perceptions and cognitive interpretations; emotional reactions and behavioural responses concur with existing research discussed in the literature review and many can be mapped on to aspects of established theoretical explanations. The novel finding is consistent indications across all studies that emotional responses do not necessarily follow a process of stages leading to resolution and completion that enable coping. Instead they represent a complex interactive and potentially fluctuating response that seemingly focuses on protection of the self in the face of the serious future-oriented threat imposed by MS.

Early denial and inhibition responses are potentially related to future-oriented fear. Uncertainty, illness individuality and asymptomatic phases allow perpetuation of short-term denial into chronic avoidance and persistent maladaptive coping. Illness perceptions or experiences of little or lost control encourage adverse reactions, for example experiences of the erosion of taken-for-granted status and personal rights resulting from physical symptoms constitute lost control due to illness. The ultimate threat of disability and wheelchair confinement also relates to the perceived lack of cure or control by medication. Ambiguity confuses illness perceptions from the beginning and when medics at diagnosis cannot map out a certain prognosis with definite treatment plan, the patient interpretation is of medical helplessness; and herein lies a strong case for psychological intervention.

From the medical perspective, professionals have to deal with the fact that it is vital to eliminate all other possible reasons for multiple symptoms and not
misdiagnose MS. Once tests confirm MS, there are no easy answers: although symptom control is good and treatment options and research are evolving, doctors cannot accompany diagnosis with unrealistic optimism. MS is individual and the threat of disability cannot easily be defined or put into perspective as the fluctuating nature of the condition means there are no clear-cut statistics on the extent and frequency of wheelchair use. The message may not be implicitly helpless but the way it is received reflects the timing of delivery and potential interpretations. While patients progress through the diagnosis process, they inevitably explore possibilities and often encounter worst-case scenarios through the internet or in disability images for fund-raising that unintentionally elevate the threat associated with MS. By the time diagnosis is confirmed, relief at receiving an explanation is common and symptoms may have subsided or disappeared. Remission may continue for months or even years, making it easy to overlook any need for lifestyle review or adaptation, especially as the background threat prompting avoidance may linger in the subconscious. While minimal and slow early physical deterioration can allow denial to be nurtured, an experience of unexpected severe temporary relapse can catastrophically exacerbate fear to prompt extreme avoidance when symptoms recede to be replaced by remittance.

From all studies it seemed possible that people diagnosed with MS could use long-term denial and avoidance approaches. Qualitative data demonstrated that this could continue for decades to disrupt wellbeing. Furthermore this was not shown in rare incidents or an isolated case: several narratives disclosed negative emotional responses that were concealed, unconscious or unresolved to the detriment of psychological health. Among participants' visual responses in the intervention study (study four), chronic denial and avoidance were represented as unknowingly related to potentially distressing responses. Visual data also revealed less dramatic but life-limiting instances resulting from avoidance.

Similarly, in both studies one and four, there were strong indications that resolution of negative emotions related to improved psychological wellbeing. Some narratives included animated accounts of powerful emotional reactions, their resolution and examples of how such processes could be disrupted to induce further distress. Thus it is appropriate to note that while the research findings support the thesis and point to the possibility that general early stage intervention may be
beneficial in resolving adverse responses and promoting adjustment, they also signpost a need for, and benefits of, individual intervention at any stage beyond diagnosis. This could aid resolution of chronic adverse responses. Alternatively, timely intervention could address the possibility that the nature of MS means linear stages of adaptation are not realistic, therefore denial or avoidance can occur at any stage. Furthermore, previously resolved emotional reactions may be subject to disruption and renewal of maladaptive approaches.

7.5 Cross-thesis Discussion of Findings in Context of Theoretical Models

Discussion in this section is organised around the six key aspects of findings that were found to interact across all studies. These are (i) pivotal emotional responses: fear; (ii) critical processes: emotional isolation; (iii) disability identity: focus for fear; (iv) illness perceptions: consequences and control; (v) theories of coping: critical emotional processes; and (vi) intervention focus: amending illness perceptions.

From the literature review, the following general background information seemed particularly pertinent to the discussion of findings in relation to the proposed thesis. These aspects provide insight into the situation context around diagnosis with MS and potential implications for response.

i) A medical culture of ambiguity results from the uncommon occurrence of MS, diagnostic difficulty, and valid perceptions of MS as incurable, uncertain, unpredictable and threatening.

ii) Although advances in disease modifying therapies to reduce damage and delay progression allow MS to be defined as treatable, this represents the very cutting edge of research, details of which are not always widely disseminated and evaluated for practice.

iii) Symptom management is good; however, local experience with, and support for, those diagnosed with MS varies widely.

iv) Patient perspectives focus on poor adaptation and psychological wellbeing, adverse emotional responses, disability and threat.
7.5.1 Pivotal emotional responses: Fear

Findings across studies in the present research indicate that emotional responses around diagnosis are seemingly pivotal in producing the early maladaptive reactions. Published research refers to evidence for comorbid depression and anxiety responses, along with other broad indications of negative emotions, including fear, threat, guilt, sadness, disgust, grief and rage (for example, Bury, 1982; Finlay, 2003; Sá, 2007). Antomak (1995) proposed that such responses represented acute shock associated with diagnosis; Sharpe and Curran (2006) indicated that future-oriented fear could result from concealing symptoms to delay adjustment; and Kalb (2007) also identified grief, anger, anxiety and guilt as temporary responses to relapse. Concepts of future-oriented fear and resentment at eroded rights evident in the narrative of participants in study one largely concur with a strong body of evidence around negative emotional responses but neither qualitative findings nor statistical results from study two confirm a comorbid role for depression with anxiety in terms of influence on approaches to coping. The statistically significant contribution of depression was to correlate negatively with distancing in one step model of multiple regression. This could possibly be explained by low motivation associated with depression hindering the use of distancing as a positive short-term response for coping. These findings further suggest a more specific emotional focus than general anxiety. Thornton, Tedman, Rigby, Basforth and Young (2006) developed a scale to assess worries more closely among patients with MS, based on rating statements about physical, social, work/daily life, family and mobility, split factorally into mobility/physical vulnerability and social/family/work/daily routine scales. The statements were not tightly worded and open to subtle interpretation, therefore not precise enough to elicit levels of specific concern or fear. Bruce and Arnett (2009) signposted the lack of preceding research in this area and proposed that worry and anxiety were related but distinct constructs. Burns et al. (2010) found that breaking anxiety factors down into distress and fear revealed long-term influences, with distress disorders at baseline associated with higher anxiety during and after treatment for depression.

Findings across studies in the present research also highlighted the possibility that anxieties and negative emotional responses to MS are not necessarily temporary. Although survey results demonstrating retrospective evaluations of early anxiety
were unsurprising (60% of participants recalled raised anxiety immediately after
diagnosis, with 50% rating this as moderate and 13% as severe), the level of fear was
unexpected, with 70% of participants recalling medium to high fear in the first three
months after diagnosis. Thinking back to the first year to eighteen months after
diagnosis, participants still rated the impact of MS diagnosis as elevated (to a
moderate to high extent by 41% and 18% respectively) and intrusion was also rated
at high and medium levels by 17% and 33% participants respectively. These
statistics support the extensive anecdotal accounts of adverse diagnosis experiences
followed by avoiding groups or any sources of information for as long as possible.
People spoke with regret about years of distancing and denial, of avoiding
information and support until it became a physical necessity, and the feeling that
they would not be as physically restricted had they exercised and found support early
on. The possibility that the anxiety and fear responses in study two were inflated
over time was considered; however, negative correlations with age and time since
diagnosis suggested this was not the case. On the contrary, it seemed possible that
recollections of fear diminished over the years since diagnosis. Data indicated that
80% of participants currently found MS concerning to a medium or high extent and
70% found it emotionally upsetting to a similar extent.

7.5.1.1 Sharpe and Curran’s (2006) Hierarchical Model of Adjustment The
focus on health anxieties suggested in recently published research (Dennison,
2009; Kehler & Hajistravropoulos, 2009) is supported by participants' narratives
around future-oriented fear in study one, indicating that early responses may be
specific. Narratives in the current research magnify the responses and contribute
further insight into the different manifestations of reactions to threat. For example, as
discussed in section 1.10, although choosing to hide early invisible symptoms could
be explained as a delaying response to translation of initial threat into fear of future
disability, as suggested by Sharpe and Curran (2006), two participants demonstrated
that adjustment was not delayed but chronically avoided. One participant concealed
her MS from her parents for eight years and another persisted with concealment,
inhibition and avoidance throughout her lifelong career. While the first could be
interpreted as a response to a debilitating relapse that instilled unrealistic fear of
incapacity, it was not a temporary phase as indicated by Kalb (2007); in fact, the
participant's aversive reaction could be traced back to seeing posters of people with
MS in wheelchairs on the day she was diagnosed. This highlighted the power of visual information and the heuristic quality and impact of the wheelchair image. It is also important to note that in both cases, participants' narratives were characterised by continuing negative responses and poor emotional coping. Uncertainty about the future has previously been found to correlate with fatalistic coping (Buelow, 1991) and denial, avoidance and behavioural disengagement have more recently been correlated with anxiety (Brakjovic et al., 2009).

7.5.1.2 Working Models of Adjustment to MS and Chronic Illness Newly published work by Dennison, Moss-Morris and Chalder (2009) and Moss-Morris (2013) highlighting the need for revised theory on responses to chronic illness, and MS in particular, position emotional responses at the core of proposed models. Neither A Working Model of Adjustment to MS (Dennison et al., 2009) nor A Working Model of Adjustment to Chronic Illness (Moss-Morris, 2013) consider the critical function of emotions or evaluate the micro-processes involved to throw any further light on interactive influences. The current research suggests that processes are potentially critical and subject to long-term fluctuating influence on coping and wellbeing. The quantitative research for study two also highlighted the need for a valid fear-response measure for MS. The scale designed for the questionnaire survey provides a useful starting point for developing and testing a measure of specific aspects of fear and related constructs, such as mobility, economic, responsibility and identity focussed issues. Improving measurement and understanding of fear and anxiety responses could usefully guide the practice of diagnosis delivery, patient information and support.

7.5.2 Critical processes: Emotional isolation

Social support has been shown as important for coping in other research (Dennison, 2009); however, the critical concept of emotional isolation (being isolated with emotions) is not widely discussed in published literature. The important facet of this finding in the present research is the independence of emotional isolation from social contact: in other words, it did not arise from lack of social support.

Study two highlighted the fact that perceived levels of available emotional and practical support differed, with fewer participants identifying access to emotional support (55%) compared to practical support (70%). Choice seemed to contribute as well as availability and over 30% of participants sought no more than low levels of

235
emotional support. While 54% used medium levels of emotional support, only 11% of participants sought emotional assistance with current coping. These results support indications from study one in which participants' narratives revealed that emotional isolation could be a conscious choice as well as an unintentional aspect of response or potentially subconscious. In participants' storied experiences of MS, being isolated with negative emotions also represented a dynamic and interactive aspect that could influence or moderate emotional responses. Isolation with future-oriented fear, in particular, was represented as potentially damaging and pervasive.

7.5.2.1 Wundt's Interconnecting Emotional Processes

The concept of emotions as dynamic, interacting and persistent aligned with Wundt's (1907) definition of an emotion resulting from a combination of interconnecting processes that could produce arousal at the time of the experience and thereafter. This was demonstrated particularly around future-oriented fear and resentment. Narrative indicators of the potentially detrimental effect of emotional isolation with future-oriented fear in study one are also supported by statistically significant indications in study two that anxiety, fear and not seeking emotional support may predict long-term poor psychological wellbeing.

The concept of not expressing emotional reactions to stressful events resonates to some extent with inhibition responses addressed in expressive writing interventions researched extensively by Pennebaker and colleagues (as discussed in section 1.12.1). Pennebaker, Colder and Sharp (1990) considered emotional responses to unresolved stressful events that were not understood. Potential embarrassment or guilt meant responses were not shared and inhibition was used to avoid revealing emotions behaviourally, which created denial. In current narratives emotional isolation is manifested in two different processes: firstly as a result of denial, rather than being its precursor; secondly as an unconscious position rather than a conscientious behavioural response. In participants' narratives around MS, isolation may be a response to an emotional focus with future orientation rather than, or as well as, the concealment of the emotion in response to past experience.

The theme of emotional isolation as one aspect of complex emotional processes should be subject to further research. Mapping responses and interactions to understand and evaluate their impact could be used to identify opportunities for preventing emotional isolation or for ensuring that it is not perpetuated.
7.5.3 Disability identity: Focus for fear

Comparing manifestations of anxiety and threat across the current research, the focus on disability and visible symptoms can be interpreted as a fear, primarily, of challenged identity. Potentially subconscious processes of emotional isolation functioned in the urge to protect social identity and avoid association with a stigmatised or stigmatisable disability identity. This represented a powerful motivational force in narrative accounts of concealing decreasing mobility. Perceived areas vulnerable to identity threat that provided so strong a focus for fear included career status, parental role and responsibility, and sexual attractiveness. Fear of discrimination, being overlooked and loss of agency were also evident.

The threat that disability represented was consistent across the research, with wheelchair fear evident in studies two and four. Fear and anxiety were also identified as significant separate predictors of avoidance. Survey findings indicated that fear resulting from seeing other people with physical deterioration was higher than fear evoked by images of disability or disabled people. As proposed by Kehler and Hajistavropoulos (2009) and Dennison (2009) in previous research, this would suggest that health-specific fears may contribute to poor outcome as well as general anxiety. A subsequent paper by Dennison (2010) further suggested that the stigmatised identity of disability made people avoid support groups, which offered potentially additional explanation of why people avoid seeking support, as demonstrated in study two. Whereas wheelchair threat and aversion to mobility aids seemed to create anxiety, fear and avoidance behaviour, among those who had confronted the necessity and used such equipment being able to get about represented regaining some aspect of independence, rather than additional loss. This was particularly true of mobility scooters that did not seem as stigmatised as wheelchairs. In support of findings by Dennison (2010), participants' responses in studies one and four suggested that adaptation to wheelchair use was not as damaging as the fear of stigma. Aspects of relief and resilience were expressed, with wheelchairs contextualised as just equipment, personalised by accessories.

7.5.3.1 Identity Process Theory: Explaining Wheelchair Threat

Models of identity as a complex process for defining and protecting the self (as discussed in section 1.6.1) may explain these fear responses to potential disability. Breakwell's (1986) consideration of intra-psychic (cognitive and emotional) responses within her theory
could explain maladaptive coping as a strategy for deflecting threat, with interpersonal and intergroup strategies influencing active rejection of the idea of belonging to MS groups. Considering why the wheelchair image is so fear-inducing may explain responses. For example, it may relate to some attribution (rather than perception) of dehumanisation of the person to a state of helplessness and dependency. It is possible that perceptions or interpretations of deformity are repulsive, not beautiful or less than perfect as suggested by one participant's narrative. In this case, it is possible that the fundamental fear of physical loss is derived not only from an image through a social lens of group stigma, but also resulting from lack of information on the reality, or meaning of, wheelchair use among people with MS. This links to the potential importance of beliefs about MS to responses.

7.5.4 Illness perceptions: Consequences and control

Illness beliefs or cognitions are important because they influence the way people respond to diagnosis (Leventhal, Meyer, & Nerenz, 1980; Leventhal & Nerenz, 1985; Leventhal, Nerenz, & Steele, 1984; Meyer, Leventhal, & Guttman, 1985) and research indicates that they are also associated with adjustment and outcomes among people with MS, notably in terms of perceptions of helplessness or lack of control over severe consequences (Moss-Morris & Jopson, 2003; Spain, Tubridy, Kilpatrick, Adams, & Holmes, 2007; Vaughan, Morrison, & Miller, 2003; Weinman et al., 1996). Findings across studies in the current research suggested that participants' illness perceptions reflected the culture of medical ambiguity unqualified by any positive perspective on information relating to the safety record of established drug treatments that are available (as discussed by Hohlfield, 2010) or, more importantly, any grasp of the MS nursing outlook on self-regulation affording personal control over common symptoms, including bladder problems and fatigue.

7.5.4.1 Commonsense Model of Illness Representations: A Framework of Illness Representations in Current Research As discussed in section 1.7, patients' interpretations are used to define a framework of constructs that can be used to evaluate and build beliefs about a condition. Narrative concepts of future-oriented fear in study one reflecting uncertainty around progression and unpredictable prognosis were echoed by the negative perceptions of MS as incurable, affording poor control and having high emotional consequences in study two. Findings from
the survey confirmed that 90% of patients accurately defined MS as long-term and 60% considered they had a good understanding of the condition. MS is an individual condition, so perceptions of illness effect rated as high by 42% and medium by 46% are subject both to idiographic illness presentation and personal interpretation. The majority of participants rated symptom impact as high (31%) or medium (51%) and it is possible that this could reflect some characteristic of the self-selected sample; however, perceptions of treatment control were rated as low by 32% of participants and medium by 41%; with 45% perceiving only low levels of personal control and 45% considering their control to be medium. In terms of consequences and cure, these figures concur with findings in published research and they may indicate that the necessarily cautious approach adopted by medics when describing treatment possibly makes a lasting impression that dominates the patient perspective.

Similarly, in study four much of the rescripting involved amending perceptions of poor control to introduce aspects of support and symptom management that contribute to the concept of control. Acknowledging fear and avoidance of wheelchairs in some cases included recognition of how control had been gained by using equipment or mobility aids, such as sticks or a wheelchair. It was noticeable that, whereas participants gradually reflected and alternated on past, present and future as they related experiences through spoken narratives in study one, the succinct visual method in study four created an holistic representation that seemed to facilitate a connected overview. Some participants gained insight into resilience they had not previously acknowledged. This simultaneously provided an heuristic reminder for future reference of how they had used aspects of control, how they had become resilient, and ways in which they could develop new approaches.

The inevitable and, currently to a large extent unavoidable, ambiguous process of diagnosis seemed to be the first stage in instilling uncertainty for the future. As well as general anxiety related to this uncertainty, powerful perceptions of fatalistic or potentially devastating disability consequences may create a helpless heuristic that could invoke a strong emotional fear response. One reaction to this was to avoid cues that evoked the fear of consequences for which there seemed to be low perceived control and no cure: avoiding MS groups and centres where people in wheelchairs provided living examples of illness consequences. Contrary to theories suggesting that maladaptive coping represents an early phase in adjustment, subject to appraisal
and amendment, or a temporary crisis response, this adverse coping was potentially persistent, particularly in the absence of visible symptoms.

Specialist MS nurses are well informed but not always available and, since MS is relatively rare, local medical knowledge and even specialist interpretation is variable (for example as shown by Hawkes and Giovannoni, 2010). Research indicates that patients are unhappy with the communication from medics (for example, Forbes, White & Taylor, 2006; Johson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008; Solari et al., 2007). Local support group availability varies and such organisations or centres have difficulty attracting the newly diagnosed, thus many people access information only from internet sources, with different perspectives of unknown provenance. Research into framing early information and evaluating its interpretation would provide professionals delivering diagnosis with a succinct model for presenting the future in a realistic context without inducing extreme fear.

7.5.5 Theoretical models of coping: Explaining pivotal emotional processes in current research

Literature research found that MS does not easily map on to any one theory of chronic illness due to the uncertainty and individuality of the condition. Theories of adaptation and coping, such as Leventhal’s Self-regulatory Model (1980) and Taylor's (1983) proposed process of cognitive adaptation through meaning, mastery and enhancing life by adopting illusions of control, do not accommodate the fluctuating, uncertain and multi-symptomatic characteristics of MS. It is also possible that adoption of coping strategies according to factors such as illness perceptions is hindered due to uncertain perceptions of MS.

The complex and fluctuating approaches to coping and their potential relationship with emotional responses revealed in the narrative analysis of participants' accounts in study one could not be explained by any one model. Findings in study two supported the diversity demonstrated by the qualitative research: while 70% of participants in study two used maladaptive approaches to coping a little of the time, 25% used them moderately or a lot of the time. Escape-avoidance was used by 39% of participants at moderate levels and 51% adopted this approach a little. Distancing was less common, with 36% of participants using this a little; 49% distancing a small to medium amount; and 14% using a moderate to high level of distancing. Some participants made little of no use of active coping (30%).
High levels of active coping approaches were evident for only 14% of participants and medium levels for 55%. Individual condition presentation and incoherent prognosis may be contributory factors in the diversity and this could create decision-making problems in the absence of suitable mentors and peer support in-person from others experiencing similar symptoms.

7.5.5.1 Leventhal's (1980) Self-regulatory Model: Problems of Appraisal in Current Research

As discussed in section 1.7.1, a common feature of existing theories is some form of appraisal of selected coping strategies according to outcomes. Adopting coping strategies may be automatic in terms of addressing needs and not necessarily related to acceptance; however, moving on to appraise and beneficially amend approaches requires some level of acceptance. Overall evaluation of research in the present thesis indicates that one characteristic acute response to MS is a powerful focus on the future. In MS, one of the major concerns is the unpredictable future and the fluctuating symptom presentation. It is not possible to assess coping strategies against unknown, unwanted or unacceptable future outcomes. Furthermore, the present research suggests that potential future perceptions may invoke powerful emotional responses and the processes involved are possibly of pivotal importance in adaptation.

7.5.5.2 Working Models of Adaptation to MS

As discussed in section 1.10.1, recently proposed working models for adaptation to MS in particular, and chronic illness in general, include emotional responses as central (Dennison, 2010, & Moss-Morris, 2013). Moss-Morris considers that adverse emotions are not necessarily damaging unless they become persistent. The majority view of early responses to diagnosis with chronic illness is that they represent a temporary stage in adaptation, resembling a grieving process for loss of health. Alternatively, they may relate to the crisis of diagnosis. However, findings from studies in the present thesis suggest that early responses are influenced by adverse illness perceptions and they may have long-term effect.

In the absence of benchmark outcomes or approachable expectations against which to appraise adopted strategies, it is possible that selected coping remains unchanged and becomes habitual. The crux of the problem seems to be that when illness perceptions focus on potentially devastating consequences, future-oriented fear creates powerful emotional-based motivation for avoidance. While processes of
emotional expression facilitate integration and resolution, retaining negative emotional responses creates isolation. Emotional isolation with future-oriented fear represents an unhelpful and damaging position, with unshared disruption of emotions perpetuating adverse responses and hindering acceptance and adaption.

Magnifying the central role of emotions in the above proposed working models (Dennison et al., 2009; Moss-Morris, 2013) such that they represent influential processes rather than temporary responses may provide a means of unravelling and understanding the influence of illness perceptions on both cognitive and affective responses. As discussed in section 1.8, illness perceptions have been found to influence outcome in MS. Findings in relation to emotional processes in this thesis (see Figure 8, section 2.6.3) suggest that they may filter illness perceptions to influence coping approaches, which may in turn have an impact on long-term outcome. Indeed, it seems possible that magnifying 'emotional responses' to consider them as 'emotional processes' in Leventhal's self-regulatory model (see Figure 1, section 1.7.1) may offer a less-convoluted approach to updating the model instead of the very detailed working models proposed by Dennison et al. (2009) and Moss-Morris (2013). This approach to revising existing well-established theory would have the advantage of retaining and building on the well-tested evidence for the role of illness perceptions and coping approaches.

7.5.6 Intervention based on models of coping: Amending illness perceptions
The notion that illness perceptions or beliefs influence responses and coping is well established and they are also proposed as influential in, and predictive of, outcomes, as discussed in section 7.5.4. The literature also indicates that illness experiences and perceptions can be expressed in drawings, including insight into anxieties and perceptions of illness in the case of heart attack that relate to recovery (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). The physical size of drawings has demonstrated relevance, with bigger drawings associated with greater concern and slower recovery (Broadbent, Ellis, Gamble, & Petri, 2006). Abstract impressions of headache have provided rich insight into holistic experiences (Broadbent, Niederhoffer, Hague, Corter, & Reynolds, 2009), with perceptions of severity, control and time; and the relationship with, along with reactions to, the headache pain. Not only is it possible for people to express responses visually but they may also experience intrusive or involuntary images related to psychological disorders,
including post traumatic stress and anxiety disorders (Brewin, Gregory, Lipton, & Burgess, 2010).

7.5.6.1 Uncertainty in MS: Problems Applying the Commonsense Model of Illness Representations

Illness perceptions may have the potential to create an unnecessarily catastrophic heuristic, particularly linking MS with wheelchair-bound disability. A striking example was evident in one response to the feasibility study (see Figure 32). Summarising an experience of diagnosis, the image shows how delivery may be interpreted as dismissive and unsupportive ('discharged ... only see you ... if GP cannot cope ... blah blah'); with iconic heuristics of severe disability drawn as reactions from both patient and companion.

Figure 32: Participant's representation of being diagnosed with MS (Study Three)

As discussed in section 1.3, it is possible that a balanced view is not necessarily available due to the culture of ambiguity people face before and during the process of diagnosis. Indeed, given uncertain prognosis, it could be argued that the concept of adverse individual outcome should be discussed. However, this cannot be contextualised in terms of the probability of disability, which is not succinctly
defined. Frequently delivered advice to get on with life and return when symptoms worsen may promote avoidance. Meanwhile, as discussed in section 1.4, advancing research into disease modifying treatments heralds time for change as the newly diagnosed need to be encouraged to engage with the difficult process of weighing up the long-term benefits of early treatment against short-term side effects. Thus, early intervention could prevent suppression of unwanted fearful heuristics and potentially damaging avoidance.

7.5.7 Drawing on models of expressive writing: Findings from visual methods

Extensive research into expressive writing suggests that intensively writing about a stressful experience may short-circuit the coping process by encouraging confrontation, preventing inhibition or concealing, and providing opportunity for insight and making sense of events (for example, Pennebaker, 2004; Pennebaker & Chung, 2006; Pennebaker, Kiecolt-Glaser & Glaser, 1988; Pennebaker, Mayne & Francis, 1997; Pennebaker & Seagal, 1999). Pennebaker and colleagues consistently found that short term elevation of stress was not maintained while long-term benefits were evident from only a few relatively brief sessions.

7.5.7.1 Therapeutic Visual Methods: Potential Application Demonstrated in Feasibility Study

Drawing on concepts of expressive writing as a means of potentially accelerating coping processes and using visual methods for representing illness perceptions, the present intervention study evaluated the use of visual methods for expressing responses to MS. Drawing has an established therapeutic role as a cognitive therapy to address unhelpful responses by rescripting adverse images and redefining responses by introducing positive aspects. This has been successfully tested as a treatment for depression (Brewin et al., 2009) and shown to be as effective as image exposure in treating intrusive memories in depression (Hagenaars & Arntz, 2012). Findings from the feasibility study (study three) in this research indicated that participants' drawings demonstrated illness perceptions of control and consequences. There was also clear opportunity for introducing positive aspects. Rich data demonstrated that lack of artistic ability was not a barrier as a variety of approaches were used, including diagrams and iconic shapes. Research into art therapy suggests that existing experience or developed ability in art represents familiar cognitive processing that may hinder uninhibited expression of responses not usually accessed by verbal processing (Shaverien, 1992).
7.5.8 Findings in context: Considering illness perceptions, identity and coping

While no robust statistically significant changes resulted from the intervention, descriptive statistics and supporting qualitative data concurred with findings from expressive writing, as discussed in section 1.12, in terms of acute elevation of poor mood and negative emotions. However, there were also examples of reduced fear of disability. Visual data of rescripting and supporting qualitative feedback suggested that this method afforded insight into perceptions of control and how they could be adjusted to include holistic representations of support. Creating an image that demonstrated the advantages of taking control motivated participants to engage with consequences. Catastrophic and subconscious images of consequences, such as helplessness, could be amended by introducing realistic aspects of personal control. Findings from this study further highlighted the profound fear of wheelchair identity revealed in narratives in study one and as discussed in literature reviewed in section 1.5.2. Adjusting the concept of the wheelchair to represent an item of equipment controlled by the user rather than an item that hijacked identity seemed to be a potentially successful way of addressing fear. If nothing else, it opened a dialogue around the meaning of wheelchair use where previously this seemed impossible. Perceptions of controlling mobility equipment to facilitate physical and social improvement presented a more positive outlook; while they may contribute to identity they could be controlled and personalised.

As well as confronting fears, overcoming concealment and facilitating insight (as proposed by Pennebaker and colleagues), participants in the present study unintentionally represented resilience they had developed in response to MS and they commented on being unaware of this. As discussed in the comparative evaluation of visual and verbal methods of expression (sections 1.12.1 to 1.12.4), findings in the current research demonstrated that visually representing experiences and responses provided a quick method of producing an holistic overview. Furthermore, awareness that was not usually expressed may be accessed. Reflection was important. While some participants worked silently, others' comments as they worked indicated that drawing initiated a rapid chain of visual responses. A verbal overview of the experience of MS as represented was often provided and prompting was not always necessary for introducing positive aspects as some participants rescripted automatically. Participants took ownership, developed their own
rescripting and personal metaphors. For many, the intervention represented something of a revelation and many provided unsolicited ad hoc feedback in the following weeks to confirm several benefits of the task, including how they felt they could exercise control; having an holistic view of MS that was not previously considered; and providing a way of showing important others a balanced view of MS or using the image as a prompt for discussing MS. Images also provided an aide memoire for future coping.

7.6 Implications for Practice

Findings from the present studies concur with those in published research in terms of responses to MS and they additionally magnify the potential importance of emotional responses. It is possible that early illness perceptions formed in a culture of uncertainty and ambiguity create an unrealistically negative heuristic of helplessness, fatalistic disability and fear of the future. Contrary to current models of coping, early adverse responses may persist and they may negatively influence long-term coping and wellbeing.

Visual methods allow people to express responses they would not necessarily be aware of or readily talk about. They are also quicker than talking therapies for accessing and organising complex concepts into coherent personal narratives. The feasibility and pilot studies (three and four) showed that visual methods are acceptable to, and practical for, people with MS, including those with physical and/or cognitive fatigue, limited dexterity or who experience difficulties speaking. It is important to distinguish between art therapy as a diagnostic tool and visual methods of cognitive therapy that is owned by patients who engage in the task.

Visual methods could be used to promote a balanced perspective on illness perceptions in an early intervention and provide an heuristic of control rather than of helplessness. Early intervention may prevent emotional isolation with future-oriented fear and promote engagement with MS as an aspect of life rather than a dramatic threat to identity. One-to-one delivery represents higher cost than group therapies; however, the relatively speedy access to, and amendment of, problems could achieve results in fewer sessions than in six sessions of counselling. Patients would also take
away images and a practical method they could use themselves. Therefore, three clear areas of implications for practice may be suggested.

1 Professional Guidance: Disseminating research findings among professionals Firstly, there is a need to promote professional awareness of the impact of early interactions with patients during the diagnosis process. Offering clinicians succinct patient-centred guidelines for providing pragmatic interpretation of diagnostic information, translation into lay terms and clear, empathetic delivery of information would enhance professional-patient communication.

2 Illness Perception Interventions Secondly, early intervention should be encouraged to promote balanced illness perceptions. Such interventions should be based on holistic evaluation of the condition, contextualising uncertainty and considering the outlook for treatment and support. This could promote engagement to the benefit of long-term wellbeing.

3 Potential Usefulness of Visual Methods Thirdly, tentative results from the present research suggest that visual methods could provide a patient-centred, effective and economic means of intervention delivery.

7.7 Implications for Research

Findings from the studies in this thesis support existing research into MS and further emphasise the need for evaluation of health-specific emotional responses as separate factors from general anxiety. Emotional processes may be pivotal in explaining early responses, particularly in terms of the role of illness perceptions in persistent adverse coping. Four specific points of focus for continued research would contribute to progress in this area.

1 There is a need to develop and test a measure of MS-specific fears.
2 Associations between early stage illness perceptions and fear merit investigation.
3 The evaluation and measurement of processes of emotional isolation, with negative perceptions and fears at different stages during and after diagnosis, should be undertaken.
4 It is worth conducting a randomised controlled trial of an intervention using visual methods.

7.8 Strengths and Limitations of Research

7.8.1 Study design
This cross-sectional research relied on recall of responses to early stages around diagnosis and the following 12 to 18 months. Recall is influenced by time and by present position, so aspects of retrospective data may have been forgotten or inflated. It is worth noting that negative correlations with age and time since diagnosis suggest that inflation; however, suppression was possible. A longitudinal, prospective study would provide stronger data.

The pre/post design of study four meant that participants were completing the questionnaire immediately before and immediately after completing the task. Knowing that they were about to engage in a task of visual expression may have influenced baseline scores. Completing the questionnaire immediately after drawing responses to MS meant participants had reviewed their condition and this could have influenced the scores. At least two participants commented on the fact that reviewing their MS negatively influenced their responses. Even though the task was beneficial, immediately filling in the questionnaire meant they were feeling negative. Therefore a longer follow-up period would have been suitable.

7.8.2 Measure of fear
The MS-specific measure of fear was based on an extensively amended version of the Bypass Grafting Fear Scale. There is potential for testing and developing the scale on a large sample of MS participants and in the context of other questionnaires.

7.8.3 Sample, recruitment and participants
One of the difficulties of recruiting nationally from MS centres and groups is in keeping track of all questionnaires and monitoring response rate. Some centres required board of trustees' approval, which involved different processes of approval before questionnaires could be despatched. Information was provided about online
and paper copies, with the latter supplied to centres or groups when requested. Centres rely on part-time volunteers, some of whom were unaware of the research and therefore did not pass the questionnaires to the centre manager. Questionnaires were lost, found in piles of unopened mail, or stacked with magazines and newspapers. It was by careful enquiries made during follow-up calls that the fate of some batches of questionnaires was established.

Participants in studies one and four were members of MS therapy groups. Studies two and three were promoted on line and by means of flyers and posters distributed to national support groups, including MS therapy centres and the MS Society. All participants were self-selected volunteers who were in touch with support groups, thus the population of people diagnosed with MS who have not engaged with any MS community is not represented. Since the focus of this thesis is early adverse responses, such as avoidance, it could be argued the samples in these studies are not representative of the cohort the research proposes to study. Conversely, all participants have been through the process of diagnosis and experienced the early stages. It can also be argued that the responses of these participants could be considered as moderated by group engagement, support and/or membership, for example in terms of access to balanced information and availability of emotional as well as social support.

Published research suggests that support is a positive aspect and that group membership is beneficial, therefore there is no reason to consider that belonging to groups has an adverse influence. It is worth noting that most groups and centres meet during the day, therefore members are unlikely to be in full-time employment. This is reflected in the samples for studies one and four.

Sample size was small in study four. Recruitment was through two centres, with the majority of participants from one centre. The advantage of using the centre was that the majority of participants completed the task in the professional environment of a typical consultation room rather than in a more relaxed home environment. This was more representative of a practice context.
7.9 Concluding Comments

Early intervention may prevent initial maladaptive responses from becoming persistent and in turn improve long-term wellbeing. Addressing early ambiguity and providing a balanced view of illness perceptions may prevent unrealistically negative perceptions of helplessness and catastrophic consequences from invoking future-oriented fear. Promoting a balanced, holistic understanding and highlighting realistic potential for control may reduce threat and fear, and help to prevent denial, avoidance and emotional isolation. In turn, this may moderate long-term maladaptive coping responses to improve psychological wellbeing.

Some patient-oriented perspective on interpretation of diagnosis delivery needs to be introduced into the medical arena. That is, doctors could be encouraged to appreciate patients' understandings and interpretations of the culture of ambiguity associated with MS. This may usefully provide the opportunity to intercept or short cut disproportionately pessimistic fears as it seems potentially dangerous to leave specific fears unchallenged and unprocessed. Greater understanding of the fears associated with illness perceptions could pave the way for effective methods of challenging and adjusting them to promote positive adaptation.

In particular, there appears to be a real need for data on the use of wheelchairs and mobility aids among people with MS. Currently, there are no definitive data on the extent and type of mobility support required as these are influenced by the occasional regular use of, or even fluctuating need for, assistance from wheelchairs or mobility scooters. A coherent perspective could dispel the catastrophic wheelchair-bound image that seems to be a potential source of both acute and chronic fear for people diagnosed with MS.
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256


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Appendices
Appendix I

Chapter 2, Study One

a) Gee's (1991) analysis: Diagrammatic summary of structure analysis process

b) Transcript annotation following Labov's (1972) analysis: Identifying and differentiating specific storied experiences relating to MS

c) Narrative extracts in order of told (narrative order): Showing narrative structure

d) Annotation applying Gee's (1991) analysis: Transcripts analysed in narrated order

e) Annotation on formatted narratives using Gee's (1991) analysis

f) Case-wise findings: Emotional responses revealed by Gee's analysis within narratives defined by Labov's analysis

Note: Sample transcripts showing key stages of narrative analysis include handwritten notes, responses and observations. They show initial possible interpretations and information considered relevant to the analysis.
a) Gee's narrative analysis: summary of structure analysis process

Structure Framework

1. Idea Units (tone)
   - pause / hesitation
   - pronunciation / pitch
   - intonal categorizing
   - alters emphasis
   - influences interpretation

   one idea unit

2. Lines (argument or idea)
   - related to one topic group of lines - each giving idea about overarching topic
   - basic building blocks of narrative

3. Stanza (idea focus)
   - related parts - often / usually pairs
   - related to one topic group of lines - each giving idea about overarching topic

4. Strophes
   - Both strophes and parts are sufficiently cohesive to facilitating titling i.e. they can be clearly 'headed'

5. Parts
   - 'sub' stories as key parts of the narrative
   - larger units of overall narrative

Concludes with five levels of analysis

Focusing system

Five levels of analysis: structure, syntax and cohesion, main line/non-main line, psychological subjects, focusing
b) Transcript annotation following Labov's (1972) analysis

Example One/Interview 9: Alex (data set 7). Identification of narratives by part.
The first 149 lines of this transcript show how narrative is not necessarily told in chronological sequence of events and not isolated from other comments/narratives. This extract traces diagnosis narrative (blue); the relapse narrative (red) is underway.

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[I General chat about computers / old-fashioned punch cards / print outs][3.47]

P Any way, that's by the by, really. So, you've been diagnosed, what, nineteen eighty six ... ?

P Twenty four years.

I What stage are you at now? You come to the centre – tell me a bit about where you've come from with this.

P I was fine until I had my daughter, which is eight years ago. I was absolutely fine. I worked full time until I had my son which is ... he's eleven now and I was absolutely fine. Nothing. No symptoms at all. I had my daughter and, I think, she was born in July and in the January I was flat on my back, couldn't move.

P But I got better, um, but it took six months and I've never been as bad as that again, thank God.

I Gosh, yes.

P Where's the wood? I'll touch the wood later. No it ... Oh, there we go. It's a bit of formica or whatever. It's the most scary thing on the planet.

I Yes. So what happened when you were first diagnosed? In the very first place?

P I had a [retrobarbaromeuritis], which is inflammation of the optic nerve. And I worked in London and, of course, I went to my GP in the morning and he said 'you really ought to go to hospital.' And he said, "Oh, you work in London; go to Moorfields." And Moorfields
61 was like a couple of miles down the road from where I worked. So I
took to Moorfields and I was there all day and I was there again the
next day and then they asked me to go to the National Hospital.

64 I Right.

65 P And they didn't diagnose me at that stage, but they suspected that I
had MS.

66 I And did they tell you that?

68 P No. No he didn't. Because it's multiple. You have to wait for
several attacks to see if... they don't know really.

70 I No.

71 P So that was just my first experience of, but that was just the
optic nerve.

73 I Right. And then did that continue or did that just clear up... and
...

75 P Yeah, that cleared up and I had it. I had it a couple of times.

76 I Yeah.

77 P But really, I was fine. Okay.

78 I Thinking back on it did you have any other symptoms or
anything?

80 P Nothing at all and really, when I had Katie... I'm God!

81 I And were you, had anybody... were you sort of aware or was
there any diagnosis that made you think about anything you could be
doing or couldn't be doing after the eye?

84 P I did. What I did do was I made sure I kept fit. Because after a
while, I kept going back to the doctor and they said eventually, they
did say, "Yeah, you know, we think it's MS." So I didn't tell my

87 parents for years. I hadn't told my parents.

88 I Okay.

89 P So I probably knew for about eight years before I told my
parents.
I Really?

P There was no need. No need! Don't want to scare the living daylight out of them. And, um, where was I? Losing thread now...

I So you'd had the diagnosis – the doctors eventually said 'they think it was'...

P Yes. So I kept fit. Because I knew it was in the background. I used to go swimming every week. I used to make sure I kept fit. And, er, when I did start going to see an MS person, they put me on a diet.

I Although I don't follow it at all now, they put me on a diet, some recommended things to do. And I just started being sensible. You know, not going out all night. Just being really boring – not being boring but just being sensible. Because I knew that this was lurking in the background but that's all. Really.

P That was just initially, after the eye symptoms.

I Yes, or that it might be.

P It was kind of a relief. It was kind of a relief because I knew something was wrong but I didn't know what it was. And the fact that it had a name was, was alright. Because my mum thought I had a brain tumour. You know because I'd had an MRI. Mum thought I had a brain tumour. There's all these things going on. And just to find out I had MS was a relief because I knew I was alright.

I Yes.

P To get a name to it. And you can, I didn't read any books or anything.
120 I Did you have any information at the time or when you were first diagnosed?

122 P I didn’t want to know. I didn’t want to know. I was alright. I’m okay.

124 I Did you know anything about it before? Had you heard about it – what did you know about MS?

126 P Nothing. All I remember was which I used to find really scary, was on the tube you get all these adverts for MS. I don’t know if they still do them. These horrible, the MS Society do these horrible adverts for MS and they are people in wheelchairs and people in such a terrible state. And I think that’s wrong. Because a lot of people aren’t like that with MS! Okay, a lot of people are [assertive and cross] but it’s very mixed bag. And I think to advertise, I know it’s advertising and all the rest, I mean it’s really and I always remember going up on the tube and seeing all these adverts and I used to try to block it out! And thinking, ‘Not me! I’m fine!’

131 I Yeah

132 P But to start with it was quite a shock. I always remember going down the tube at Waterloo, thinking, ‘God, that noise’ [Speechless, tutting noise] [Starts speaking]

137 I It’s hard to imagine how it must feel. So you’ve got something – or we think you’ve got something – so it’s not even that clear cut is it really? It doesn’t tell you much at that time.

138 P No, but at least when I did have my major attack I knew exactly what it was! [wry laugh]

139 I So you were forewarned really.

140 P And I phoned the doctor and I said, ‘Look, look (you know) this is serious!’

141 I So this was after your little girl was born?
Continued: Transcript annotation following Labov's (1972) analysis.

Example two/Interview 3: Brenda (data set 2). Identification of narrative.

The following extracts show the identification of maternal (mauve) and diagnosis (green) narratives across the transcript. (Parts and line numbers for all relevant narratives in this transcript were noted on this first page.)

1  Interview 3  25.5.10
2  
3  Preamble about recording, checking recorder working and explaining 
4  that "I will transcribe".
5  
6  I  Basically, what I'm looking for is – I'm interested in peoples' own 
7  stories – so, where they're at at this minute, obviously, you come to 
8  the centre, you've been diagnosed for ten years. Um, you know, I'm 
9  just interested in how you cope with MS now and the story of where 
10  you've come from and where you've at, really. Um ... not an easy one, 
11  and an awful lot to tell. So, how are things at the moment? How are 
12  you?
13  
14  P  How am I? Well, I say I'm fine, because you are. Unless you are 
15  severely disabled you just carry on every day with your life, so. Um ...
16  
17  I  You use the centre?
18  
19  P  Yes. Um. I used to work here, so I've only just started using the 
20  facilities. I stopped in December when Jackie came on board, so.
21  
22  I  So were you the administrator?
23  
24  P  Was that December, was that right? Yes. I was in the office until 
25  then but I'd come along because I'd wanted to do more – to do 
26  something – and had been recommended this place by somebody else 
27  I knew who had multiple sclerosis. Um. And came along and whilst I 
28  was being assessed, the ... they ann... well, they were just chatting, and 
29  said that the woman in the office was leaving. So "I can help you out 
30  with that for a bit ... keep ... you know " next thing it was three years 
31  later.
32  
33  I  Right, okay [laugh]
34  
35  P  You know how it is ... So um.
36  
37  I  So, were you working when you were first diagnosed?
38  
39  P  Yes, yes and it was [recording not clear??] that I had optic 
40  neuritis probably, um, seventeen years ago. Um, and at the time I had 
41  it, it went away of its own accord, um. I only found out subsequently, 
42  well, nine years ago, that actually the doctor at the time had said, well, 
43  put MS on my notes but he hadn't actually told me. He hadn't actually 
44  said, "Now then, there are things you need to think about."
45  
46  I  So you weren't told!
47  
48  P  I wasn't told. They wrote it in my notes. I was working for myself 
49  and then when I then claimed on my policy, of course there was 
50  nothing they could do. It was written on my notes that I had multiple 
51  sclerosis. So, in fact, that was quite common at the time. Very 
52  common to not tell people because they didn't want to give bad news 
53  to people. About you know, life-limiting conditions. So, um, so –
I And, I think, particularly with those circumstances, really, as I
say, you're a mother, you have two children, what are your priorities
...

P Priorities, yeah, exactly. And I kept thinking, oh well, this, maybe
this will go away, sort of thing because it was to do with the optic
neuritis and it was ... something was happening and no-one was
saying anything ...

I So, they didn't tell you anything ?

P No, they wouldn't say anything there at A+E. The GPs wouldn't
say anything but I think I can understand, you know, they're GPs. You
know. They wanted to make absolutely sure before giving bad news.

I Yes

P Um, one of them, um, had a child the same age as my daughter,
so vaguely knew each other ... so ... I could see for him that was fairly
difficult, to tell someone of his own age that this is your life, sort of
thing.

I Yes

P Um, so ... I'm trying to think what happened, anyway, from there.
obviously, got invited back to do various tests, which took between
my husband, and the GP and myself, just getting every available
cancellation, managed to do it in three months. [laugh]

I [laugh] Right.

P Ha, ha, ha ... it's not good is it? It does not make the NHS sound
positive.

I No

P So, anyway, I got back for the date for when they were giving me
my results. Ended up seeing a newly qualified doctor, who sat there
obviously didn't want ... and I ended up walking around the
department, with my notes, saying, "Will anybody, please, explain to
me, before I leave, what this actually says?! And there were nurses
going, "Ooh, would you like a cup of tea?" - 'NO! I WANT to
KNOW! And THAT doctor can't tell me - she can't tell me or she
hasn't got the responsibility to tell me!! And I was in the Royal
Surrey! It's probably on their, on their CCTV footage of me having a
tantrum, going, "Will somebody ... " I was in tears!

I I'm not surprised ...

P Absolute tears.

I How enormously frightening.

P Having already guessed what it was, but having also, because,
there's so much information by this time, find out what else it could
be, which was much worse. And also I had a friend with muscular
dystrophy and hers started with problems in her legs ... so I was ...

I Distraught....
Yes, it wasn't a good moment. Er, that. I have to say ... and I don't think the NHS covered itself in glory at all.

That's horrendous.

Awful, isn't it? I think it's awful.

Horrific, I mean, what a way to start someone off on ... you know ... on coping with something that they are going to have to, I mean, just the whole process of diagnosis? How can this happen?

And also, why put a junior doctor on rotation, probably, wanting to choose which one they want to specialise in. Why give them a relatively young person who's likely to have MS?

Yes, yes.

That was just poor organisation on the part of the hospital.

And there should be someone else who can be called on!

And there should have been ...

You know, a senior nurse ... somebody ...

There should have been a nurse there who was able to walk back in and say, "Look we need to talk." With the duty doctor and help the junior doctor. Cause I was old enough to know that ...

So, how old were you ...

So, if you take ... I'm forty seven now, it was ... I was thirty seven.

So I was old enough to know. I had two children and enough junior doctors looking at bits of me that I'd rather they weren't looking at [laugh] ... you know ... I wasn't out to hurt that person.

You were also married and you were a family woman and not desperate to get back to mum and you wouldn't need and adult with you, so to speak ...

No, no. No, I didn't. And as I say, I ... er ... I didn't want it to be the worst news and muscular dystrophe, that would have been three years.

You know, MS by that point was not, sadly, the worst ... I just wanted to know.

MS was a relatively unknown ...

Yes, yes. So really.

So what happened after that?

What happened after that was, I phoned the GP and, as I say, and got through, and he said, "Do you want to come in? I'll come up to you. You can come to me at home or come into the surgery." I said, "No, I'll come into the surgery. I don't want ..." you know the home ...

I'd rather it was in the surgery. And so he just said, you know, it is MS. And I'm afraid I cried again.

I think it's very normal, really.

[upset] I makes me sad just thinking about it ...
I'm not surprised, I mean it's quite a difficult sort of... really, it's not something that's ever going to go away. That whole process...

I think it was not a good way for it to be handled, but I have to say, I've heard worse, here/about how the NHS handle things.

I've read of some... I mean, I've done some lit research and, obviously, I've done quite a lot of research and some of what I've read supports the fact that there is more to be done to maybe indicate the stories and show that there is... And there is at the moment, the MS Society as well are trying to promote more 'on the ground' help and appreciation at the time of, not just for the future research.

The MS Society's new advertising campaign is quite good. So there... just in the optician's this morning, I was going to have my eyes checked and I was in the opticians and you know, as you do, you flick through something and whilst you wait, and I can't remember what type of magazine it was but it was just... I need financial advice, I need to know about MS and there was a woman there and it was just very simply...

What happens now?

Yes, what does this mean?

Yes, because this seems to be one of the things. So, there you are: you have two children; you have this horrendous thing that's happened to your body; um, you're not getting any answers; what happened? How do you... What do you prioritise? How do you cope with that stage? How did this, how did you continue, get on...? What about telling your other half? How did he?

He was very good. He was alongside most of the way. I didn't want him to come to the hospital that day, but I should have done actually, because, he would have been much calmer and he would have found... because, by this time I was so upset... but I'd left him at home with the children. Um, that's right, no, we were going for a... he was picking me up and we were going out for... we were taking the children out for pizzas. Um... my daughter was still bottom shuffling, she was about one and a half by this time...

I Yes

Oh no, I think she'd just got up on her feet. So, you know, we decided to go, you know, take the eldest one for a pizza and manage with her... and that's what we did... and so I was...

And so he picked you up and that's what happened?

Yeah, that's what we did, yeah. Because what do you do? Do you say to your seven year old, "Oh no, we can't go out now, I've just had some bad news."

I No

So... I'm sorry, I didn't think I'd feel like this [upset]
"He said, "you may not have got three hours all at once but you would have been around the department two or three days and we would have slowly gone through all of this, which I've had to give you in a..." He was very good. Yeah, so... um. [pause] So that was very good. But what he said was I was never to have any more children because they... because the episodes came after the birth of my son and then after my daughter even though there were other symptoms going on, they believed I should never... And I said to him, "No that's not your decision, that's our decision, really. I think that's our decision." Um... I Yes — _ P And, he just said, "Absolutely! But you do need to be aware that you are likely to have a really bad something if you have another child." And I really, really wanted another child but my husband went and had a vasectomy because he didn't want to put me through it again. And I was furious... I couldn't speak to him. I was so angry. It... it affected our relationship. Because, that again was my choice. It was not for him to take the choice away from me. And I did say to him, if I want another child, I will have one. I was so angry... ha, ha, ha... [laughing and shouting]... I said "I'M TRYING A CHILD! I'LL FIND SOMEONE THAT CAN GIVE ME A CHILD!!!" HA! HA! HA! It. But it was my choice. It was not for other people to make that decision: that's how I felt about it. So there were choices taken away from you... But I never thought about that. And the next day, I th... I thought that was a big one for me. I always wanted three children. And... um... yeah. And it was something that was taken away. If I wanted them within a relationship..."
Something you've talked about and you're aware of and you're consciously...

... but it's something you had thrown at you...?

... but it was a decision he made...

... and he told me before I had time to deal with it. He'd gone and...

He told you before or afterwards?

Before... but it was, by that time, it was literally the next day that he was going to have it done and no matter what I said, he went. And I was angry... so angry... that... as I say, I didn't talk to him for a long time. Other than, basic, you know, child needs to go to school... you know, that... that was it... we had very little conversation. I was so angry.

How did you feel about yourself, then? [pause] You must have...

as a person, that must have been quite difficult to...

I think I was too angry to really think about how I felt... and then there was...

I mean all that anger?

It was my anger... just... [pause... gasp] I just couldn't bel [ieve... unfinished]... I was... someone who said they loved me then to take... to be able to then make a decision... it just seemed... I kept saying to him, "You're not my father! I'm not a child! You're not my father! If I'd wanted a father I wouldn't have married you! I've..."

I don't need another one...

I don't need another one.

And had he ever treated you like that before?

No. No, no...

So... but he didn't do things like that...

No. No, it was completely out of character. It was his fear. It was fear, which he would now admit. Because... watching what I was like...

... the thought of the next episode being so much worse. I can understand the fear but that still was not...

No. At the time, too difficult...

"And, you know, as... he was sadly one of the ones that got an infection as well, so it was not... an unpainful experience. So... I admit, I was not sympathetic! I kept going, "YOUR FAULT! YOU CHOSE TO DO IT! DON'T COMPLAIN!" [laughs] I think was what I said! Ha, ha, ha [laugh]
I [laugh] Wonderful! [laugh] The anger was vented!

P Yes. In fact, oh, looking back at it, I can see it was fear. [serious again]

I Yes

P You know...

I And has he ever talked about that... and...?

P Oh, we did after. A long time after he did but... not now, it's gone, it's in the past. It's nothing to be worried about now. Because it's how it... influenced... it, it's the fact that you had MS influenced...

P [interrupts] Yes.

I ... your relationship and your life, not just in terms of you.

P Yes. No. It did... it obviously had...

I Yeah. Okay. So you then... you moved on from that... you've, um, since then... I suppose... what about, well... do you still work part-time?

P I still work. I work part-time. Um we... I stopped working for the newspaper. What I'd been doing was quite challenging. I'd... even...

I was working for them as a freelancer I was helping run a joint venture in Russia, which was obviously a lot of travel and was based in Moscow. So I was going over to Moscow about three, four, five, six times a year...

P [interrupts] Yes.

I Doesn't help your fatigue, does it?

P No. So um and more um taking people and things, so er, um...

I Right...

P And [feint ironic laugh] had [laugh]...

I Fairly major re-training! Makes me sound quite normal doing silly things at this stage...[laugh]

P [laugh] and also, he just... quite a determined character... very nice, quite quiet [you know, he's not in your face]. He's really quite quiet... and, um... [pause]... anyway, so he got offered a position in chambers, which was very prestigious one... one that um dealt with lots of engineering issues, so it dealt with the Ladbroke Grove enquiry with the train crash, um, the Heathrow enquiry... various things like that, so they needed people who understood engineering.

I Yes

P Anyway, they basically offered him the job and they said to him, you know, "Go home, open a bottle of champagne with your wife and then send the letter back to us." They gave him the letter there, after...

I Brilliant!
Interview 3: Brenda (data set 2) Extraction of defined narratives

Example Narrative 1: Diagnosis delivery

**DIAGNOSIS DELIVERY (D)**

**Diagnosis delivery: abstract D/A**

*(original lines 247-249)*

I ended up walking around the department, with my notes, saying, "Will anybody, please, explain to me, before I leave, what this actually says?!"

**Diagnosis delivery: orientation D/O**

*(original lines 245-247)*

P So, anyway, I got back for the date for when they were giving me my results. Ended up seeing a newly qualified doctor, who sat there obviously didn't want... and

**Diagnosis delivery: complicating action D/CA**

*(original lines 249-256)*

And there were nurses going, "Ooh, would you like a cup of tea?" "NO! I WANT to KNOW! And THAT doctor can't tell me -- she can't tell me or she hasn't got the responsibility to tell me!"

And I was in the Royal Surrey! It's probably on their, on their CCTV footage of me having a tantrum, going, "Will somebody ..." I was in tears!

I I'm not surprised..

P Absolute tears.

**Diagnosis delivery: evaluation D/E**

*(original lines 258-296)*

P Having already guessed what it was, but having also, because, there's so much information by this time, find out what else it could be, which was much worse. And also I had a friend with muscular dystrophy and hers started with problems in her legs ... so I was ...

I Distraught...

P Yes, it wasn't a good moment. Er, that, I have to say ... and I don't think the NHS covered itself in glory at all.

I That's horrendous..

P Awful, isn't it? I think it's awful.

I Horrific, I mean, what a way to start someone off on ... you know ... on coping with something that they are going to have to, I mean, just the whole process of diagnosis? How can this happen?

P And also, why put a junior doctor on rotation, probably, wanting to choose which one they want to specialise in. Why give them a relatively young person who's likely to have MS? [14.28]

I Yes

P That was just poor organisation on the part of the hospital.

I And there should be someone else who can be called on!

P And there should have been ...

I You know, a senior nurse ... somebody..

P There should have been a nurse there who was able to walk back in and say, "Look we need to talk." With the duty doctor and help the junior doctor. Cause I was old enough to know that ...

I So, how old were you ...

P So, if you take ... I'm forty seven now, it was ... I was thirty seven. So I was old enough to know.

I had two children and enough junior doctors looking at bits of me that I'd rather they weren't looking at [laugh] ... you know ... I wasn't out to hurt that person.

I You were also married and you were a family woman and not desperate to get back to mum and you wouldn't need and adult with you, so to speak ...

P No, no. No, I didn't. And as I say, I ... er ... I didn't want it to be the worst news and muscular dystrophy, that would have been three years.

I Yes

P You know, MS by that point was not, sadly, the worst ... I just wanted to know.

I MS was a relatively unknown ...

P Yes.
Diagnosis delivery: result D/R
(original lines 298-303)
P You know, MS by that point was not, sadly, the worst ... I just wanted to know.
I MS was a relatively unknown ...
P Yes.
I So what happened after that?
P What happened after that was, I phoned the GP and, as I say, and got through, and he said, "Do you want to come in? I'll come up to you. You can come to me at home or come into the surgery." I said, "No, I'll come into the surgery. I don't want ..." you know the home ... I'd rather it was in the surgery. And so he just said, you know, it is MS. And I'm afraid I cried again.

Diagnosis delivery: coda D/C
(original lines 305-309)
P [upset] I makes me sad just thinking about it ...
I I'm not surprised, I mean it's quite a difficult sort of ... really, it's not something that's ever going to go away. That whole process ...
P I think it was not a good way for it to be handled, but I have to say, I've heard worse, here, about how the NHS handle things.

Example Narrative 2: Lost maternal choice

LOST MATERNAL CHOICE (M)
Lost maternal choice: abstract M/A
(original lines 6657-671)
But you do need to be aware that you are likely to have a really bad something if you have another child." And I really, really wanted another child but my husband went and had a vasectomy because he didn't want to put me through it again. And I was furious. I couldn't speak to him. I was so angry.

Lost maternal choice: orientation M/O
(original lines 659-665)
P He was very good. Yeah, so ... um. [pause] So that was very good. But what he said was I was never to have any more children because they ... because the episodes came after the birth of my son and then after my daughter even though there were other symptoms going on, they believed I should never ... And I said to him, "No that's not your decision, that's our decision, really. I think that's our decision." Um...

Lost maternal choice: complicating action M/CA
(original lines 680-684)
P N...n..no, [ambiguous - suddenly doesn't seem to want to leave husband as totally negative] now my husband said it was also his choice and I said, "Yes, absolutely! But it was one we should discuss." And doing it then, when everything was so new -- when the news was so new. To make that, sort of, big decision ...
(original lines 704-708)
P ... and he told me before I had time to deal with it. He'd gone and ...
I He told you before or afterwards?
P Before ... but it was, by that time, it was literally the next day that he was going to have it done and no matter what I said, he went.

Lost maternal choice: evaluation M/E
(original lines 677-678)
But it was MY choice. It was not for other people to make that decision: that's how I felt about it.
(original lines 691-694)
P And I thought that was a big one for me. I always wanted three children. And ... um ... yeah.
I And it was something that was taken away.
P Yeah: if I wanted them within a relationship.
(original lines 695-702)
I Yes, yes ... very, very difficult, because how do you, you know ... it's obviously something you've ... or ... come to terms with ...?
P [pause] Yes, [swallows hard] it's something you make ... [36.53]
I Something you've talked about and you're aware of and you're consciously ...
P [interrupts halfway through above] ... if you consciously ...
I ... but it's something you had thrown at you ...?
P ...but it was a, a decision he made ...

(original lines 729-736)
I And had he ever treated you like that before?
P No. No, no ...
I So ... but he didn't do things like that
P No. No, it was completely out of character. It was his fear. It was fear, which he would now admit. Because ... watching what I was like ... the thought of the next episode being so much worse. I can understand the fear but that still was not ...
I No. At the time, too difficult ...

Lost maternal choice: result and embedded evaluation M/R +EmE

(original lines 671-677)
It did affect our relationship. Because, that again was my choice. It was not for him to take the choice away from me. And I did say to him, if I want another child, I will have one. I was so angry ... ha, ha, ha ...[laughing and shouting] ... I said "I'M TRYING! A CHILD! I'LL FIND SOMEONE THAT CAN GIVE ME A CHILD!!" HA! HA! HA!

(original lines 686-689)
P And also I said to him, things like, if we can't have children, "What about all those other people that needed a donation -- sperm donors?" And he then said, "I never thought about that." And I said, "No but you DIDN'T allow me to talk about it." [pause]

(original lines 708-726)
And I was angry, so angry ... that ... as I say, I didn't talk to him for a long time. Other than, basic, you know, child needs to go to school ... you know, that ... that was it ... we had very little conversation. I was so angry.
I How did you feel about yourself, then? [pause] You must have ... as a person, that must have been quite difficult to ...
P I think I was too angry to really think about how I felt ... and then there was ...
I I mean all that anger?
P It was my anger ... just ... [pause ... gasp] I just couldn't bel [ieve - unfinished] ... I was ...
someone who said they loved me then to take ... to be able to then make a decision ... it just seemed ...
I kept saying to him, "You're not my father! I'm not a child! You're not my father! If I'd wanted a father I wouldn't have married you! I've ..."
P Would he have done ...
P "... I've had a father. I know what's that like." [pause]
I I don't need another one ...?
P I don't need another one.

(original lines 737-744)
P And, you know, as, as ... he was sadly one of the ones that got an infection as well, so it was not ... an unpainful experience. So ... I admit, I was not sympathetic! I kept going, "YOUR FAULT! YOU CHOSE TO DO IT! DON'T COMPLAIN!" [laughs] I think was what I said! Ha, ha, ha ...
I [laugh] Wonderful! [laugh] The anger was vented!
P Yes. In fact, oh, looking back at it, I can see it was fear. [serious again]

Lost maternal choice: coda M/C

(original lines 746-754)
P You know ...
I And has he ever talked about that ... and ...?
P Oh, we did after. A long time after he did but ... not now, it's gone, it's in the past. It's nothing to be worried about now.
I Because it's how it ... influences ... it, it's the fact that you had MS influenced ...
P [interrupts] Yes.
I ... your relationship and your life, not just in terms of you.
P Yes. No. It did ... it obviously had ...
d) Annotation applying Gee's (1991) analysis: Transcripts in narrated order

Interview 3: Brenda (data set 2)
The following examples show analysis of 'diagnosis delivery' and 'lost maternal choice' narratives on data in the participant's narrated order.

Interview 3: Narrative extracts in order of telling (narrated order)

DIAGNOSIS DELIVERY (D)

Diagnosis delivery: orientation D/O
(original lines 245-247)

P: So, anyway, I got back ... the date for when they were giving me my results.

Diagnosis delivery: abstract D/A
(original lines 247-249)

I ended up walking around the department with my notes, saying "Will anybody, please, explain to me before I leave what this actually says?!

Diagnosis delivery: complicating action D/CA
(original lines 249-256)

...went in the nurses' room asking: "Ooh, would you like a cup of tea?/" And anybody come, going 'Will somebody..." I was in tears.

Diagnosis delivery: evaluation D/E
(original lines 258-296)

P: Having already guessed what it was, but having also because, there's so much information by this time, find out what else it could be, which was much worse. And also I had a friend with muscular dystrophy and hers started with problems in her legs...

I: That's horrendous...

P: Awful, isn't it? I think it's awful.
Horrific, I mean, what a way to start someone off on … you know … on coping with something that they are going to have to, I mean, just the whole process of diagnosis? How can this happen?
P And also, why pull a junior doctor on rotation, probably, wanting to chase which one they want to specialise in. Why give them a relatively young person who's likely to have MS? [14:28]
I Yes
P That was just poor organisation on the part of the hospital.
I And there should be someone else who can be called on!
P And there should have been …
I You know, a senior nurse, somebody …
P There should have been a nurse there who was able to walk back in and say …
"Look we need to talk." With the way doctor and help the junior doctor. Cause I was old enough to know that …
I So, how old were you …
P So, if you take ... I’m forty seven now, it was … I was thirty seven. So I was old enough to know I had two children and enough junior doctors looking at bits of me that I'd rather they weren't looking at [laugh] … you know … I wasn’t out to hurt that person.
I You were also married and you were a family woman and not desperate to get back to mum and you wouldn’t need and adult with you, so to speak.
P No, no. No, I didn’t. And as I say, I’d rather it was something I didn’t want it to be the worst news and muscular dystrophy. That would have been three years.
I Yes
P >You know, MS by that point was not, sadly, the worst … I just wanted to know.
I MS was a relatively unknown …
P Yes, Yes. So that was …

Diagnosis delivery: result D/R
(original lines 298-303)
P —> You know, MS by that point was not, sadly, the worst … I just wanted to know.
I MS was a relatively unknown …
P Yes.
So what happened after that?

What happened after that was I phoned the GP and as I say, and got through, and he said, "Do you want to come in? I'll come up to you. You can come to me at home or come into the surgery." I said, "No, I'll come into the surgery. I don't want..." you know, it was quite a difficult sort of... really, it's not something that's ever going to go away. That whole process... I'm not surprised, I mean it's quite a difficult sort of... really, it's not something that's ever going to go away. That whole process...

Diagnosis delivery: coda D/C
(original lines 305-309)

I think it was not a good way for it to be handled, but I have to say, I've heard worse, about how the NHS handle things.
LOST MATERNAL CHOICE (M)

Lost maternal choice: orientation M/O
(original lines 659-665)

P He was very good. Yeah, so um. [pause] So that was very good. But what he said was I was never to have any more children because they ... because the episodes came after the birth of my son and then after my daughter, even though there were other symptoms going on, they believed I should never... And I said to him, "That's not your decision, that's our decision. I think that's our decision." Um...

Lost maternal choice: abstract M/A
(original lines 665-671)

But you do need to be aware that you are likely to have a really bad something if you have another child." And I really really wanted another child but my husband went and had a vasectomy because he didn't want me through it again. And I was furious. I couldn't speak to him. I was so angry.

Lost maternal choice: result with embedded evaluation M/R +EmE
(original lines 671-677)

It did affect our relationship. Because, that again was my choice. It was not for him to take the choice away from me. And I did say to him, if I want another child, I will have one. I was so angry... ha, ha... [laughing and shouting]. I said "I'M TRYING A CHILD! I'LL FIND SOMEONE THAT CAN GIVE ME A CHILD!!" HA! HA! HA!

Lost maternal choice: evaluation M/E
(original lines 677-678)

But it was MY choice. It was not for other people to make that decision; that's how I felt about it.

Lost maternal choice: complicating action M/CA
(original lines 680-684)

P N... no, [ambiguous - suddenly doesn't seem to want to leave husband as totally negative] now my husband said it was also his choice and I said, "Yes, absolutely!"
But it was one we should discuss. And doing it then when everything was so new - when the news was so new / To make that, sort of, big decision... /  

Lost maternal choice: result M/R  
(original lines 686-689)  
P: And also I said to him, things like, if we each have children. What about all those other people that needed a donation - sperm donors? And he then said, "I never thought about that." And I said, "No, but you DIDN'T allow me to talk about it." (pause)  

Lost maternal choice: evaluation M/E  
(original lines 691-694)  
P: And I thought that was one for me. I always wanted three children. And ... um ... yeah.  
I: And it was something that was taken away.  
P: Yeah, if I wanted them within a relationship.  

Lost maternal choice: evaluation M/E  
(original lines 695-702)  
I: Yes, yes ... very, very difficult, because how do you, you know ... it's obviously something you've ... or ... come to terms with ...?  
P: [pause] Yes, [swallows hard] it's something you make ... [36.53]  
I: Something you've talked about and you're aware of and you're consciously ...  
P: [interrupts halfway through above] If you consciously ...  
I: ... but it's something you had thrown at you ...?  
P: ...but it was a, a decision he made ...  

Lost maternal choice: complicating action M/CA  
(original lines 704-708)  
P: ... and he told me before I had time to deal with it. He'd gone and ...  
I: He told you before or afterwards?  
P: Before ... but it was, by that time, it was literally the next day that he was going to have it done and no matter what I said, he went.
Lost maternal choice: result M/R
(original lines 708-726)

And I was angry. So angry. That was it. I didn't talk to him for a long time. Other
than basic, you know. Child needs to go to school... you know that... that was it...
we had very little conversation. I was too angry.

I How did you feel about yourself, then? [pause] You must have... as a person, that
must have been quite difficult to...

P I think I was too angry to really think about how I felt... and then there was...

I I mean all that anger?

P It was my anger. Just. [pause... gasp] I just couldn't be [leave - unfinished]

I was... someone who said they loved me, then to take... to be able to then make a
decision... it just seemed... I kept saying to him, "You're not my father! I'm not a
child! You're not my father! If I'd wanted a father, I wouldn't have married you. I've...

I Would he have done...

P ... I've had a father. I know what that's like." [pause]

I I don't need another one...?

P I don't need another one.

Lost maternal choice: evaluation M/E
(original lines 729-736)

I And had he ever treated you like that before?

P No. No.

I So... but he didn't do things like that

P No. No, it was completely out of character. It was his fear. It was fear, which he
would now admit. Because... watching what I was like... the thought of the next
episode being so much worse. I can understand the fear, but that still was not...

I No. At the time, too difficult...

Lost maternal choice: result M/R
(original lines 737-744)

P And, you know, as... he was sadly one of the ones that got an infection as,
well, so it was not... an unpleasant experience. So... I admit. I was not sympathetic.
Lost maternal choice: coda M/C

(original lines 746-754)

I: You know...

P: Oh, we did after a long time after he did it... not now. It's gone; it's in the past.

I: Because it's how it... influences it. It's the fact that you had MS influenced...

P: [interrupts] Yes...

I: ... your relationship and your life, not just in terms of you.

P: Yes, No. It did... It obviously had...

1)

Huge empathy kept going

[laughs] I think was what I said! Ha, ha, ha [laugh]

I: [laugh] Wonderful! [laugh] The anger was vented!

P: Yes. In fact, or looking back at it, I can see it was fear. [serious again]
e) Annotation on formatted narratives using Gee's (1991) analysis

Interview 3: Analysis following Gee's linguistic model
Data in narrated order are reconstructed following annotation in the preceding stage. Data are read/recordings played to inform interpretative analysis.

LOST MATERNAL CHOICE

PART ONE Dealing with professional advice
STROPHE ONE Being told not to have children
STANZA 1
1 He was very good. Yeah, so ... um. [pause]  
2 So that was very good.

STANZA 2
1 But what he said was I was never to have any more children  
2 because they ... because the episodes came  
3 after the birth of my son  
4 and then after my daughter

STANZA 3
1 even though there were other symptoms going on,  
2 they believed I should never ...

STROPHE TWO Our decision
STANZA 4
1 And I said to him,  
2 "Look, that's not your decision,  
3 that's our decision, really.  
4 I think that's our decision." And, um...

STANZA 5
1 And, um, he just said, "No, absolutely,  
2 But you do need to be aware  
3 that you are likely to have a really bad something  
4 if you have another child."

STANZA 6
1 And I really)  
2 (really wanted another child
STROPHE THREE Disagreement

STANZA 7
1 but my husband went and had a vasectomy
2 because he didn't want to put me through it again.

PART TWO Anger and frustration

STROPHE FOUR Impact on marriage

STANZA 8
1 And I was furious.
2 I couldn't speak to him.

STANZA 9
1 I was so angry.
2 It did affect our relationship.

STANZA 10
1 Because, that again was my choice.
2 It was not for him to take the choice away from me.

STANZA 11
1 I did say to him, if I want another child,
2 I will have one.

STANZA 12
1 I was so angry ... ha, ha, ha ... [laughing and shouting]...
2 I said "I'M TRYING A CHILD!

STANZA 13
1 I'LL FIND SOMEONE
2 THAT CAN GIVE ME A CHILD!!" HA! HA! HA!

PART THREE Denied her right to choose
STROPHE FIVE Unfair decision

STANZA 14
1 But it was MY Choice.
2 It was not for other people
3 to make that decision:
4 that's how I felt about it.

STANZA 15
1 N.n...no, [ambiguous - suddenly doesn’t seem to want to leave husband as
totally negative] now my husband said it was also his choice
and I said, "Yes, absolutely! But it was one we should discuss."

STROPHE SIX Resentment and accusation

STANZA 17
1 And also I said to him, things like,
2 if we can't have children,
3 "What about all those other people
4 that needed a donation – sperm donors?"

STANZA 18
1 And even he then said,
2 "I never thought about that."
3 And I said, "No
4 but you DIDN'T allow me to talk about it." [pause]

STANZA 19
1 And I thought that was a big one for me.
2 I always wanted three children.
3 And... um... yeah, Yeah:
4 if wanted them within a relationship.

PART FOUR No opportunity to deal with the dilemma

STROPHE SEVEN Excluded and cheated

STANZA 20
1 [pause] Yes, [swallows hard] it's something if you make... [36.53]
2 ... if you consciously...

STANZA 21
1 ...but it was a, a decision he made...
2 ... and he told me before I had time to deal with it.

STANZA 22
1 He'd gone and...
2 [He told you before or afterwards?]
3 Before... but it was, by that time, it was literally the next day
4 that he was going to have it done
5 and no matter what I said, he went.

STROPHE EIGHT Angry and unable to understand

STANZA 23
1 And I was angry,
2 so angry... that... as I say,
3 I didn't talk to him
4 for a long time.

STANZA 24
1 Other than, basic,
2 you know, child needs to go to school...
3 you know, that... that was it...
4 we had very little conversation.
STANZA 25
1 I was so angry.
2 I think I was too angry to really think
3 about how I felt...
4 and then it was... It was my anger...

STROPHINE NINE Husband not father: different roles

STANZA 26
1 just... [pause]...I just couldn't be [love - unfinished]... it was... someone who said they loved me
2... then to take... to be able to then make a decision...
3... it just seemed...

STANZA 27
1 I kept saying to him,
2 "You're not my father!
3 I'm not a child!!
4 You're not my father!

STANZA 28
1 If I'd wanted a father
2 I wouldn't have married you!

STANZA 29
1 I've..."
2 "...I've had a father.

STANZA 30
1 I know what's that like...[pause]
2 I don't need another one.

PART FIVE Understanding and resolution

STROPHINE TEN Understanding

STANZA 31

Little energy in this.
[And had he ever treated you like that before?]
1. No, No, so...
2. "Oh, didn't it *sound* like that?" Innuendo brings his back...

STANZA 31
1. It was his fear.
2. It was; fear which he would now admit.

STANZA 32
1. Because... watching what I was like...
2. the thought of the next... episode being so much worse...

STROPHIC ELEVEN Minor retribution
STANZA 33
1. And, you know, as, as...
2. he was sadly one of the ones that got an infection as well;
3. so it was not...
4. an unpleasant experience.

STANZA 36
1. "YOUR FAULT!
2. YOU CHOSE TO DO IT!
3. DON'T COMPLAIN!"
4. [laughs]
5. I think was what I said! Ha, ha, ha [laughs]
I can see it was fear. [serious again]

STROPHE TWELVE Moving on

STANZA 37 (39)

1 In fact, oh, looking back at it,
2 I can see it was fear. [serious again]

STANZA 38 (40)

1 You know...
2 Oh, we did after.
3 A long time after he did that...
4 not now,

STANZA 39 (41)

1 it's gone, it's in the past.
2 It's nothing to be worried about now.

STANZA 40 (42)

[It, it's the fact that you had MS influenced...]

1 [interrupts] Yes.
2 Yes. No. It did ... it obviously had...

The resolution is not as important /

dramatic as the argument/ resolution.
f) Case-wise findings: Emotional responses revealed by Gee's analysis within narratives defined by Labov's analysis

Data Set 1: Interview 2  Participant: Val

<table>
<thead>
<tr>
<th>Labov's analysis: attributed narratives</th>
<th>Labov's analysis: Defining emotional concepts</th>
<th>Gee's analysis: narrative parts</th>
<th>Gee's analysis: emotion perspective / response</th>
</tr>
</thead>
</table>
| 1 Enemy threat                         | - disability is enemy: treated MS as a disability right from the start  
- masks denial (engages only with MS as enemy to be fought)  
- no denial of concept of threat ruling her and interacts with entire outlook  
- strength/power: important since childhood; despises weakness | Enemy narrative  
1 Fighting the enemy  
2 Accepting the enemy | • Emotional isolation with MS (El)  
• MS isolated from her (PE)  
• Self labelling: equated herself as disabled (PE)  
• Fighting enemies (PE)  
• Singular battle – her alone throughout (El/PE)  
• Concept of accepting – accepting fight (PE) |
| 2 Learned discrimination threat        | - keeps MS to self  
- masks a form of denial  
- life patterned by stigmat/discrimination | Discrimination threat  
1 Concealing MS  
2 Telling people  
3 Sympathy threat  
4 Mistrusting people | • People threaten: fear of social threat (PE / FoF)  
• Isolated with threat: social and physical (El)  
• Protecting identity – stigma and discrimination (PE / FoF) |
| 3 Future-oriented fear at diagnosis    | - loss of control (6)  
- discrimination threat (4) | FoF at diagnosis  
1 Falling to pieces  
2 Benefit finding | • Isolated with multiple sources of fluctuating fear (FoF / El)  
• Active fear + passive threat (FoF)  
• Fluctuating fear – but underlying life threat  
• Individual/alone: accepted probs but not MS (El)  
• Understood disability as threat – subconscious/passive constant threat that guided/ruled (FoF) |
| 4 Social isolation: people don't help | - culture of religion / wealth  
- discrimination / stigma  
- high powered but does not engage positively with people  
- links to control / has to control / negative responses | People don't help  
1 Childhood inferiority  
2 Parents' deaths  
3 Family outcasts  
4 Threatened with social care | • Inferiority and stigma since childhood (PE)  
• Emotionally strengthened for destiny (PE)  
• Learned negative aspect of disability (PE / FoF)  
• Inferiority and stigma imposed by others (PE)  
• Rejection being family outcasts (PE / El)  
• Cultural context  
• Fighting – not trusting – destiny (PE / El) |
| 5 Control trait: shaped from childhood | - shaped from childhood: having to take charge wanting to take charge – ruthless  
- loss of control = future-oriented fear  
- active fear = invokes attitude and behaviour  
- loss of control creates trauma = anticipated loss is emotional | Control  
1 Shaped by childhood  
2 Needs control  
3 Controlling illness  
4 Perceived childhood role  
5 Ultimate control of MS | • Isolated + enforced responsibility since childhood (El / PE)  
• Control driven by negative emotions (PE)  
• Fight – learned to fight (PE)  
• Had to be an individual – fear of not being in control (FoF / El / Pi)  
• Control – need to control – destiny |
| 6 Age-focussed fear                   | - passive fear that she faces head on  
- loss of control: the reality  
- It was marriage / not age: fear of age played out by illness resulting from wedding | Age-related FoF  
1 Sub-conscious threat | • Future-oriented fear related to age (FoF)  
• Determination – future oriented  
• Driven by fear  
• Paradox of control and fear |

297
<table>
<thead>
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<th>Labov's analysis: attributed narratives</th>
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<th>Gee's analysis: narrative parts</th>
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<tbody>
<tr>
<td><strong>1 Diagnosis delivery:</strong> anger and fear</td>
<td>- retrospective narrative of active fear and anger at delivery, lack of explanation - sadness is current in passive sense with retrospective focus - current retrospective sadness in the context of reviewing from her new identity her response in previous identity - active anger diagnosis time reduced to hurt/pain recounting experience: reducing to hurt and pain facilitates coping</td>
<td><strong>Diagnosis delivery</strong> 1 Recalling emotional meltdown 2 Inadequate 3 GP providing understanding</td>
<td>• Active distress and anger mutate to current, active, stress and urgency (FoF) • Frustration / desperation, fear / intense distress (FoF – retrospective evaluation) • Disbelief and disgust – anger – replay (Resolved FoF – replayed in past tense) • Concern, guilt and retained embarrassment – incredulity and disbelief – re-evaluation of past – acceptance (Resentment) (R)</td>
</tr>
<tr>
<td><strong>2 Motherhood choice withdrawn: violated rights</strong></td>
<td>- residual anger in active expression balanced by acceptance - structure for coping but still retains anger - passive versus active anger - identity change as she is not a mother of three children as she wanted to be - hurt and pain</td>
<td><strong>Lost maternal choice</strong> 1 Dealing with prof advice 2 Anger and frustration 3 Denied right 4 No opportunity to deal w dilemma 6 Understanding and resolution</td>
<td>• Vividly recounts fury and shared resolution: evaluation and interpretation (NOT EI) • Marital discord, anger, disbelief = frustration (resentment at eroded rights) (R) • Still angry; but resolved / Resolution in plural/past - active anger and resentment – angry in a different way (resentment: altered perspective on anger) (R) • Understanding in singular/present – personal impact / loss of rights – unfairness (eroded rights)</td>
</tr>
<tr>
<td><strong>3 Diminished fear</strong> Fear reduce by</td>
<td>- acceptance</td>
<td><strong>Diminished fear</strong> 1 No longer fearful for herself 2 Planning ahead</td>
<td>• Discussed/coped with fears to diminish threat (FoF versus dislike) • Reduced future-oriented fear and personal threat • Now: regret, unfairness, concern (FoF diminished – not real fear – accepting facilitates change of status)</td>
</tr>
<tr>
<td><strong>4 Coping with threat:</strong> MS as alien</td>
<td>MS as invasive alien allowed her to deny rather than accept MS. - no identity with MS - something that had taken over Used to avoid frightening child also gave her some definition. Alien related to her fear- provided process of coping w unknown. Faith process = alternative process of coping, producing calm rather than fear.</td>
<td><strong>MS as alien</strong> 1 Explaining to son</td>
<td>• Uncertainty distanced from her identity • Insecurity, uncertainty and Ignorance (PE role as parent – protecting son) • Lack of understanding = inability to explain – acceptance facilitates understanding and reduces FoF</td>
</tr>
<tr>
<td><strong>5 MS Identity downgrades fear</strong></td>
<td>- anger from lost maternal choice modified to annoyance/irritation. Accepting does make MS defining + leads to reduced fear. - two-way interaction with the 'Faith Process' and identity (connects with re-defined identity from loss of maternal choice).</td>
<td><strong>MS Identity</strong> 1 MS not the person</td>
<td>• Accepting does not mean labelling • Irritated and annoyed but no longer traumatic (no resentment) (no R) • MS not her – preserving her identity – understanding/accepting MS as something but it is not her – not labelling (no resentment) (no R)</td>
</tr>
<tr>
<td><strong>6 Faith process for coping</strong></td>
<td>- process for achieving calm - faith does not take away the hurt or pain but facilitates coping This can be compared to the concept of the alien – the &quot;alien&quot; as a process allowed her to cope with, and explain, the unknown.</td>
<td><strong>Faith process</strong> 1 Inward-looking response 2 Existential faith 3 Faith as a process</td>
<td>• More inward looking • Process to go through but hurt not necessarily reduced – not 'lucky' to have belief / less religious now</td>
</tr>
</tbody>
</table>
### Labov's analysis: attributed narratives

1. Prescribing error
   - resentment
   - retaliation
   - no fear
   
   Retrospective retaliation described. Plus active retaliation noted by wanting story recorded. Fear from unknown, not what is happening – no point in fear. Resentful at suggestion of fear.

2. Physical rejection: unattractive disability
   - interprets rejection as physical
   - her physical attractiveness / charm does not secure her job
   
   Links lost job and disability, seen as lost attractiveness. Rejection is hers – she defines disability as unattractive.

3. Rejecting Invisible MS
   - MS not part of her identity
   - lives with MS but it is not her
   
   Would not tell people about MS as does not accept it as part of her identity. Something she lives with. Seem to resent it in other contexts. Here she rejects it.

4. Negative family interactions
   - negative emotional association with family
   - mean to family
   
   Lack of positive emotional responses. Irritation/dismissal. Cuts family out: does not want to talk about father/brother; mother resented as wants to 'fix it'.

5. Resentment and maternal friction
   - resentment at loss of control
   - projects resentment on mother
   - perfectionist/judgemental
   
   Despises, belittles 'mothering' tendency. Begins to indicate understanding of mother's response: cuts it. Dislikes mother for what she always has been.

6. Ambiguous social capital
   - seeks self assurance
   - physical attractiveness
   
   Seeks assurance she can still be manipulative in her 'new life'. Not got own way because disability physically unattractive. Using flirting relates to resentment at reduced attractiveness. Rejection. When attractiveness as social capital doesn't work she is resentful and self esteem is lowered.

### Labov's analysis: defining emotional concepts

1. Prescribing error
   - Blames inexperienced doctor
   
   2. No practical resolution
   
   3. Validation does not calm resentment

### Gee's analysis: narrative parts

1. Active negative emotions: resentment, contempt, disgust and blame = vengeful (R)
2. Unresolved anger and lost control - anger
3. Need for revenge / vindictive (R)
4. Active emotions, disgust, contempt, resentment and blame – active expression of unresolved / compounded emotions

### Gee's analysis: emotion perspective / response

1. Short term resolution over-ridden by dismissive anger and resentment (R)
2. Injustice, resentment and blame (R)
3. Physical rejection – prejudice / stigma
4. Riddled with ambiguity – guilt / blame
5. Sense of guilt/offloading responsibility/possible deception (self + others). Seeking endorsement / relinquishing responsibility. Injustice and resentment (R)
6. Not her prob, not responsible, resentment (R)
7. Unresolved anger
8. Fight against identity with MS – rejecting MS and fighting
9. Negative emotions / actively negative interactions
10. Patronises mother

### Family responses to MS

1. Negative emotions / actively negative interactions
2. Patronises mother
3. Opinionsated and not open minded
4. Anger, resentment and negative attitude excludes opportunity for resolution
5. No way out – trapped with negative MS (EI) through dogmatic and opinionated inability to consider alternative interpretations

### Maternal friction

1. Active irritation / resentment at mother
2. Loss of control: resentful and intensely negative
3. Egotistic, impatient, selfish/self isolating
4. Taken for granted friends but collective/anonymous emotional isolation with negative associations (EI)
5. Dismisses friends: ambiguity, isolation from friends and with family. Self centred, egotistic, not understanding. Irritation, anger, impatience leads to resentment and she is isolated with this (R / EI)

### Control – fighting – she feel victimized – her insular fight – isolating (EI). Loss of power – resentment Patronising and alienating of mother. Created own drama (EI) which builds her resentment (R)
### 7 Colleague interaction intolerance
- Resents colleague's attitude
  - Intolerant

### 1 Colleague does not accept disability
- Accepting means moving forward

### 8 Beautiful boyfriend: emotional void
- Physical and material
  - Emotional void
  - Retaliation
  - The boyfriend who is beautiful and rich is retaliation. ‘Look, see’ retaliation expressed to doctor.

### Beautiful boyfriend
- Confidence-boosting exercise
  - Self reassurance of attractiveness
  - Physical attractiveness important
  - Positive reinforcement – not lost attractiveness
  - Superfluous – appearance not affection
  - Confidence boosting – about her confidence

### 9 Resents reduced attractiveness
- Irritated she says
  - Resentful
  - Vain
  - Her own perception/interpretation that others find stick/indicator of disability less attractive. Defines herself as beautiful and ‘a looker’ has everything to be attractive. Disability unattractive; resents it. Uses it as excuse?

### Reduced physical attractiveness
- Men’s reactions to her
- Disability is not attractive
  - Anger, irritated and resentful (R)
  - Lost love – explained through physical rejection – her sense of rejection / loss
  - All physical

### 10 Resents perfectionist mother
- Resents mother
  - Mother as perfectionist
- Angry with mother. Resents mother as artist and for wanting perfection. Twists mother’s concern into negative.

### Perfectionist mother
- Cannot accept her as not perfect
- Relationships with parents changed

### 11 Maternal connection: lost control
- Resents mother’s ability to do things
  - Associates mother with loss of control rather than helping her.

### Maternal connection
- Lost independence / control
  - Resentment / exasperation at her mother
  - Isolating / independence seeking
  - Intense frustration
  - Isolates herself to try and regain independence – lost independence from parental/maternal input

### Notes
- Contempt, intolerance and disapproval
- Anger: shouted resentment / frustration
- Frustration that negative MS dominates
- Dismissive of others: contempt / disapproval / intolerant of those who do not behave as she does
- Active anger and frustration/negativity
- Subconsciously aware she could be more accepting (R and anger) Constant awareness of negative and resentment at this (R)
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<tr>
<td>1 Nursing wife: frustration and concern</td>
<td>Pre-diagnosis responses to caring for terminally ill wife - inability - frustration - concern Benefit finding from relief after wife's death. Relief from both knowing what diagnosis is, and explanation of inability to cope with wife's needs. Retrospective evaluation of inability results in concern: frustration changes from active emotion to passive retrospective concern.</td>
<td>Nursing wife</td>
<td>• Unresolved regret, frustration, conflict • Intermittently passive and active • Loneliness and isolation (El) • Fear of future relationships – social isolation / loss of wife and partner (El) • Lack of confidence and uncertainty Ruminating – on his current situation</td>
</tr>
<tr>
<td>2 Diagnosis process: uncertainty</td>
<td>- uncertainty - relief Link to inability and frustration of looking after wife and relief from wife's death and being able to reassure daughters and father.</td>
<td>Diagnosis process 1 From person to person 2 Losing patience 3 Seeing wrong people 4 Specialist doesn't know how to tell him 5 Doctor passes him on</td>
<td>• Frustration and desperation • Uncertainty and lack of support • Coping persona hides desperation • Avoids distressing others Negative emotional impact - frustration – isolated with diagnosis experience (El)</td>
</tr>
<tr>
<td>3 Paternal concern</td>
<td>- mirroring relief but this is more urgent: emotional response to diagnosis and being able to calm daughters' concerns - concern for daughters' wellbeing. Also reducing his fear for them. Sense of urgency. Shared relief only once daughters have been calmed.</td>
<td>Paternal emotions 1 Daughters' response</td>
<td>• Addresses resolves daughters' concerns (PE) Thinks first of his daughters and family commitments to them and his father. Does not offload his concerns on to them but deals with their concerns (El)</td>
</tr>
<tr>
<td>4 Reassuring his father</td>
<td>- calming father: reducing shock - mirroring his relief Relief related to calming father is different from daughters. Calms father, reduces shock by mirroring his relief. Reassuring related to calm engagement and dealing with MS. If he is calm and experiencing relief, he can reduce shock for father. Different engagement and response from that to daughters. Shared relief achieved by him imparting his own relief to his father.</td>
<td>Reassuring his father 1 Just a typical relationship</td>
<td>• Minimises stress to father Does not share his concerns with him but calms father (El)</td>
</tr>
<tr>
<td>5 Personal isolation: Needs hugs</td>
<td>- loneliness and isolation - benefit finding Could be described as coda to entire emotional cohesion within narratives. Uses paternal role and role as son to reinforce relief, limit concern and facilitate benefit finding. The emotional coda that seems to apply is concept of being alone: lonely and isolated in emotional dealings with MS. Fundamental is interaction with loss of wife: daughters have their agendas. His responsibility for dealing with his and everyone's emotional responses. Relates to benefit finding.</td>
<td>Hugs narrative 1 Needs affection 2 Needs physical contact 3 Concealing feelings</td>
<td>• Isolation, loneliness and need affection • Lacks emotional support • Hides the reality of his feelings from himself. (El)</td>
</tr>
<tr>
<td>Labov's analysis: attributed narratives</td>
<td>Labov's analysis: Defining emotional concepts</td>
<td>Gee's analysis: narrative parts</td>
<td>Gee's analysis: emotion perspective / response</td>
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<tr>
<td>1 Blindness threat</td>
<td>- fear - relief</td>
<td>Blindness threat</td>
<td>• Relief resolved initial fear</td>
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<td></td>
<td>Fear of blindness and relief followed by withdrawal. Withdraws from the threat of MS.</td>
<td></td>
<td>• Assertive, confident: no uncertainty</td>
</tr>
<tr>
<td>2 Denial: self blame and responsibility</td>
<td>- self blame</td>
<td>Denial</td>
<td>• Threat to fit and attractive identity (FoF)</td>
</tr>
<tr>
<td></td>
<td>- sense of responsibility for not downsizing stress Did not pay attention to MS threat in first stages. Partly offloads responsibility on image of extreme disability he encountered. Not successful. Had responsibilities but was in denial and carried on too long before downsizing to a simpler approach.</td>
<td>1 Retrospective realisation of denial</td>
<td>• Vulnerability / visible disability threat (FoF)</td>
</tr>
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<td></td>
<td></td>
<td>2 Getting involved earlier may have helped</td>
<td>• Ashamed of previous pride and arrogance – guilt, blame</td>
</tr>
<tr>
<td>3 Business social: identity issues and isolation</td>
<td>- fear of identity threat - sad and emotionally flat - patronised by premature ageing - inadequacy - inferiority - lost social power Lost physicality – threat = fear of identity challenge. He was physically strong, powerful, confident and arrogant: to avoid threat he downsized. Sadness, emotional flatness, inferiority and emotions related to inadequacy. Patronised by associations that infer premature aging. Emotionally withdraws.</td>
<td>Business social 1 Downsizing networking 2 Awareness of reduced physical strength 3 No longer a leader 4 No longer the 'social animal'</td>
<td>• Intense sadness – personal and singular, his ownership • Withdraws in response to threat (FoF) • Humiliated and humbled – no longer the person he was is humiliating • Frustrations resolved to sadness Personal emotions and unshared responses/ speaking in singular (El)</td>
</tr>
<tr>
<td>4 Challenged sexual identity/attractiveness</td>
<td>- feels pathetic and embarrassed - inadequate sexuality - unable to cope with feelings - lost confidence - fear of threat Massive sense of loss and diminished status. Threat to his sexual identity as a charming, attractive and powerful male. He cannot project his personality beyond the physical – the physical identity was the basis for his confidence. Identity challenge is biggest threat that produced denial / withdrawal. Huge sense of emotional unrest, threat, responsibility and blame.</td>
<td>Sexual identity / attractiveness 1 Changed approach to women 2 Aware of others’ reactions 3 Avoids acknowledging awareness</td>
<td>• Invasive sense of loss at reduced status • Social isolation and inadequacy (El) Denial but sense of threat and blame – negative.</td>
</tr>
<tr>
<td>5 Read, thinking and uncertainty</td>
<td>- uncertainty - patronised Loss of everything he was sure of. Physical stature, power and social identity threatened. Instead of counteracting he avoided challenges. Mentions caveats and uncertainty – relates to loss of confidence, understanding and identity. Threatened by uncertainty. Trying to fill his mind and expand thinking but that is not helping. Philosophical improvements lead to uncertainty. Concerned his children may humour him and being patronised undermines his confidence.</td>
<td>Read, thinking and uncertainty</td>
<td>• Emotionally unsettling search for identity • Expanding mental capacity = uncertainty • Rumination and retrospective evaluation (El)</td>
</tr>
<tr>
<td>6 Existential threat</td>
<td>- blame - punishment - vulnerability - fearful MS sent as punishment for arrogance. Felt infallible and strong but now weak and vulnerable. No religious focus but considers mystical explanation based on punishment. Has to shut this out. This threatens psychologically: his sanity would be threatened. Fearful for mental stability in context of punishment-based mysticism.</td>
<td>Existential 1 Belief in greater power: mysticism not religion. 2 MS is punishment 3 No longer a leader</td>
<td>• Disturbing emotions: guilt / retention (El) • Punishment for past hubris or excessive pride – concept of punishment has become a threat (FoF)</td>
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<td>Labov's analysis: attributed narratives</td>
<td>Labov's analysis: Defining emotional concepts</td>
<td>Gee's analysis: narrative parts</td>
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<tr>
<td>1 Relief and inferiority</td>
<td>- relief at the MS explanation</td>
<td>Relief and inferiority</td>
<td>• Relief resolution to life-long inferiority</td>
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<td></td>
<td>- inferiority - lack of self-importance</td>
<td>1 Dismissive diagnosis</td>
<td>• Resilience and emotion suppression</td>
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<td></td>
<td>Although diagnosis brings relief through</td>
<td>2 Suspected it was MS</td>
<td>• Isolating with coping (EI)</td>
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<td>explanation of symptoms, it is dismissed as</td>
<td>3 Severe numbness</td>
<td>Minimised MS related to previous experiences</td>
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<td>mild. The inferiority originally associated</td>
<td>and hospitalisation</td>
<td>of being devalued / dismissed and having</td>
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<td>with all the problems has shifted to</td>
<td>4 Specialist minimises</td>
<td>credibility questioned (PE)</td>
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<td>inferiorly related to her condition.</td>
<td>interest</td>
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<td>5 Minimising MS</td>
<td></td>
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<tr>
<td>2 Lifelong questioned credibility</td>
<td>- loneliness</td>
<td>Questioned general credibility</td>
<td>• Lack of empathy / emotional support</td>
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<td></td>
<td>- isolation</td>
<td>1 Losing sight</td>
<td>• Lack of confidence / sense of inferiority</td>
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<td></td>
<td>- questioned credibility</td>
<td>2 Minimizing problems</td>
<td>(PE)</td>
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<td></td>
<td>She is alone with diagnosis and invisible</td>
<td></td>
<td>• Calms her inner panic in isolation (EI)</td>
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<td>symptoms. Lifelong questioned credibility in</td>
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<td>terms of ability now shifted to her condition.</td>
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<td>3 Relief and resolution</td>
<td>- relief at dyslexia</td>
<td>Relief and resolution</td>
<td>• Chronic inferiority has evolved into</td>
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<td></td>
<td>- resolution</td>
<td>1 Explanations for</td>
<td>unfairness (PE)</td>
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<td></td>
<td>Identifying dyslexia brings relief alongside</td>
<td>unexplained problems</td>
<td>• Lacks close emotional connections: isolation</td>
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<td>MS and resolution from put-downs and</td>
<td>2 Bumbled along</td>
<td>from family (EI)</td>
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<td></td>
<td>rejection. She is able to build self-esteem</td>
<td>3 Thankful for reasons</td>
<td>• Grateful for any help</td>
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<td></td>
<td>and reconsider her feeling of failure.</td>
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<td>4 Sense of belonging</td>
<td>- feels accepted</td>
<td>Sense of belonging</td>
<td>• Shared experiences = emotional support</td>
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<td>- found a meaningful identity - self worth</td>
<td>1 Shared experiences</td>
<td>• Acceptance enabling = isolation relief</td>
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<td>- certainty</td>
<td>2 Mutual understanding</td>
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<td>She has a lifelong problem with not being</td>
<td>3 Acceptance</td>
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<td>accepted, being put down and not fitting in.</td>
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<td>She did not fit but now she has found</td>
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<td>acceptance among others with MS.</td>
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<td>5 Inferior MS and questioned credibility</td>
<td>- inferiority</td>
<td>Questioned MS credibility</td>
<td>• Invisible MS renews credibility challenge</td>
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<td></td>
<td>- others with visible MS questioned her</td>
<td>1 Invisible MS</td>
<td>(PE)</td>
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<td></td>
<td>- feels dismissed</td>
<td>2 Others in denial: her</td>
<td>• Rejection and unfairness</td>
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<td>Unimportance/mildness of her condition.</td>
<td>credibility questioned</td>
<td>• Dismissal of distancing from MS (stands</td>
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<td>Plays it down in response to or mirroring</td>
<td>3 Benefit finding</td>
<td>back - relinquishes responsibility)</td>
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<td>others responses to her. Still feels inferior.</td>
<td></td>
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<td>6 Failure and disappointment</td>
<td>- dumb cluck</td>
<td>Failure and disappointment</td>
<td>• Childhood + lifelong shaping (PE)</td>
</tr>
<tr>
<td></td>
<td>- rejection by parents</td>
<td>1 How you were</td>
<td>• Ability to cope in spite of criticism (PE -</td>
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<td></td>
<td>- hurt and resentful</td>
<td>brought up</td>
<td>coping / EI and standing back)</td>
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<td>- numbness and emotionally withdrawn</td>
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<td>Parents disappointed and dismissed her.</td>
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<td>School didn't know what to do with her.</td>
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<td>Rejected, hurt, resentful. Her resentment is</td>
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<td>qualified by relief but she distances herself</td>
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<td>from negative aspects. Very neutral.</td>
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<td>Emotionally withdrawn — numbed by experiences</td>
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<td>and protects herself.</td>
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<td>Labov's analysis: attributed narratives</td>
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<td><strong>1 Diagnosis fear</strong></td>
<td>- future-oriented fear</td>
<td>Diagnosis narrative</td>
<td>- Subconscious threat (FoF)</td>
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<td></td>
<td>- threat</td>
<td>1 Optic nerve: specific problem</td>
<td>- Self isolating past and present (El)</td>
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<td></td>
<td>Adverts promoted future-oriented fear,</td>
<td>2 Receiving diagnosis</td>
<td>- Threat/shock contextualised, retained</td>
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<td>which promoted denial and adjustment for</td>
<td>3 Responding to diagnosis</td>
<td>- Unresolved shock = anger / resentment (R)</td>
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<td></td>
<td>worse-case scenario. Long term emotional</td>
<td>4 Future-oriented fear</td>
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<td>response. The fear progressed from active</td>
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<td>fear to passive fear following putting 'safety</td>
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<td>net' in place but it was 'in the background'</td>
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<td>scenario that translates into threat.</td>
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<td><strong>2 Relapse horror and humiliation</strong></td>
<td>- passive fear</td>
<td>Relapse narrative</td>
<td>- Unresolved active control of pent-up,</td>
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<tr>
<td></td>
<td>- horror</td>
<td>1 Christmas related fear</td>
<td>unresolved emotional responses (FoF)</td>
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<td></td>
<td>- humiliation</td>
<td>2 Retrospective terror</td>
<td>- Isolation with future-oriented fear (El)</td>
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<td></td>
<td>- terror</td>
<td>3 Coping alone</td>
<td>- Continuation of negative emotions</td>
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<td>Worst-case scenario realisation of future</td>
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<td>- Retrospective horror – unresolved</td>
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<td>oriented fear. But calm: the fear of future</td>
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<td>terror actively controlling her fear and</td>
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<td>threat that had been there terminated to be</td>
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<td>stress (FoF – long term)</td>
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<td>replaced by a new terror. The blocked-out</td>
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<td>Isolated with condition and fear (El)</td>
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<td>fear of future is realised.</td>
<td></td>
<td>Helpless = retained terror and helplessness(EI)</td>
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<tr>
<td><strong>3 Maternal response: turmoil and regret</strong></td>
<td>- active fear</td>
<td>Maternal response</td>
<td>- Sense of rejection / resentment at not</td>
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<tr>
<td></td>
<td>- long term horror</td>
<td>1 Helpless mother</td>
<td>being able to care for baby – disbelief</td>
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<td></td>
<td>- emotional turmoil</td>
<td>2 Maternal loss</td>
<td>(R)</td>
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<tr>
<td></td>
<td>- regret</td>
<td>3 Never normal</td>
<td>- Regret and maternal loss – personal loss</td>
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<td>Highly emotional unresolved response with</td>
<td></td>
<td>and resentment at not being able to carry on</td>
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<td>no sense of relief that the children are</td>
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<td>(R)</td>
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<td>fine and a self-focussed regret. Loss of</td>
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<td>- Distress, loss, helplessness and isolation</td>
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<td>motherhood rather than parental care.</td>
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<td>(R / El / FoF – all unresolved and not</td>
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<td>Husband did not want to support - would not</td>
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<td>evaluated)</td>
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<td>bath baby/wash cloths. Short term fear at</td>
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<td>Loss = anger / distress / on-going regret</td>
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<td>horror and parental roles.</td>
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<td>(R)</td>
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<td><strong>4 Fear of future/end</strong></td>
<td>- across narratives as well as focus on end</td>
<td>Fear of Future</td>
<td>- Catastrophises situations (FoF)</td>
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<tr>
<td></td>
<td>of life</td>
<td>1 Dare not think ahead</td>
<td>- Extreme future fear and unrealistic terror</td>
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<td></td>
<td>- horror and humiliation exacerbate fear</td>
<td></td>
<td>(FoF)</td>
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<td>- as well as fear of future 'end', retrospective fear from diagnosis and relapse still active</td>
<td></td>
<td>- Isolates herself from (and with) MS (EI)</td>
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<td>- evaluating worst case scenario = terror</td>
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Appendix II

Chapter 3, Systematic Review

a) Systematic Review: Criteria and ratings used for quality assessment of papers
b) 3.4.3, Table 4, Summary information on papers and findings: Abbreviations
a) Systematic Review: Criteria and ratings used for quality assessment of papers

1 = Aims  
2 = Design  
3 = Sample participants  
4 = Procedure  
5 = Data  
6 = Conclusion, Discussion  

G = Good level of clarity  
M = Moderately clear but with some minor ambiguity  
P = Poor clarity

<table>
<thead>
<tr>
<th>Paper no / first author/pub date</th>
<th>1</th>
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<th>Notes</th>
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<tbody>
<tr>
<td>1 Aikens (1997) Exclude</td>
<td>G</td>
<td>M</td>
<td>P</td>
<td>G</td>
<td>M</td>
<td>P</td>
<td>Low participant nos. (22) Bias in sample/education/MS status, N/A Life stressors measured.</td>
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<td>5 Beiske (2008)</td>
<td>G</td>
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<td>G</td>
<td>M</td>
<td>P</td>
<td>Anxiety separated from depression and need for further research into anxiety.</td>
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<td>14 da Silva (2011)</td>
<td>G</td>
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<td>P</td>
<td>G</td>
<td>M</td>
<td>P</td>
<td>Sep focus on anxiety Good quality research</td>
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| 15 Dahl (2009)                |   |   |   |   |   |   | Focus on complex SEM
<p>| 16 d’Alisa (2008)             | x |   | x | x | x | x | High proportion of Ps with progressive Unconvincing argument for SEM/data processing. Complex data breakdown but ultimate oversimplification |
| 17 Dennison (2009)            |   |   |   |   |   |   | Systematic review of psychological correlates of adjustment in patients with MS. Important background but N/A to review |
| 20 Frushwaid (2001)           | x |   | x | x | x | x | Anxiety not a separate focus from depression. Limited value: only just on topic. Background. |
| 21 Gay (2010)                 | x | x | x | x | x | x | Trait anxiety influence on depression |
| 22 Giordano (2011)            | x | x | x | x | x | x | Compares anxiety / depression |
| 23 Goretti (2009)             | x | x | x | x | x | x | Anxiety important independent of other factors for QoL. Mental QoL. Coping strategies |
| 26 Janssens (2003)            | x | x | x | x | x | x | Ps + partners. Diagnosis stage. |
| 27 Janssens (2006)            | x | x | x | x | x | x | Anxiety/distress. Partners 2-yr follow up |
| 29 Janssens (2003)            |   |   |   |   |   |   | Another write up of study 26 from different perspective of disability and QoL. Same findings. |
| 30 Jopson (2003)              | x | x | x | x | x | x | Illness identity, lack of coherence and anxiety. Illness representations model for predicting adjustment (rather than coping). |
| 31 Julian (2009)              | x | x | x | x | x | x | Significant limitations acknowledged in discussion. Pilot study level. Background only. |
| 32 Kalb (2007)                |   |   |   |   |   |   | Supplement general review. N/A. |
| 33 Kehler (2009)              | x | x | x | x | x | x | Many limitations. Overlap in data. Clarity not established. Background only. |
| 34 Korostil (2007)            | x | x | x | x | x | x | Good epidemiological info. Background N/A. |</p>
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<td>37 Marrie (2009)</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>Focus on depression. Min. info. on anxiety as separate. Low applicability to sys review.</td>
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<td>40 Nicholl (2001) Exclude – N/A</td>
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<td>Focus on evaluation of screening measures. Good background. N/A to sys review q’s.</td>
</tr>
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<td>41 Pakenham (2006)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>Appraisal, coping strategies, positive outcomes and distress (incl. anxiety/depression).</td>
</tr>
<tr>
<td>43 Pakenham (2007) Exclude – Lit review</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Interpretation of MS/outcome. Important to lit review. N/A.</td>
</tr>
<tr>
<td>45 Poder (2009)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>Social anxiety. Relevant but not fundamental to sys review research q’s.</td>
</tr>
<tr>
<td>51 Szilasiova (2011)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>Focus on depression. Limited anxiety focus.</td>
</tr>
</tbody>
</table>
### Statistics Tests
- Chi-square
- Cross-sectional design
- Kruskal-Wallis
- Longitudinal design
- Logistical regression
- Multiple regression
- Mann-Whitney
- Pearson's correlation
- Regression
- Spearman correlation

### Measures
- Acceptance of Chronic Health Conditions Scale (ACHSS)
- Ambulation Index (AI)
- Bradburn Affect Balance Scale (BABS)
- Beck Anxiety Inventory (BAI)
- Beck Anxiety Inventory for Primary Care (BAI-PC)
- Beck Depression Inventory (BDI)
- Beck Depression Inventory – self report (BDI-II)
- Beliefs About Emotions Scale (BES)
- Barthel Index (BI)
- Brief Illness Perceptions Questionnaire (BIPQ)
- Comorbid Alcohol Abuse (CAGE)
- Cognitive Appraisal of Health Status Scale (CAHS)
- Cognitive and Behavioural Responses to Symptoms Questionnaire (CBRSQ)
- Clock Drawing Test (CDT)
- Coping about Health Injuries and Problems (CHIP)
- Chicago Multiscale Depression Inventory (CMDI)
- Coping with MS Scale (CMSS)
- Coping Orientation for Problem Experiences (COPE)
- Coping Orientation for Problem Experiences – New Italian Version (COPE-NVI)
- Expanded disability status scale (EDSS)
- Expanded disability status scale, self report (EDSS-S)
- Eysenck Personality Questionnaire (EPQ)
- Functional Assessment of MS quality of life instrument (FAMS/FAMSqo)
- Functional Independence Measure (FIM)
- General Handicap Attitude Scale (GHAS)
- General Health Questionnaire (GHQ)
- General Symptom Checklist (GSCL-25)
- Hospital Anxiety Depression Scale (HADS)
- Hospital Anxiety and Depression Scale – Anxiety (HADS-A)
- Hamilton Anxiety Rating Scale (HARS)
- Hamilton Depression Rating Scale (HDRS)
- Health Related Quality of Life (HRQoL)
- Hamilton Rating Scale for Anxiety (HRSA)
- Hamilton Rating Scale for Depression (HRSD)
- Hopkins Symptom Checklist (HSCL)
- Health Utility Index (HUI)
- Impact of Events Scale (IES)
- Illness Intrusiveness Rating Scale (IIIRS)
- Illness Perception Questionnaire (IPQ)
- Illness Perception Questionnaire–Revised (IPQ-R)
- Jalowic Coping Scale (JCS)
- Krupp's Fatigue Severity Scale (KFSS)
- Mayo-Portland Adaptability Inventory (M PAI-cog)
- Modified Fatigue Impact Scale (MFIS)
- Mini Mental State Examination (MMSE/MMI)
- Multiple Sclerosis Fatigue Scale (MSFS)
- MS Neuropsychological Screening Questionnaire (MSNSQ)
- MS Quality of Life Inventory (20 items) (MSQoL-54)
- MS Stressor Scale (MSSS)
- Paced Auditory Serial Addition Task (PASAT)
- Purpose In Life scale (PIL)
- Profile of Mood States – Short Form (POMS-SF)
- Psychological Vulnerability Scale (PVS)
- Rankin Scale (RS)
- Structured Clinical Interview DCM-IV (SCID)
- Symptom Checklist (SCL-90)
- Self-efficacy for Managing Chronic Disease (SEMCD)
- Health Survey (SF-36)
- Sickness Impact Profile (SIP)
- Social Phobia Inventory (SPIN)
- Social Support Questionnaire (SSQ)
- Social Support Questionnaire (SSQ-6)
- State Trait Anxiety Inventory (STAI)
- Telephone Interview for Cognitive Status - Modified (TICS-M)
- Toronto Alexithymia Scale (TAS)
- Visual Analogue Scale (VAS)
- World Health Organisation Quality of Life-100 Scale (WHQoL-100)
- Work and Social Adjustment Scale (WSAS)
- Ways of Coping Questionnaire (WOCQ)
- Zung Anxiety Rating Scale (ZARS)
- Zung Depression Rating Scale (ZDRS)
- Zerssen Emotional State Scale (ZESS)
Appendix III

Chapter 4, Study Two

a) University of Surrey Ethics Committee letter of favourable ethical opinion

b) Questionnaire

c) Factor analysis matrices

d) Letter introducing study to MS groups

e) Letter of thanks for assistance with research

f) Participant information sheet

g) Participant consent form

h) Guidelines for assisting with questionnaire completion

i) Debriefing information

j) Recruitment poster

k) Regression analyses model summaries and correlation tables
Ms Bridget E Jones
Psychology
FAHS

Ethics Committee

03 July 2012

Dear Ms Jones

Anxiety Responses to Multiple Sclerosis: Potential predictors of poor adjustment and coping EC/2012/61/FAHS

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 3 July 2012.

The final list of documents reviewed by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of the project</td>
</tr>
<tr>
<td>Detailed protocol for the project</td>
</tr>
<tr>
<td>Information sheet for participants</td>
</tr>
<tr>
<td>Standard letter introducing project to support groups</td>
</tr>
<tr>
<td>Consent form</td>
</tr>
<tr>
<td>Questionnaire</td>
</tr>
<tr>
<td>Guidelines for helper</td>
</tr>
<tr>
<td>Risk assessment</td>
</tr>
<tr>
<td>Recruitment advert</td>
</tr>
<tr>
<td>Debriefing Information sheet</td>
</tr>
<tr>
<td>Thank you for help with the study letter</td>
</tr>
</tbody>
</table>

This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research. If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University’s Ethics Committee.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Glenn Moulton
Secretary, University Ethics Committee
Academic Registry
b) Questionnaire

Note: Type size has been reduced and layout condensed to fit appendices.

Experiences of Multiple Sclerosis:
A study of responses to diagnosis and living with MS

Information about your own experience and responses is vital to this research. We appreciate your valuable opinions and will treat them with respect.

Researcher
Bridget Jones, PhD research student in health psychology
B.E.Jones@surrey.ac.uk

Supervisor
Dr Victoria Senior
V.Senior@surrey.ac.uk

School of Psychology, University of Surrey, Guildford, Surrey GU2 7XH.
01483-681681

Completing the questionnaire will take about 40 minutes.

► Please read the information sheet and sign the consent form before starting.
► Please be as honest and accurate as you can. There are no right or wrong answers.
► This questionnaire is anonymous and separate from all contact and consent details.

If someone else is helping you to fill in the questionnaire

► Please ask anyone helping you to read the guidelines provided for them before starting.

The information you provide is valuable.
Thank you for your time and for sharing your thoughts and feelings.
Part 1  General Information

1  Are you: female ....  male ....

2  Age: years ....

3  What ethnicity do you consider yourself to be?
   White British ....
   White Irish ....
   White Scottish ....
   White Other (please specify) ....
   White and Black Caribbean ....
   White and Black African ....
   White and Asian ....
   Mixed Other (please specify) ....
   Indian ....
   Pakistani ....
   Bangladeshi ....
   Black or Black British Caribbean ....
   Black or Black British African ....
   Black or Black British Other ....
   Chinese ....
   Other (please specify) ....

4  Do you live alone? yes ....  no ....

5  Are you: single .... married or living with a partner .... divorced or separated .... widowed ....

6  Do you have children? yes ....  no .... How many boys? ....  How many girls? .... Please indicate their ages

7  Do you hold any of the following education qualifications? GCSE / 'O' levels .... 'A' levels .... vocational qualification .... higher education diploma/certificate .... degree .... postgraduate .... other ....

8  Are you in employment? paid full time .... paid part time .... unemployed .... other .... job title/description ....
   voluntary work ....
   Please indicate job title/description/type of voluntary work or write n/a if not applicable.

9  In what year and/or month were you diagnosed with MS? year .... month ....

10  What diagnosis or definition of MS were you given when first diagnosed? relapsing remitting .... primary progressive .... secondary progressive .... benign .... other (please specify) ....

11  Have you been given any updated definition or diagnosis of MS? yes ....  no .... If yes, in what year and/or month were you given an updated diagnosis? ....
    If yes, what is the revised diagnosis or definition of MS? relapsing remitting .... primary progressive .... secondary progressive .... benign .... other (please specify) ....

12  Have you been given a diagnosis of alexithymia? yes ....  no ....

13  Have you been given a diagnosis of memory impairment/loss? yes ....  no ....

14  Have you experienced any relapses in the last 12 months? 1 ....  2 ....  3 ....  more than 3 .... none ....

15  Are you currently relapsing? yes ....  no ....
Part 2: Your general health NOW
We are interested in how your general health has been over the last few weeks. Please think about now and recent aspects of health, not those from the past. Read each question and response one at a time and tick which response most nearly applies to you.

<table>
<thead>
<tr>
<th>Have you recently...</th>
<th>Tick response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. been able to concentrate on whatever you are doing?</td>
<td>better than usual&lt;br&gt;same as usual&lt;br&gt;less than usual&lt;br&gt;much less than usual</td>
</tr>
<tr>
<td>2. lost much sleep over worry?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>3. felt that you are playing a useful part in things?</td>
<td>more so than usual&lt;br&gt;same as usual&lt;br&gt;less than usual&lt;br&gt;much less than usual</td>
</tr>
<tr>
<td>4. felt capable of making decisions about things?</td>
<td>more so than usual&lt;br&gt;same as usual&lt;br&gt;less than usual&lt;br&gt;much less than usual</td>
</tr>
<tr>
<td>5. felt constantly under strain?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>6. felt you could not overcome your difficulties?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>7. been able to enjoy your normal day-to-day activities?</td>
<td>more so than usual&lt;br&gt;same as usual&lt;br&gt;less than usual&lt;br&gt;much less than usual</td>
</tr>
<tr>
<td>8. been able to face up to your problems?</td>
<td>more so than usual&lt;br&gt;same as usual&lt;br&gt;less than usual&lt;br&gt;much less than usual</td>
</tr>
<tr>
<td>9. been feeling unhappy and depressed?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>10. been losing confidence in yourself?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>11. been thinking of yourself as a worthless person?</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
<tr>
<td>12. been feeling reasonably happy, all things considered</td>
<td>not at all&lt;br&gt;no more than usual&lt;br&gt;rather more than usual&lt;br&gt;much more than usual</td>
</tr>
</tbody>
</table>

Part 3: MS and your life NOW
Please list the three most important factors that you believe caused your MS. List the items placing the most important first or write N/A.

1. ........................................................................................................................................
2. ........................................................................................................................................
3. ........................................................................................................................................................

Please read each question separately and indicate the extent to which each is true. Tick the relevant number on the scale of 0-10 for the way you feel about MS now.

<table>
<thead>
<tr>
<th>1. How much does MS affect your life?</th>
<th>0 1 2 3 4 5 6 7 8 9 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. How long do you think MS will continue?</td>
<td>A very short time&lt;br&gt;Forever</td>
</tr>
<tr>
<td>3. How much control do you feel you have over MS?</td>
<td>Absolutely none&lt;br&gt;Extreme control</td>
</tr>
<tr>
<td>4. How much do you think treatment can help the MS?</td>
<td>Not at all&lt;br&gt;Extremely helpful</td>
</tr>
<tr>
<td>5. How much do you experience symptoms from MS?</td>
<td>Not at all&lt;br&gt;Severely</td>
</tr>
<tr>
<td>6. How concerned are you about your MS?</td>
<td>Not at all&lt;br&gt;Extremely</td>
</tr>
<tr>
<td>7. How well do you understand your MS?</td>
<td>Not at all&lt;br&gt;Very well</td>
</tr>
<tr>
<td>8. How much does MS affect you emotionally: making you angry, scared, upset or depressed</td>
<td>Not at all&lt;br&gt;Extremely</td>
</tr>
</tbody>
</table>
How does MS influence your everyday activities now?
Please read the following statements and rate them on a scale of 0-8, where 0 indicates no impairment and 8 indicates severe impairment because of MS.

|  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| 1 | My ability to work is impaired | 0 1 2 3 4 5 6 7 8 |
| 2 | My home management is impaired (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) |  |
| 3 | My social leisure activities are impaired (going out with other people, on outings, dating, going to parties, bars and so on) |  |
| 4 | My private leisure activities I do alone at home are impaired (reading, gardening, sewing, walking alone) |  |
| 5 | Forming and maintaining close relationships with others, including those I live with, are also impaired |  |

Part 4. How do you respond NOW to living with MS?
Please read each statement and indicate how it is generally true for you now. Some days and aspects will bring different responses but think about what you usually do these days about MS stress.
Please think about each statement separately and respond to one at a time, ticking one of the choices.
Select answers that are true for you. Consider yourself and not how other people may respond.

<table>
<thead>
<tr>
<th></th>
<th>I usually do this:</th>
<th>not at all</th>
<th>a little</th>
<th>medium amount</th>
<th>a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I turn to work or another activity to take my mind off MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>I get upset and let my emotions out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I try to get advice from someone about what to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I concentrate my efforts on doing something about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I say to myself that this isn't real</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I admit to myself that I can't deal with it, and give up trying</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7</td>
<td>I discuss my feelings with someone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>I talk to someone to find out more about problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9</td>
<td>I daydream about not having MS</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td>I get upset, and am really aware of it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I make a plan of action</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I try to get emotional support from friends and relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>13</td>
<td>I just give up trying to reach my goals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I take additional actions to try to get rid of problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I refuse to believe in any of the MS problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I let my feelings out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I talk to someone who could do something concrete about problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I sleep more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>I try to come up with a strategy about what to do</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>I get sympathy and understanding from someone</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>I give up the attempts to get what I want</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I think about how I might best handle problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>When possible, I pretend that it hasn't really happened</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>I use the computer/internet or watch television to think about it less</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>I ask people who have had similar experiences what they did</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>I feel a lot of emotional distress and I find myself expressing those feelings a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>I take direct action to get around problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>I reduce the amount of effort I'm putting into solving problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>I talk to someone about how I feel</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>I think hard about what steps to take about MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>I try to act as though it hasn't even happened</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>I do what has to be done, one step at a time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Make light of it: refuse to think about MS seriously</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Carry on as if nothing has happened as much as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>Don't let it get to me: refuse to think too much about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>Try to forget the whole think</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Look for 'the silver lining' so to speak: look on the bright side</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>Go along with fate: sometimes I just have bad luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>I wish problems would go away or somehow be over</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Hope a miracle would happen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41</td>
<td>Have fantasies or wishes about how things could turn out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>Make myself feel better by eating, drinking, smoking or relying on medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43</td>
<td>Avoid being with people in general</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44</td>
<td>Refuse to believe in the MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45</td>
<td>Take it out on other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>Sleep more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part 5. In your everyday life NOW, how do you seek support and who from?
Indicate who helps you to live with MS and how they help. Please be honest and realistic. These questions are not designed to evaluate people but to understand the type of support required. Please tell us about people (by role or relationship, not name) who are important in your life. There is space for up to seven entries. (Family, friends, colleagues, doctor, nurse or other medical professionals, carers or any
Enter up to seven persons (for example, husband, mother, doctor etc.), one by one, then read each question and think about how much the person supports you in that way. Tick a box between 1 and 7 to indicate the extent of support:

<table>
<thead>
<tr>
<th>Person 1</th>
<th>never</th>
<th>sometimes</th>
<th>always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Do you talk to and share your feelings with this person?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Can you turn to and lean on this person in times of difficulty?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Does the person provide practical help?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Can you spend time with the person socially?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part 6 When you were FIRST DIAGNOSED and MS was confirmed, how did you respond? Please read each statement separately. Indicate how often each was true in the first 1-2 weeks when you were diagnosed. Please give your immediate reaction and do not think too long about your reply.

| 1 I felt tense or 'wound up' | Most of the time | A lot of the time | From time to time, occasionally | Not at all |
| 2 I still enjoyed the things I used to enjoy | Definitely as much | Not quite as much | Only a little | Hardly at all |
| 3 I had a sort of frightened feeling like ‘butterflies’ in the stomach | Not at all | Occasionally | Quite often | Very often |
| 4 I could still laugh and see the funny side of things | As much as I always could | Not quite as much now | Definitely not so much now | Not at all |
| 5 I had a sort of frightened feeling as though something awful was about to happen | Very definitely and quite badly | Yes, but not too badly | A little, but it doesn’t worry me | Not at all |
| 6 I could still feel cheerful | Not at all | Not often | Sometimes | Most of the time |
| 7 I felt restless as if I had to be on the move | Very much indeed | Quite a lot | Not very much | Not at all |
| 8 I felt as if I was slowed down | Nearly all the time | Very often | Sometimes | Not at all |
| 9 Worrying thoughts went through my mind | A great deal of the time | A lot of the time | Not very often | Very little |
| 10 I lost interest in my appearance | Definitely | I don’t take as much care as I should | I may not take quite as much care | I take just as much care as ever |
| 11 I had sudden feelings of panic | Very often indeed | Quite often | Not very often | Not at all |
| 12 I still looked forward with enjoyment to things | As much as ever I did | Rather less than I used to | Definitely less than I used to | Hardly at all |
| 13 I could not sit at ease or feel relaxed | Definitely | Usually | Not often | Not at all |
| 14 I could still enjoy a TV programme, good book or radio | Often | Sometimes | Not often | Very seldom |
Part 7 Thinking back to the first 3 months after you were diagnosed

Please read each statement separately. Indicate the extent to which each was true for you during the first 1-3 months after you were diagnosed with MS. Tick the extent to which each statement concerned or frightened you:

1 = no concern or fear, 2-4 = low fear, 5-7 = medium fear, 8-10 = high fear.

<table>
<thead>
<tr>
<th>The following concerned me when I was first diagnosed:</th>
<th>no fear</th>
<th>low fear</th>
<th>medium fear</th>
<th>high fear</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>1. Returning to work or carrying on working</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Seeing images of disability or people disabled with MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Not knowing how MS would physically affect me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Being dependent on someone else</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Having a partner in future or getting married</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Being in pain as MS worsened</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Being or remaining financially independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Having a normal sex life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Being in a wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Having a baby or another child, or becoming a father</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Being able to support and/or care for my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Seeing others with physical deterioration</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Losing my memory or being confused</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Coping with everyday life and household tasks</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Thinking about being physically disabled</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Having bad dreams or nightmares about the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Being able to get out and about on my own in future</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Uncertainty and not knowing what would happen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Losing or partly losing my eyesight</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part 8 During the first 12-18 months after you were diagnosed

Please read each statement separately. Recalling the first year or so after diagnosis, please indicate how often each was true for you during the 12-18 months after being diagnosed with MS.

<table>
<thead>
<tr>
<th>I thought about it when I didn't mean to</th>
<th>Not at all</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I thought about it when I didn't mean to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I avoided letting myself get upset when I thought about it or was reminded of it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I tried to remove it from memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I had trouble falling asleep or staying asleep because of the pictures or thoughts about it that came into my mind</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I had waves of strong feelings about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I had dreams about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I stayed away from reminders of it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I felt as if it hadn't happened or it wasn't real</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I tried not to talk about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Pictures about it popped into my head</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Other things kept making me think about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I was aware that I had a lot of feelings about it but I didn't deal with them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I tried not to think about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Any reminder brought back feelings about it</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. My feelings about it were kind of numb</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part 9 Responding to relapse

This section is relevant only if you have experienced a relapse since you were diagnosed. How long in years and months was it after being diagnosed that you first experienced a relapse?

Thinking back to either the first significant relapse. Please read each of the following statements separately. Indicate the extent to which each was true for how you responded to the first relapse.

<table>
<thead>
<tr>
<th>The following statements were generally true when I relapsed</th>
<th>not at all</th>
<th>a little</th>
<th>medium amount</th>
<th>a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. At first, I did not associate the problems with an MS relapse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Relapsing made me concerned about my future independence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. After the relapse I got back more or less to 'normal' for me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I knew immediately that I was having a relapse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I coped with practicalities beforehand: home, family and/ or work</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Forgetting relapse and getting back to 'my normal' took a long time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Relapsing made me concerned about physical disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I felt uncertain about the future after the relapse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I had always expected a relapse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you have had more than one relapse, did you respond differently after you had experienced the first one? yes ...... no ......

If you have had more than one relapse, did they all follow a similar pattern of symptoms? yes ...... no ......

Please add any further comments you would like to make about your experience of relapse and how you responded both at the time and in the months after your health stabilized again.
Part 10 Mobility and disability

Please answer the following questions about how MS influences your mobility and disability now.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Frequently</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you use a stick, sticks or crutches in your home or garden?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Do you use a stick, sticks or crutches to get about outside home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Do you use a walking frame or rollator in your home or garden?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Do you use a walking frame or rollator to get about outside home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do you need assistance with personal care (washing, showering etc.)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Do you need assistance with dressing/undressing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Do you experience/have provision for loss of bladder control?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part 11 How would you express your responses in an image instead of answering questions?

Please complete this section of the questionnaire.

Sending an image is optional but very important in this research. Answering questions about personal thoughts and feelings is not always easy. We are interested in whether creating an image is a good way of expressing feelings that are difficult to put into words. We would like to know how you feel when you are doing this and/or after you have expressed your feelings in some way other than by responding to questions.

Three steps for sending your drawing/image/diagram:

1. Please draw your response to MS. Express your response to diagnosis, any aspect or phase, or how you generally feel.
   Give your image a title or add notes if you wish.

Guidance Notes:
- You can use drawing, doodle or art-type tools on the computer and print out a copy.
- The diagram, map, drawing or painting may be complex or simple, showing something real or imagined, actually or abstract.
- The image could be as simple as patches of colour, lines or squiggles.

2. Write your code (see overleaf) on the back of the paper or on a separate sheet.
   If using a separate piece of paper, send it with your image.

   3A) Did drawing make you think or focus in a different way from answering questions?
      Yes  No .................................................................

   3B) Did you find writing or drawing at all useful for expressing how you feel?
      Yes  No .................................................................

3. Please post your questionnaire and/or image, with code and answers, in a sealed envelope to:
   Bridget Jones
   School of Psychology, A5
   FREEPOST GI197
   University of Surrey
   Guildford, Surrey, GU2 7XH

Please note:
- Unfortunately, we cannot return images, so please do not send original images that you want to keep. Send a photocopy or scan and print the image.
- Anonymous code for your questionnaire:
  To complete your questionnaire, create your personal code. This will ensure that each questionnaire is recorded and anonymous. Your code will be your age, your initials and the time in years you have been diagnosed with MS.
  My code is .................................................................
  You have to write your code on the back of your drawing, so write it on a piece of paper.

Dummy Example:
- The code for 45 years old Anne Person who has had MS for 12 years will be 45AP12
- The code for 27 year old Yin Mann who has been diagnosed with MS for 3 years will be 27YM3

Your code links the image with your questionnaire, ensuring it is anonymous. Please do not write any personal details (name etc.) on the drawing.

Do you have any comments?
Please make any comments or give any information that was not covered in the questions or above.

THANK YOU.
c) Factor analysis matrices

**Fear scale (BGFS amended) factor analysis matrices**

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization
Rotation converged in 12 iterations Pattern Matrix

**Pattern matrix**

<table>
<thead>
<tr>
<th>Factor</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>p7grid - diagnosis stage fears: coping with everyday life</td>
<td>.912</td>
<td>.026</td>
<td>-.118</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: getting around in future</td>
<td>.853</td>
<td>.005</td>
<td>.024</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: being physically disabled</td>
<td>.846</td>
<td>-.290</td>
<td>-.117</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: memory loss / confusion</td>
<td>.818</td>
<td>.137</td>
<td>-.016</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: uncertainty</td>
<td>.814</td>
<td>-.199</td>
<td>-.069</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: physical uncertainty</td>
<td>.772</td>
<td>-.244</td>
<td>-.048</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: dependent on someone</td>
<td>.763</td>
<td>-.111</td>
<td>-.050</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: potential pain</td>
<td>.752</td>
<td>.182</td>
<td>.042</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: wheelchair</td>
<td>.695</td>
<td>-.282</td>
<td>-.17</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: losing eyesight</td>
<td>.621</td>
<td>-.010</td>
<td>.082</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: financial independence</td>
<td>.594</td>
<td>.171</td>
<td>.240</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: continuing work</td>
<td>.592</td>
<td>.066</td>
<td>-.023</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: nightmares about future</td>
<td>.569</td>
<td>-.150</td>
<td>.046</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: sex life</td>
<td>.540</td>
<td>.200</td>
<td>.264</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: supporting / caring for family</td>
<td>.501</td>
<td>.007</td>
<td>.379</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: future partner or marriage</td>
<td>.315</td>
<td>-.002</td>
<td>.301</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: others' visible disability</td>
<td>.478</td>
<td>-.518</td>
<td>.121</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: disability images</td>
<td>.087</td>
<td>-.459</td>
<td>.209</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: parenthood probs</td>
<td>-.061</td>
<td>-.116</td>
<td>.646</td>
</tr>
</tbody>
</table>

**Structure matrix**

<table>
<thead>
<tr>
<th>Factor</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>p7grid - diagnosis stage fears: being physically disabled</td>
<td>.874</td>
<td>-.510</td>
<td>.265</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: getting around in future</td>
<td>.862</td>
<td>-.227</td>
<td>.390</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: coping with everyday life</td>
<td>.855</td>
<td>-.213</td>
<td>.271</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: uncertainty</td>
<td>.833</td>
<td>-.415</td>
<td>.294</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: physical uncertainty</td>
<td>.818</td>
<td>-.450</td>
<td>.300</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: memory loss / confusion</td>
<td>.774</td>
<td>-.083</td>
<td>.325</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: dependent on someone</td>
<td>.767</td>
<td>-.313</td>
<td>.275</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: wheelchair</td>
<td>.763</td>
<td>-.488</td>
<td>.300</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: potential pain</td>
<td>.721</td>
<td>-.025</td>
<td>.352</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: others' visible disability</td>
<td>.870</td>
<td>-.656</td>
<td>.362</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: supporting / caring for family</td>
<td>.661</td>
<td>-.155</td>
<td>.593</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: losing eyesight</td>
<td>.659</td>
<td>-.184</td>
<td>.349</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: financial independence</td>
<td>.651</td>
<td>-.006</td>
<td>.483</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: nightmares about future</td>
<td>.629</td>
<td>-.307</td>
<td>.300</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: sex life</td>
<td>.599</td>
<td>.035</td>
<td>.482</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: continuing work</td>
<td>.564</td>
<td>-.093</td>
<td>.226</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: future partner or marriage</td>
<td>.444</td>
<td>-.108</td>
<td>.436</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: disability images</td>
<td>.300</td>
<td>-.497</td>
<td>.278</td>
</tr>
<tr>
<td>p7grid - diagnosis stage fears: parenthood probs</td>
<td>.248</td>
<td>-.145</td>
<td>.628</td>
</tr>
</tbody>
</table>

**Factor correlation matrix**

<table>
<thead>
<tr>
<th>Factor</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.000</td>
<td>-0.271</td>
<td>0.429</td>
</tr>
<tr>
<td>2</td>
<td>-0.271</td>
<td>1.000</td>
<td>-0.069</td>
</tr>
<tr>
<td>3</td>
<td>0.429</td>
<td>-0.069</td>
<td>1.000</td>
</tr>
</tbody>
</table>
Relapse scale factor analysis matrices

Pattern matrices

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>p9grid - future uncertainty</td>
<td>0.920</td>
<td>0.004</td>
<td>-0.050</td>
</tr>
<tr>
<td>p9grid - concerned about phys disb</td>
<td>0.842</td>
<td>-0.006</td>
<td>0.021</td>
</tr>
<tr>
<td>p9grid - rel brought future concern</td>
<td>0.780</td>
<td>-0.030</td>
<td>-0.002</td>
</tr>
<tr>
<td>p9grid - long time to get back to normal</td>
<td>0.422</td>
<td>0.072</td>
<td>0.382</td>
</tr>
<tr>
<td>p9grid - recognised rel</td>
<td>0.100</td>
<td>0.645</td>
<td>-0.285</td>
</tr>
<tr>
<td>p9grid - rel always expected</td>
<td>0.169</td>
<td>0.552</td>
<td>0.190</td>
</tr>
<tr>
<td>p9grid - not recognise rel</td>
<td>-1.110</td>
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<td>p9grid - coped with practicalities before</td>
<td>-0.037</td>
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Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization
Rotation converged in 9 iterations

Structure matrix

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<td>p9grid - recognised rel</td>
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<td>p9grid - rel always expected</td>
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Factor correlation matrix

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### COPE 1,2,3 factor analysis matrices

#### Pattern Matrix

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<td>grdp4 now: planning</td>
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<td>.127</td>
</tr>
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<td>grdp4 now: active coping</td>
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<td>grdp4 now: active coping</td>
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<td>grdp4 now: active coping</td>
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<td>grdp4 now: seeking instrumental soc support</td>
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<td>grdp4 now: seeking instrumental soc support</td>
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Extraction Method: Principal Axis Factoring  
Rotation Method: Oblimin with Kaiser Normalization  
Rotation converged in 5 iterations

#### Structure matrix

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<td>grdp4 now: active coping</td>
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COPE 10, 11, 13 factor analysis matrices

Pattern matrix

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<td>gridp4 now: denial</td>
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Extraction Method: Principal Axis Factoring
Rotation Method: Oblimin with Kaiser Normalization
Rotation converged in 7 iterations

Structure matrix

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<td>gridp4 now: denial</td>
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<tr>
<td>gridp4 now: denial</td>
<td>.144</td>
<td>-.069</td>
<td>.298</td>
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Factor correlation matrix

<table>
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<td>.374</td>
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<td>1.000</td>
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<tr>
<td>3</td>
<td>.374</td>
<td>-.230</td>
<td>1.000</td>
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</table>

322
d) Letter introducing study to MS groups

[Appropriate Contact/Centre Manager / Administrator/ Address]

Dear

Re: Multiple Sclerosis study

I am a PhD health psychology student at Surrey University and I am researching responses to multiple sclerosis. I am recruiting participants for a questionnaire study that has been reviewed and approved by the University of Surrey Ethics Committee.

I am seeking the opinions of 250-300 participants who have been diagnosed with MS. Therefore, as you can imagine, I would greatly appreciate your and the group's assistance and support. I would be grateful if you could bring my study to the attention of those who visit your centre. I include a poster for display or distribution among the members. Please feel free to photocopy this or contact me for further copies. To explain the study, I enclose copies of the information sheet and consent form that are provided with each questionnaire.

Volunteers can take part by following the internet link provided on the poster. I can also provide paper copies of the questionnaire with freepost address for their return for those who would prefer this. The poster includes contact details to request a paper copy — either my telephone number at the university or email.

If it would be convenient, I could send you a batch of questionnaires for anyone visiting the centre to take away, fill in and return directly to me. Please do contact me with any queries or comments about any of the enclosed or other aspects of the research.

I would like to assure everyone that the information participants provide will be valued and treated with respect. All information will be anonymous.

I hope this study will make a contribution to understanding the bigger picture of how people cope with MS. The research aims to contribute information on the type of support that could be offered to those with MS and when support is needed. This is the third study as part of this research. The MSTG at Guildford were brilliantly helpful with the first study, providing information and members responded by generously sharing experiences.

I do hope you will be able to circulate the details. Please do email me if there is anything I can do to inform members and enable them to participate.

With best wishes.
Your sincerely,
e) Letter of thanks for assistance with research

[Appropriate Contact/Centre Manager / Administrator/ Address]

Dear

Re: Multiple Sclerosis study

Thank you for your help with the above study and particularly for taking the time to make this information available to your group.

The response was excellent. We have now finished recruiting volunteers and all the information from the questionnaires is being processed. We greatly appreciate the time your members gave up to complete the questionnaires and the information they provided is invaluable.

If you have any queries or would like further information, please do not hesitate to contact me.

Please pass on our sincere thanks and best wishes to the members of your group.

With best wishes.
Your sincerely,
A Study of Responses to Diagnosis and Living with MS
Participant Information Sheet (June 2012)
This study has been reviewed and received a favourable opinion from the University of Surrey Ethics Committee.

Thank you for expressing an interest in this study or multiple sclerosis (MS), which is part of PhD research in Health Psychology at the University of Surrey. Please read the following information and feel free to discuss this with someone else before deciding to take part.

What is this study about?
The study is intended to find out about how people responded to being diagnosed with MS and then how they continue to feel about living with the condition. The research aims to understand thoughts and feelings about MS, about how people think and cope.

Why is it useful?
Understanding ideas, thoughts and concerns about MS will indicate what sort of information and support is needed and when to help people living with the condition.

Who is eligible to take part?
You are eligible if you have a confirmed diagnosis of MS. It does not matter what the type or precise definition is or how long it has been since you received the diagnosis.
You have to be at least 18 years old to participate.

What does participating involve?
You will be asked to fill in a simple questionnaire. This can be done on line by following the link provided. If you prefer, a paper version can be filled in. Filling in the questionnaire takes about 40 minutes. There is an optional question if you wish to add further information.
• You may ask someone to read out the questionnaire to you and complete it for you.
• This is not about being right or wrong but about your opinions that are so important.

What if thinking about MS is stressful?
Participants’ wellbeing is important and the researcher does not want anyone to feel upset by considering how they felt or feel about MS. You may withdraw at any stage.

What are the possible benefits of taking part?
You will not benefit directly but the experiences and honest opinions you and other participants share are vital in this research. The findings will help us to show what MS information and support should be offered and when it is most likely to be useful.

What happens to your information?
All information is anonymous and it will be stored securely in accordance with the Data Protection Act (1998). The researcher is the only person who has access to contact details and these will be destroyed when the study is finished.

How long will the study continue?
The study will continue through September, October and November 2012.

Any questions?
Please ask me (Bridget) or my supervisor if you have any questions.

Researcher  Bridget Jones  Email  bj00030@surrey.ac.uk
Supervisor  Dr. Victoria Senior  Email  V.Senior@surrey.ac.uk  Tel 01483 686866

Thank you for taking the time to read this information sheet.
g) Participant consent form

Multiple Sclerosis Study

- I the undersigned voluntarily agree to take part in the study on The Experience of Multiple Sclerosis: A study of responses to diagnosis and living with MS.

- I have read and understood the Information Sheet provided. I have been given the opportunity to contact the researcher to ask questions on all aspects of the study and have understood any advice and information given as a result.

- I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. I may stop filling in the questionnaire if I do not wish to continue.

- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS)

Signed .................................................................
Date .................................................................

Name of researcher/person taking consent (BLOCK CAPITALS)

Signed .................................................................
Date .................................................................

For anyone assisting with questionnaire completion by reading or filling in responses

Please read the 'Guidelines for Assisting with Questionnaire Completion'.
All information is anonymous, this form is not linked to the questionnaire and paper copies will be retained separately. Information will be stored securely in accordance with the Data Protection Act (1998). The researcher is the only person who has access to personal information and this will be destroyed when the study is completed.

Please sign below to indicate that you agree not to divulge any information you learn during your role as helper. Thank you.

Name of helper assisting with questionnaire completion (BLOCK CAPITALS)
Signed .................................................................
Date .................................................................
h) **Guidelines for assisting with questionnaire completion**

Guidelines for Assisting with Questionnaire Completion

**Information sheet and consent form**
Before beginning, please ensure that you have read the information sheet to the participant. Please ensure that the participant has signed the consent form.

**Questionnaire**
The person will respond to personal and sensitive questions about MS, so please try not to be embarrassed or uncomfortable by the questions or answers.

Please read the following guidelines.
1 Please remember that the information provided is anonymous. None of the information provided on the questionnaire should include personal details about the participant, yourself or any other person.

2 Ensure the person is ready to listen and respond, and willing to continue at all times.

3 Read out the information and instructions, and complete the questions, in the order provided on the questionnaire.

4 Read clearly without expressing opinions, do not place any emphasis in your tone of voice or indicating your feelings in facial expressions.

5 Do not express opinion about either the questions or the participant's response.

6 If the participant wishes to pause or stop at any time, please do so.

7 The information every participant provides is personal and sensitive. We are very grateful for everyone's help and honesty. Please respect the person's contribution by keeping their personal information confidential.

**Thank you for helping with the study.**

**Support for Carers**
As well as providing information and support for those diagnosed with MS, national organisations are also aware of the needs of family, carers and those close to someone with MS. If you need any information about MS or support, local groups always welcome those who are close to their members. The following are contact details for national centres.

**MS National Therapy Centres**
Multiple Sclerosis National Therapy Centres, PO Box 126, Whitchurch, SY14 7WL
Tel: 0845 367 0977
Email: info@msntc.org.uk

**MS Society**
MS National Centre (MSNC), 372 Edgware Road, London, NW2 6ND
Tel: 020 8438 0700
Fax: 020 8438 0701

Scotland
MS Society Scotland, Ratho Park, 88 Glasgow Road, Ratho Station, Newbridge, EH28 8PP
Tel: 0131 335 4050
Fax: 0131 335 4051

Wales
Multiple Sclerosis Society Wales/Cymru, Temple Court, Cathedral Road, Cardiff, CF11 9HA
Tel: 029 2078 6676
Fax: 029 2078 6677

Northern Ireland
MS Society Northern Ireland, The Resource Centre, 34 Annadale Avenue, Belfast, BT7 3J
Tel: 02890 802 802
i) Debriefing information

Debriefing Information

The study set out to explore how people with MS deal with the condition and in what ways they can be supported. We appreciate the information you have shared. It will be handled anonymously, treated with respect and used to contribute to this study.

Thank you for completing the study.

Researcher  Bridget Jones  Email  bj00030@surrey.ac.uk
Supervisor  Dr. Victoria Senior  Email  V.Senior@surrey.ac.uk

Support Groups
Please remember that the local and national groups to which you may belong are there to provide information and support. The following contact details may be helpful

MS National Therapy Centres
Contact Details
Multiple Sclerosis National Therapy Centres, PO Box 126, Whitchurch, SY14 7WL
Tel: 0845 367 0977
Email: info@msntc.org.uk

MS Society
MS National Centre (MSNC)
372 Edgware Road, London, NW2 6ND
Tel: 020 8438 0700
Fax: 020 8438 0701

Scotland
MS Society Scotland
Ratho Park, 88 Glasgow Road, Ratho Station, Newbridge, EH28 8PP
Tel: 0131 335 4050
Fax: 0131 335 4051

Wales
Multiple Sclerosis Society Wales/Cymru
Temple Court, Cathedral Road, Cardiff, CF11 9IA
Tel: 029 2078 6676
Fax: 029 2078 6677

Northern Ireland
MS Society Northern Ireland
The Resource Centre, 34 Annadale Avenue, Belfast, BT7 3JJ
Tel: 02890 802 802
Being Diagnosed With Multiple Sclerosis: What did it Mean to You?

Please HELP with a study of Experiences of MS.

HOW?
Tell me about your feelings and experiences.

WHY?
Understanding how you think will show what type of useful support is needed and when.

WHERE?
Tell me at www.fahs.surrey.ac.uk/survey/Multiple_Sclerosis_Study/
For a paper copy, please ring me, Bridget, on 01483 876939 or email B.E.Jones@surrey.ac.uk
All responses are anonymous.

WHO AM I?
I am Bridget, a mature student studying for a PhD in Health Psychology at the University of Surrey. Please get in touch.

THANK YOU
Your knowledge will be valued, respected and used to try and help everyone with MS.

This study has been given a favourable ethical opinion by the University of Surrey Ethics Committee.
**k) Regression analyses model summaries and correlation tables**

### 4.6.1 (Table 12) Model summary with predictors for regressing anxiety, fear, impact and coping on GHQ

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<th>SE $B$</th>
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<td>malcope</td>
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$R = .62; R^2 = .37; \text{adjusted } R^2 = .34; F(12,191) = 9.71^{**}$

**Pearson Correlations**

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*Note:*** $p < .001$, ** $p < .01$, * $p < .05$*
### 4.6.1 (Table 13) Model summary, with predictor variables in hierarchical regression of demographics, diagnosis variables, early impact, and coping on GHQ

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$R = .27; R^2 = .07; \text{adjusted } R^2 = .04; \Delta F (3,72) = 1.95$

| model 2 | (Constant) | 15.450 | 5.232 |
| age in years                              | -.161 | .094  | -.232 |
| time (months) since diagnosed             | .016  | .008  | .270  |
| time since updated diagnosis              | -.010 | .014  | -.095 |
| HADSa                                     | .013  | .191  | .010  |
| HADSD                                     | .128  | .259  | .071  |
| BGFStot                                   | .040  | .026  | .270  |
| IESInt                                    | -.165 | .127  | -.260 |
| IESavoid                                  | .206  | .097  | .307**|

$R = .45; R^2 = .20; \text{adjusted } R^2 = .11; \Delta F (5,68) = 2.15$

| model 3 | (Constant) | 10.312 | 8.446 |
| age in years                              | -.088 | .091  | -.126 |
| time (months) since diagnosed             | .010  | .008  | .173  |
| time since updated diagnosis              | -.007 | .013  | -.064 |
| HADSa                                     | -.024 | .178  | -.020 |
| HADSD                                     | -.005 | .240  | -.003 |
| BGFStot                                   | .046  | .026  | .312  |
| IESInt                                    | -.161 | .114  | -.253 |
| IESavoid                                  | .160  | .095  | .237  |
| cope4                                     | -.671 | .405  | -.270 |
| woc2                                      | -.305 | .204  | -.164 |
| woc6                                      | -.023 | .244  | -.015 |
| SOSmeanemot                               | -.115 | .439  | -.042 |
| SOSmeanprac                               | .096  | .420  | .032  |
| activecope                                | .013  | .121  | .015  |
| malcope                                   | .614  | .183  | .485***|

$R = .66; R^2 = .43; \text{adjusted } R^2 = .29; \Delta F (7,61) = 3.55**$

**Note:** ***p = <.001, **p = <.01, *p = <.05**
### Pearson correlations

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<th>11 woc2</th>
<th>12 woc6</th>
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**Note:** ***p < .001, **p < .01, *p < .05

Dependent Variable: GHQtot

Predictors in Model 1: (Constant), time since updated diagnosis, age in years, time (months) since diagnosed

Predictors in Model 2: (Constant), time since updated diagnosis, age in years, time (months) since diagnosed, HADSa, IESavoid, BGFSot, HADSd, IESint
### 4.6.1 (Table 14) Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on GHQ

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R = .63; R² = .39; adjusted R² = .35; F (13,186) = 9.18

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Note: **p = <.01, *p = <.05, p = <.05
4.6.2 (Table 15) Model summary and significant predictors in standard regression of age, diagnosis variables, early impact and coping on WASAS

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R = .54; R² = .29; adjusted R² = .24; F (13,188) = 5.99***

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Note: ***p < .001, **p < .01, *p < .05
### 4.6.2 (Table 16) Model summaries and significant predictors in regression of early impact and emotional support on to maladaptive coping (malcope) and escape-avoidance (WOC6)

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<th>variable</th>
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<th>β</th>
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<td>.127</td>
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<tr>
<td>HADSd</td>
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<td>-.106</td>
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<td>BGFStot</td>
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<td>.010</td>
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</table>

| model 2: standard regression on outcome variable WOC 6 |
| (Constant) | 11.779 | .783  |       |
| HADSa     | .050  | .077  | .054  |
| BGFStot   | .016  | .009  | .146  |
| IESint    | .142  | .038  | .296***|
| R = .45; R² = .19; adjusted R² = .18; F (3,222) = 17.51*** |

| model 3: standard regression on outcome variable malcope |
| (Constant) | 15.297 | 1.400 |       |
| BGFStot   | .021  | .010  | .163* |
| Relfutconcern | -.002 | .009  | -.011 |
| cope4     | .192  | .118  | .105  |
| HADSa     | .189  | .088  | .176* |
| R = .33; R² = .11; adjusted R² = .09; F (4,220) = 6.69*** |

### Pearson correlations

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<tr>
<td>2. HADSa - .584*** .629*** .610*** .410***</td>
</tr>
<tr>
<td>3. HADSd - .433*** .512*** .237***</td>
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<tr>
<td>4. BGFStot - .580*** .385***</td>
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<tr>
<td>5. IESint - .666***</td>
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<td>6. IESavoid -</td>
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<td>3. BGFStot - .575***</td>
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<td>4. IESint -</td>
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<td>3. Relfutconcern - .119* -.123*</td>
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<tr>
<td>4. cope4 - .058</td>
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<td>5. HADSa -</td>
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Note: ***p = <.001, **p = <.01, *p = <.05
### 4.6.2 (Table 17) Model summaries of standard regression and significant predictors of IES avoidance

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Pearson correlations

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Note: ***p = < .001, **p = < .01, *p = < .05
### 4.6.2 (Table 18) Model summaries of standard regression and significant predictors of IES intrusion

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\[ R = .68; R^2 = .46; \text{adjusted } R^2 = .46; \text{ } F(3,223) = 63.80*** \]

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</tr>
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\[ R = .79; R^2 = .63; \text{adjusted } R^2 = .56; \text{ } F(6,75) = 20.86*** \]

**Pearson correlations**

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<tbody>
<tr>
<td>1 IESInt</td>
<td>-0.609***</td>
<td>0.512***</td>
<td>0.576***</td>
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</tr>
<tr>
<td>2 HADS a</td>
<td>-</td>
<td>0.581***</td>
<td>0.627***</td>
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<tr>
<td>3 HADS d</td>
<td>-</td>
<td>-</td>
<td>0.428***</td>
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<tr>
<td>4 BGFStot</td>
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</thead>
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<td>1 IESInt</td>
<td>-0.610***</td>
<td>0.566***</td>
<td>0.664***</td>
<td>-0.184*</td>
<td>-0.142</td>
<td>-0.219*</td>
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<td>2 HADS a</td>
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<td>0.532***</td>
<td>0.538***</td>
<td>-0.114</td>
<td>-0.070</td>
<td>-0.056</td>
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</tr>
<tr>
<td>3 HADS d</td>
<td>-</td>
<td>-</td>
<td>0.318**</td>
<td>-0.025</td>
<td>-0.035</td>
<td>-0.040</td>
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</tr>
<tr>
<td>4 BGFStot</td>
<td>-</td>
<td>-</td>
<td>-0.293**</td>
<td>-0.330***</td>
<td>-0.206*</td>
<td></td>
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<tr>
<td>5 age in years</td>
<td>-</td>
<td>-0.555***</td>
<td>0.415***</td>
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<tr>
<td>6 time (months) since diagnosed</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0.551***</td>
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<tr>
<td>7 time since updated diagnosis</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tbody>
</table>

**Note:** ***p < .001, **p < .01, *p < .05
Appendix IV

Chapter 6, Study Four

a) University of Surrey Ethics Committee letter of favourable ethical opinion

b) Letter introducing study to MS groups

c) Letter of thanks for assistance with research

d) Participant information sheet

e) Recruitment flyer

f) Participant consent form

g) Debriefing information

h) Questionnaire

i) Researcher Guidelines: Final Open-ended questions

j) Researcher standard guidelines: experimental condition

k) Researcher standard guidelines: control condition

l) Experimental group visual methods rescripting

m) Case-wise descriptive statistics for MS (experimental) group

n) Case-wise descriptive statistics for NMS (control) group
03 July 2012

Dear Ms Jones

Anxiety Responses to Multiple Sclerosis: Potential predictors of poor adjustment and coping EC/2012/61/FAHS

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 3 July 2012.

The final list of documents reviewed by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary of the project</td>
</tr>
<tr>
<td>Detailed protocol for the project</td>
</tr>
<tr>
<td>Information sheet for participants</td>
</tr>
<tr>
<td>Standard letter introducing project to support groups</td>
</tr>
<tr>
<td>Consent form</td>
</tr>
<tr>
<td>Questionnaire</td>
</tr>
<tr>
<td>Guidelines for helper</td>
</tr>
<tr>
<td>Risk assessment</td>
</tr>
<tr>
<td>Recruitment advert</td>
</tr>
<tr>
<td>Debriefing information sheet</td>
</tr>
<tr>
<td>Thank you for help with the study letter</td>
</tr>
</tbody>
</table>

This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research. If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University’s Ethics Committee.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Glenn Moulton
Secretary, University Ethics Committee
Academic Registry
Dear

Re: Art and Multiple Sclerosis Study

Thank you for your interest in this study, which has been reviewed and approved by the University of Surrey Ethics Committee as part of my PhD research.

So that you [and the centre organisers/trustees/ committee] are aware of what is expected of participants, I now enclose [attach if emailing] copies of the information sheet that will be distributed to those who are interested in taking part. I also enclose the consent form that participants will be requested to sign before filling in the questionnaire. I include a flyer that can be displayed on suitable notice boards or distributed among the members of your group.

Please do contact me with any queries or comments about any of the enclosed.

I am recruiting 12 participants for the study. I would like to encourage potential volunteers to speak to me beforehand, so please pass on my contact details so that I can explain the study and answer any questions.

Thank you for taking the time to make this information available to your group.

With best wishes,

Your sincerely,
Dear [Appropriate Contact/Centre Manager / Administrator/ Address]

Re: Doing Art: Does it help?

Thank you for your help with the above study and particularly for taking the time to make this information available to your group.

All the art sessions and data collection is now complete. When I have written up the results I will be in touch to let you know the outcome.

If you have any queries or would like further information, please do not hesitate to contact me.

Please pass on our sincere thanks and best wishes to the members of your group.

With best wishes,
Your sincerely,
Doing Art: Does it help?
A study of the benefits of art activities for those diagnosed with MS.

Participant Information Sheet (April 2013)
This study has been reviewed and received a favourable opinion from the University of Surrey Ethics Committee.

Thank you for expressing an interest in this study of multiple sclerosis (MS), which is part of PhD research in Health Psychology at the University of Surrey. Please read the following information and feel free to discuss this with someone else before deciding to take part.

What is this study about?
The study is intended to find out whether taking part in art sessions can help cope with MS.

Why is it useful?
Understanding what type of activities may help people deal with MS will provide evidence for the type of support that assists those diagnosed with the condition.

Who is eligible to take part?
You are eligible if you have a confirmed diagnosis of MS. It does not matter what the type or precise definition is. You have to be at least 18 years old to participate.
* You are not eligible if you are having cognitive behavioural therapy or art therapy.

What does participating involve?
You will be asked to take part in two individual art sessions. They will be held in at the centre. They will be relaxed and enjoyable.
* Each session will last 1-11/2 hours.
* The sessions will be booked at a convenient time for you: this could be on the same day, in the morning and afternoon, on two consecutive evenings or one day after the other. The two sessions should be booked close together.
* The sessions will be planned by the researcher, who will provide a variety of art materials and helpful instructions on 'getting going' with art.

What will I draw?
You will be asked to draw either your ideas about MS or anything that is unrelated.

Drawing ideas about or responses to MS
Drawing can be a good way of expressing responses to MS. Some participants will be asked to draw their response to MS during the two sessions.

Drawing still life or from existing pictures
Some participants will draw general subjects, for example any object or a copy of an existing picture. The researcher will bring objects and pictures to the sessions.

What if I find drawing my ideas about MS upsetting?
Drawing is a good way of expressing feelings about health. Participants' wellbeing is important and the researcher does not want anyone to feel upset. The researcher will be supportive. If the session is upsetting, then you may withdraw or change to a different subject.

I'm not artistic but I'd like to have a go. Do I have to be able to draw?
You do not have to be 'artistic' or be able to draw or paint. It does not matter if you have never tried before, as long as you want to have a go.
You may withdraw at any stage.

**Completing a questionnaire and giving feedback**
You will be asked to fill in a short questionnaire before and after the sessions. This will take about 10 minutes.

At the end of the second session you will be asked what you thought about the sessions. Your response will be recorded (this is quicker than writing), then it will be keyed in and the recording will be destroyed.

**What are the possible benefits of taking part?**
You will not necessarily benefit directly but your honest opinions on the experience are vital to the research. The study will indicate whether art sessions may be beneficial for anyone coping with MS.
* The sessions are intended to be supportive and friendly.
* We hope you will enjoy the sessions and be inspired to continue with this type of activity.

**What happens to your art and questionnaire?**
All information is anonymous and it will be stored securely in accordance with the Data Protection Act (1998). The researcher is the only person who has access to contact details and these will be destroyed when the study is finished.
* The drawings will be collected with the responses to the questions and used as part of the data in the study. They will be anonymous. Data will be retained for 10 years (as per University policy).

**How long will the study continue?**
The study is short term and will be completed within 1-2 months.

**Any questions or concerns about taking part?**
Please do get in touch.
Ask me (Bridget) or my supervisor if you have any questions.

Thank you for taking the time to read this information sheet.
Doing Art: Does it Help?

Please help with this study into whether art classes may be beneficial for those diagnosed with MS.

HOW CAN YOU HELP?
I am looking for 20 volunteers to take part in two, one-to-one art sessions and to tell me what they think.

WHY?
Art is helpful for expressing feelings and dealing with chronic conditions. This study looks at how art may help with MS.

WHERE and WHEN?
Here in the centre on a suitable day and time for you.

WHO AM I?
I am Bridget, a mature student studying Health Psychology at the University of Surrey. This is my fourth study into MS. The idea for art sessions came from the previous studies. Please take a look at one of the information sheets.

THANK YOU
Your knowledge and opinions will be valued, respected and used to try and help everyone with MS.

This study has been given a favourable ethical opinion by the University of Surrey Ethics Committee
Multiple Sclerosis Study  
Doing Art: Does it Help?  
Committee

• I the undersigned voluntarily agree to take part in the study into whether art is helpful for those diagnosed with MS.

• I have read and understood the Information Sheet provided. I have been given the opportunity to contact the researcher to ask questions on all aspects of the study and have understood any advice and information given as a result.

• I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

• I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. I may stop the art session at any time if I do not wish to continue.

• I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Art / Drawings
I voluntarily agree to submit art/drawings produced at the sessions as part of the data collected by the researcher. They may be used in the study and reproduced in reports, materials or displays in relation to the research.

Any identifying aspects will be removed before images are used and they will be anonymous.

I understand that the art/drawings will not be sold or used for commercial gain by the researcher.

Name of volunteer (BLOCK CAPITALS) .................................................................

Signed ................................................
Date ..................................................

Name of researcher/person taking consent (BLOCK CAPITALS) ..........................

Signed ................................................
Date ..................................................


**g) Debriefing information**

Drawing can be a good way of expressing feelings and responses that are difficult to put into words. It can also be useful for 'drawing a picture' of stresses, anxieties and concerns. Adding the neutral, less-threatening aspects of the future and the support that is available may change the picture. Actually drawing the less worrying aspects into the picture may help to keep more positive aspects in mind. Bringing images of help and some aspects of control into the picture may help to create a balanced picture of what the future may bring, so that it becomes less frightening. This helps with coping and reminds us to ask for support.

In this study, those who were drawing MS brought in the support and balancing aspects during the second session. We are interested to see if this helps reduce anxieties to create a mental image that includes positive aspects for the future.

Those who were drawing any subject may have found this relaxing.
If you were drawing general subjects you are invited to take part in sessions drawing responses to MS.

Thank you for completing the study.

**Researcher** Bridget Jones  **Email** bj00030@surrey.ac.uk

**Supervisor** Dr. Victoria Senior  **Email** V.Senior@surrey.ac.uk

**Support Groups**

Please remember that the local and national groups to which you may belong are there to provide information and support. The following contact details may be helpful.
h) Questionnaire

Doing Art: Does it help?
A study into the benefits of art classes for those diagnosed with MS.

Information about your own experience and responses is vital to this research. We appreciate your valuable opinions and will treat them with respect.

Completing the questionnaire will take about 10 minutes.

► Please be as honest and accurate as you can.
► Answers should show how you feel now.
► There are no right or wrong answers.
► This questionnaire is anonymous and will be kept separate from all contact and consent details.

The information you provide is valuable.
Thank you for your time and for sharing your thoughts and feelings.
Part 1  General Information

1  Are you:  female ....  male ....

2  Age: ....

3  What nationality / ethnicity do you consider yourself to be? 
.................................................................

4  Do you live alone? yes ....  no ....

5  Are you: single .... married/living with a partner.... divorced/separated.... widowed....

6  Do you have children? yes ....  no ....  How old are they? .............................................

7  At what age did you leave school/education ? ..............................................................

8  Do you work?  full time ....  part time ....  voluntary work ........

9  When were you diagnosed with MS? .................................................................

10  What diagnosis or definition of MS were you given when first diagnosed? 
relapsing remitting ....  primary progressive ....  secondary progressive ....  benign ....
other (please specify) .................................................................

11  Have you been given any updated diagnosis of MS? yes ....  no ....
   If yes, when?.............
   If yes, what is the revised diagnosis or definition of MS? 
relapsing remitting .... primary progressive .... secondary progressive ....  benign ....
other (please specify) .................................................................

12  Have you been diagnosed with alexithymia/memory impairment/loss: yes ....  no ....

14  Have you had relapses in the last 12 months? none.... 1 .... 2 3 .... more than 3 ....

15  Are you currently relapsing? yes ....  no ....
Part 2 Please indicate the extent to which each is true about MS now.

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<th>3</th>
<th>4</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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</thead>
<tbody>
<tr>
<td>1 How much does MS affect your life?</td>
<td>Not at all</td>
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<tr>
<td>2 How much control do you feel you have over it?</td>
<td>None</td>
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<td>3 How much do you think treatment can help MS?</td>
<td>Not at all</td>
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<td>4 How much do you experience symptoms?</td>
<td>Not at all</td>
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<td>5 How concerned are you about MS?</td>
<td>Not at all</td>
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<td>6 How well do you feel you understand your MS?</td>
<td>Not at all</td>
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<tr>
<td>7 How much does MS affect you emotionally: making you angry, scared, upset or depressed?</td>
<td>Not at all</td>
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<td></td>
<td>Extremely</td>
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</tbody>
</table>

Part 3 This table shows words that describe feelings. Please indicate how you generally feel now about each word.

1 = very slightly 2 = a little 3 = moderately 4 = quite a bit 5 = extremely

<table>
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<th>Word</th>
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<th>10</th>
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<td>Interested</td>
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<td>Extreme</td>
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<td>Distressed</td>
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<td>Irritable</td>
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<td>Excited</td>
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<td>Alert</td>
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<td>Upset</td>
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<td>Ashamed</td>
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<td>Strong</td>
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<td>Inspired</td>
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<td>Guilty</td>
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<td>Nervous</td>
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<td>Scared</td>
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<td>Determined</td>
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<td>Hostile</td>
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<td>Attentive</td>
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<td>Enthusiastic</td>
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<td>Active</td>
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<tr>
<td>Proud</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Afraid</td>
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</tbody>
</table>

Part 4 Please tick the extent to which each of the following concerns you.

1 = no concern or fear, 2-4 = low fear, 5-7 = medium fear, 8-10 high fear.

<table>
<thead>
<tr>
<th>Concern</th>
<th>no fear</th>
<th>low fear</th>
<th>medium fear</th>
<th>high fear</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Returning to work or carrying on working</td>
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<tr>
<td>2 Seeing images of MS disability/disabled people</td>
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<tr>
<td>4 Not knowing how MS will physically affect me</td>
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<tr>
<td>5 Being dependent on someone else</td>
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<tr>
<td>6 Having a partner in future or getting married</td>
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<td>7 Being in pain as MS worsens</td>
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<td>8 Being or remaining financially independent</td>
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<td>9 Having a normal sex life</td>
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<tr>
<td>10 Being in a wheelchair</td>
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<tr>
<td>11 Having a baby/another child, or becoming a father</td>
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<tr>
<td>12 Being able to support and/or care for my family</td>
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<tr>
<td>13 Seeing others with physical deterioration</td>
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<td>14 Losing my memory or being confused</td>
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<tr>
<td>15 Coping with everyday life and household tasks</td>
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<td>16 Thinking about being physically disabled</td>
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<td>17 Having had dreams or nightmares about the future</td>
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<tr>
<td>18 Being able to get out and about alone in future</td>
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<tr>
<td>19 Uncertainty and not knowing what would happen</td>
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<tr>
<td>20 Losing or partly losing my eyesight</td>
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</tbody>
</table>
**Part 5** Please give your immediate reaction to how often each statement is true. Do not think too long.

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<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel tense or 'wound up'</td>
<td>Most of the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A lot of the time</td>
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<tr>
<td></td>
<td></td>
<td>From time to time, occasionally</td>
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<td></td>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td>2</td>
<td>I still enjoy the things I used to enjoy</td>
<td>Definitely as much</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not quite as much</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Only a little</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hardly at all</td>
</tr>
<tr>
<td>3</td>
<td>I have a sort of frightened feeling like 'butterflies' in the stomach</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Occasionally</td>
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<td>Quite often</td>
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<td></td>
<td></td>
<td>Very often</td>
</tr>
<tr>
<td>4</td>
<td>I can still laugh and see the funny side of things</td>
<td>As much as I always could</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not quite as much now</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Definitely not so much now</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td>5</td>
<td>I have a sort of frightened feeling as though something awful is about to happen</td>
<td>Very definitely and quite badly</td>
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<tr>
<td></td>
<td></td>
<td>Yes, but not too badly</td>
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<td></td>
<td></td>
<td>A little, but it doesn't worry me</td>
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<tr>
<td></td>
<td></td>
<td>Not at all</td>
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<tr>
<td>6</td>
<td>I can still feel cheerful</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not often</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sometimes</td>
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<tr>
<td></td>
<td></td>
<td>Most of the time</td>
</tr>
<tr>
<td>7</td>
<td>I felt restless as if I have to be on the move</td>
<td>Very much indeed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quite a lot</td>
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<tr>
<td></td>
<td></td>
<td>Not very much</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all</td>
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<td>8</td>
<td>I feel as if I am slowed down</td>
<td>Nearly all the time</td>
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<td></td>
<td></td>
<td>Very often</td>
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<td></td>
<td></td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not at all</td>
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<td>9</td>
<td>Worrying thoughts go through my mind</td>
<td>A great deal of the time</td>
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<td>A lot of the time</td>
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<td></td>
<td>Not very often</td>
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<tr>
<td></td>
<td></td>
<td>Very little</td>
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<td>10</td>
<td>I have interest in my appearance</td>
<td>Definitely</td>
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<td></td>
<td></td>
<td>I don't take as much care as I should</td>
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<td></td>
<td>I may not take quite as much care</td>
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<td>I take just as much care as ever</td>
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<td>11</td>
<td>I have sudden feelings of panic</td>
<td>Very often indeed</td>
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<td></td>
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<td>Quite often</td>
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<td></td>
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<td>Not very often</td>
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<td></td>
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<td>I still look forward with enjoyment to things</td>
<td>As much as ever I did</td>
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<td>Rather less than I used to</td>
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<td>Definitely less than I used to</td>
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<td></td>
<td></td>
<td>Hardly at all</td>
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<td>13</td>
<td>I can sit at ease or feel relaxed</td>
<td>Definitely</td>
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<td></td>
<td></td>
<td>Usually</td>
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<td>Not often</td>
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<td></td>
<td>Not at all</td>
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<td>14</td>
<td>I still enjoy TV, a good book or radio</td>
<td>Often</td>
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<td>Sometimes</td>
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<td>Not often</td>
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<tr>
<td></td>
<td></td>
<td>Very seldom</td>
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</table>

THANK YOU.
Researcher Guidelines: Final Open-ended Questions

The following will be read to participants and their responses will be recorded and transcribed.

All participants will be asked for their general impressions of the activity and for any comments they wish to make. Participants will be asked how useful or beneficial sessions were (and in what way) and whether small group sessions would be useful. MS participants will be asked whether they found that by drawing they responded differently from talking or writing about MS.

The following provides a framework for question content.

1) Please could you tell me what you found useful about the art sessions and why.

2) In what ways do you think you would find individual or group sessions useful?

**Drawing MS**

1) In what way was drawing ideas about/responses to MS different from writing or talking about them?

2) How would you feel about drawing responses to MS in a small group art session (of 3-5, where everyone was separately doing the same thing)?

I hope you enjoyed the drawing sessions.

Thank you for helping – your help is much appreciated.
j) Researcher standard guidelines: experimental condition

The following will be read out to participants.

**Please draw your response to MS**

Express your response to diagnosis, any aspect or how you generally feel.

Make any type of drawing or image you wish – you may want to draw a diagram, picture or lots of different pictures.

Draw what you feel – what comes to mind.
Do not focus on trying to create 'a masterpiece' or fabulous work.

Please use any materials available ask if you would like any help or ideas with using any that are unfamiliar.

Experiment with some of the materials first and try them out to see what sort of effects you can get.

- Pencils
- Charcoal
- Coloured pencils
- Watercolour pencils
- Felt tipped pens
- Pastels
- Water colours

I will not chat while you are drawing. I don't want to distract you or give you ideas because this is about your drawing and feelings.

I want to tidy up some of the pencils and check the pens. I'm happy to show you how some of these work though.

**Activity Review: Preparation for time 2.**

Express interest in drawing and encourage participant-led critique of content and introduction of additional aspects:
- What aspects are expressed here?
- Are the other aspects that could be introduced.
  These could be roughly sketched/noted on this tracing paper overlay.

Review the rescripted drawing in preparation for session 2.

**Researcher guidelines for interaction during the session**

1) Focus on being occupied but available. Check materials, try them, sharpen pencils etc. Keep a low profile and do not 'watch' the participant.

2) Interact on drawing technique, materials available and how they may be used.

3) Do not guide the content of the drawing/s.

4) In response to comments on content, reflect the information back to the participants. Try to avoid engaging the participant in discussing what they are doing. If they definitely want to talk about what they are doing, and to avoid this or move them on would be unhelpful to them, then do so to the minimum extent.

5) Ensure rescripting is adequately noted.
k) **Researcher standard guidelines: control condition**

**Please select any item, picture or subject you would like to draw**

Make any type of drawing or image you wish – you may want to draw a diagram, picture or lots of different pictures.

Do not focus on trying to create 'a masterpiece' or fabulous work.

Please use any materials available ask if you would like any help or ideas with using any that are unfamiliar.

Experiment with some of the materials first and try them out to see what sort of effects you can get.

- Pencils
- Charcoal
- Coloured pencils
- Watercolour pencils
- Felt tipped pens
- Pastels
- Water colours

I will not chat while you are drawing. I don't want to distract you as it can be irritating having people talking while drawing.

I want to tidy up some of the pencils and check the pens. I'm happy to show you how some of these work though.

**Activity Review: Preparation for time 2.**

Express interest in drawing and encourage participant-led critique of content and ways to develop this or do another drawing.

Introduce tracing paper overlay as making a note of additional ideas.

Review the drawing in preparation for session 2.

**Researcher guidelines for interaction during the session**

1) Focus on being occupied but available. Check materials, try them, sharpen pencils etc. Keep a low profile and do not 'watch' the participant.

2) Interact on drawing technique, materials available and how they may be used.

3) Do not guide the content of the drawing/s.

4) In response to comments on content, reflect the information back to the participants. Try to avoid engaging the participant in discussing what they are doing. If they definitely want to talk about what they are doing, and to avoid this or move them on would be unhelpful to them, then do so to the minimum extent.

5) Ensure rescripting is adequately noted.

**NOTE:** be prepared for the fact that a participant may opt to reflect some aspect of MS in their work.
1) Experimental group visual methods rescripting

**Participant 2**

1. [Image of a hand drawing with text and symbols]
2. [Image of a head with text]
3. [Image of a building]
4. [Image of a colorful abstract design]

1 (overlay)

2 Rescribed

2 Different topics

**Participant 7**

1. [Image of a colorful abstract design]

2 Collage, above with car door open
Participant 8

1 Rescripted

1 Overlay

2 non-MS topic

Participant 10

1 Preparatory

1 Overlay

1 Rescripted + birds and flowers
(Continued: Participant 10)

2 Distorted images of body  2 Rescripted + colourful patterns on clothes

Participant 13

1 1 Overlay: circles of influence

Discussion reference (No second session)
Participant 14

1 Overlay (on white paper)

1 Overlay

1 Rescripted in one session

2 Elects for non-MS

Preparation
Participant 15

1 Overlay

1 Rescripting

2 Rescripting and overlay

Warming up:
doodle to relax/calm down

Researcher’s demonstrations of media
**Participant 16**

Discussion and reflecting

Prompts

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**Participant 17**

No second session: telephone follow up
Participant 18

1 First impression

2 Elects draw non-MS: had completed impression of MS above

Participant 19

1

1 Overlay

1 Rescripting
Session two: Non-MS session, colourful images placed on walls

Relevant prompts: Ideas from MS rescripting, outline objects from non-MS control group sessions
## Case-wise descriptive statistics for MS (experimental) group

<table>
<thead>
<tr>
<th>Variable</th>
<th>MS case scores: by case number</th>
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</thead>
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n) Case-wise descriptive statistics for NMS (control) group

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363